

## Home-Based Rehabilitation Programs: Promising Field to Maximize Function of Patients with Traumatic Spinal Cord Injury

### Abstract

**Background:** Traumatic spinal cord injury (TSCI) has profound effects on the patient's health condition and function. However current treatment strategies fail in terms of cure. Thus, rehabilitative management has become the main gadget to promote patients' residual function. The most challenging aspect of rehabilitation is high costs of inpatient rehabilitation programs and poor continuity of care while patients are transferred to home. In this regard, numerous home based rehabilitation programs have been introduced. **Objectives:** This review is an attempt to better introduce and classify different aspects of home care programs for patients with TSCI all around the world. **Methods:** A literature search was conducted in the PubMed, Medline, and Google Scholar database. Studies that addressed rehabilitative programs for patients with TSCI in their home or home-like facilities were reviewed. Reference lists from retrieved articles were also reviewed. **Results:** Home based rehabilitation can be categorized in five different but naturally relevant fields: home aids/modification, home nursing and family help, social support, home based primary care (multidisciplinary physician groups), and novel models/methods (e.g. "transitional rehabilitation" or telemedicine). **Conclusion:** Since most investigators in TSCI home based rehabilitation have only introduced their findings, there are no comparative studies available. Thus future studies should be dedicated to clinical trials evaluating clinical efficacy of different strategies. A comprehensive integrated strategy with consideration to financial and other limitations should be applied to each specific area.

**Keywords:** Home care, rehabilitation, spinal cord injuries

### Introduction

Traumatic spinal cord injury (TSCI) has profound effects on survivors' health condition and function.<sup>[1]</sup> Patients with TSCI face many difficulties while returning to their previous social roles. They would experience daily struggles with physical, psychological, and financial problems.<sup>[2,3]</sup> Given the high rate of traffic accidents leading to a high number of spinal cord-injured patients in Iran and many other countries, it is necessary to pay special attention to the management of these patients.<sup>[4]</sup>

Great efforts have been made to develop functional performance along with quality of life of patients with TSCI. The primary goal is to initiate rehabilitation programs as soon as possible after the patient's spinal cord problems have been stabilized. In this regard, there have been rehabilitation centers around the world in which both new technologies and expert staff are gathered to provide the highest level of patient care.<sup>[5]</sup>

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The ultimate goal is to help patients return to their previous function.

The cost of these rehabilitation centers is a burden to both patients and the health-care system. Patients with TSCI are not expected to be fully capable of providing an economically independent life at least for 1<sup>st</sup> years after trauma. Thus, these rehabilitation programs will be questioned as if they are affordable to run. Furthermore, the circumstances provided in these rehabilitation centers are not the same as what patients deal with, within their routine lives in home and the society. Hence, patients are not appropriately trained for real daily life.<sup>[6]</sup> The time spent in these centers is not usually enough for both patients and their family to learn their new life situations. Therefore, they would challenge numerous problems which they are not trained for.<sup>[7]</sup> Furthermore, many of these rehabilitation programs are limited in terms of education and support to patients with TSCI and does not cover their

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families. Hence, a patient not only has problems doing ordinary routines but also his/her family has no idea how to help them or even how to adapt their own personal life to new circumstances.<sup>[8]</sup>

The high cost of patient care in specialized centers along with their failure to prepare patients with TSCI for successful return to ordinary life has resulted in enormous studies trying to facilitate the transition period between being completely disabled and to live in an ordinary life. One of these solutions is programs based on home care. The natures of these programs have changed over the time. Novel programs have been developed in different countries which sometimes have led to outstanding results.<sup>[9-12]</sup> Recently, great efforts have been focused on lowering heavy costs of care in specialized centers and on developing efficacy of these services using the patient's own life circumstances. Patient's return to his/her routine life without complications leading to hospital admission is the main objective of these services.

To the best of our knowledge, there is no study reevaluating these rehabilitation and care programs. However, it is mandatory to understand various aspects of these methods to achieve optimal efficacy of them and to integrate them to obtain a maximum possible synergistic result. The aim of the present study is to describe a general overview of different home care programs and their components in patients with TSCI.

## Methods

This study was held as a review. A literature search was conducted in the PubMed, Medline, and Google Scholar database using key terms "spinal cord injury rehabilitation," "home care" and "home based rehabilitation." Studies addressed rehabilitative programs for patients with TSCI in their homes or home likes and their reference lists were reviewed from January 1990 to December 2016. English language studies introducing new methods for home care with a minimum of 10 participants were included. Case reports and theoretical studies with no participants were excluded from the study. Two independent reviewers were in charge of the literature search. The study protocol was approved by the Institutional Review Board and Ethics Committee of Tehran University of Medical Sciences.

## Results

Of the 113 exclusive titles matched to our search strategy, 110 full-text articles were available to screen for eligibility. Of these, 10 studies fulfilled the inclusion criteria and were included in the study. In addition, relevant titles were identified from the reference list of articles and screened for potential inclusion. Of these, 210 full-text articles were evaluated and only 5 matched the inclusion criteria. A total number of 15 articles were reviewed in this study [Figure 1 and Table 1].

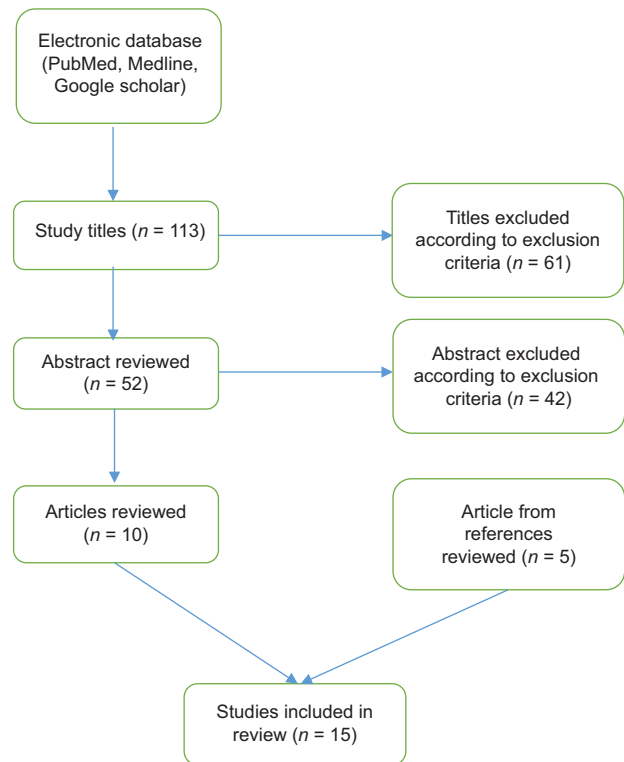


Figure 1: Flowchart of article selection process

## Home care component

Home-based rehabilitation can be categorized into five different but naturally relevant synthesizable fields:

### Home aids/modification

Physical barriers in home are among the most important environmental barriers for patients with spinal cord injury to return to normal life.<sup>[13]</sup> Administration of specially designed equipment for a specific patient and applying possible changes in home or working place architecture would help to elevate patient's sense of secure and independence. These equipment consist of mechanical/electronic devices and also those used in conservative and supportive treatments. Few studies have emphasized the importance of using home aids for patients with TSCI.<sup>[5,6]</sup> Using home aids beside application of remote control technologies may result in considerable positive changes, especially in patients with high motivation to overcome their disability boundaries and lower their dependency. Therefore, it would result in higher satisfaction and quality of life.<sup>[14]</sup>

Different categories of home aids have been assessed for efficacy in previous studies. Biering-Sørensen *et al.* found that the most common devices used are commode/shower chair on wheels or a seat, electrical bed, grab bar by the toilet, special mattress, lift/hoist, computers, and kitchen tools or cutlery with special handles. These tools were most likely to be used by patients with cervical spinal cord injury.<sup>[15]</sup> Rigby *et al.* showed that phone, TV, stereo, fan, and lights are the most common electrical devices in

**Table 1: Summary of articles reviewed**

Authors and year	Study design	Sample size	Results	Type of rehabilitation
Biering-Sørensen <i>et al.</i> (2009)	Cross-sectional	n=279	Most common aids or adaptations reported were commode/shower chair on wheels or a seat (69%), grab bar by the toilet (41%), electrical bed (44%), special mattress (28%), lift/hoist (20%), computers (39%), and kitchen tools or cutlery with special handles (14%)	Home aids
Hall <i>et al.</i> (1999)	Cross-sectional	n=82	Mean hospital days in the past year were 11 for the ventilator-independent group and 6 for the ventilator-assisted group. The latter group required more nursing level care, significantly more hours of care, and more paid attendants over the year	Home nursing
Weitzenkamp <i>et al.</i> (2002)	Cross-sectional	n=2154	Differences in an interval version of the motor portion of the FIM™ instrument accounted for 26.3% of the variance in total personal care assistance hours	Home nursing
Beedie and Kennedy (2002)	Cross-sectional	n=95	High quality of social support was associated with low hopelessness and depression scores, being more pronounced at week 18 postinjury	Social support
Elliott <i>et al.</i> (1992)	Cross-sectional	n=182	Relationships which reassured the worth of the individual were predictive of lower depression scores. To a lesser extent, relationships providing a sense of social integration were also associated with lower depression scores	Social support
Fine <i>et al.</i> (2000)	Clinical interventional	n=1140 home visits	Since 1972, a hospital-based specialty home health team consisting of a registered nurse, a registered physical therapist, and a vocational rehabilitation counselor has been serving spinal cord injury patients hospitalized previously in a university-affiliated rehabilitation center. A summary of facts about this program has been presented	Home-based primary care
Fronek <i>et al.</i> (2005)	Randomized controlled trial	n=89 home care providers	Initial between-group comparisons on subscale scores showed that the control group scored significantly higher than the treatment group (trained about sexual problems) on the knowledge subscale before the training program but scored significantly lower than the treatment group immediately following the training program and at 3-month follow-up	Home-based primary care
Fronek <i>et al.</i> (2011)	Randomized controlled trial	n=37 home care providers	Training about sexual problems can have long-lasting effects on practitioner knowledge, comfort, and attitudes in addressing sexuality issues with clients	Home-based primary care
Wallace and Kendall (2014)	Qualitative	n=220	A total of 1100 goals were classified into 18 different goal domains, representing most aspects of the ICF framework. Age was negatively related to vocational goals. Length of hospital stay was positively related to personal care goals but negatively related to community access and vocational goals	New models: Transitional rehab
Petrofsky (2001)	Pre-post trial	n=10	Subjects only undergoing clinical therapy showed about a 50% reduction in hip drop due to therapy. However, the group that used the home training device showed almost normal gait after the 2-month period	New models: EMG biofeedback
Dolbow <i>et al.</i> (2012)	Pre-post trial	n=17	Exercise adherence rates (71.7% and 62.9%) were well above the reported 35% in the able-bodied population, which provides evidence for the feasibility of a home-based functional electrical stimulation lower extremity cycling program. Younger adults with a history of being physically active have the highest potential for exercise adherence	New models: FES
Taylor <i>et al.</i> (1993)	Controlled trial	n=90	There was no difference in cardiac output between the groups. However, thigh blood flow was found to be around 65% of normal values in the spinally injured group. This returned to normal values following the retraining program. The quadriceps muscle wasted to approximately 50% of its original thickness in the first 3 weeks following spinal cord injury. The retraining program increased the muscle thickness to near normal values	New models: FES
Kowalczewski <i>et al.</i> (2011)	Randomized controlled trial	n=13	FES-ET on a workstation, supervised over the Internet, is feasible and may be effective for patients who can meet the residual motor function requirements of our study	New models: Telerehabilitation

Contd...

Table 1: Contd...

Authors and year	Study design	Sample size	Results	Type of rehabilitation
Phillips <i>et al.</i> (2001)	Randomized controlled trial	n=111	Preliminary evidence suggests that in-home telephone or video-based interventions do improve health-related outcomes for newly injured SCI patients	New models: Telerehabilitation
Van Straaten <i>et al.</i> (2014)	Pre-post trial	n=16	A high-dose scapular stabilizer and rotator cuff strengthening program using telerehabilitation for supervision holds promise for shoulder pain treatment in manual wheelchair users with SCI	New models: Telerehabilitation

FIM – Functional independence measure; FES – Functional electrical stimulation; FES-ET – FES-exercise therapy; SCI – Spinal cord injury; EMG – Electromyogram; ICF – International classification of functioning, disability and health

TSCI patients' daily life. Patients declared that utilization of these devices developed their independency, sense of value, and self-confidence.<sup>[9]</sup> Remote control devices used to adjust temperature, opening and closing doors and windows, turning lights, TV, and etc., on and off may also be useful to elevate patients' independence and contribution to perform home chores.<sup>[16]</sup>

Health-care equipment also has a great value in maintaining patients' health and preventing secondary complications. According to Stiens *et al.*, examples of such equipment are as follows: "bowel and bladder supplies including catheters, leg and bed bags, laxatives, suppositories, gloves, incontinence briefs, underpads, lubricants, and digital stimulators; pulmonary ventilation equipment including continuous positive airway pressure and bi-level positive airway pressure machines, humidifiers, ventilators, and suction and inhalation-exhalation machines; Skin care supplies including pillows, foam blocks, positioning wedges, dressings, emollients, and decompression."<sup>[16]</sup>

An occupational therapist is usually responsible for choosing the best home aids based on patient's needs. Before discharging from hospital, the occupational therapist would visit the patient's house. According to the level of the spinal cord injury and previous abilities of the patient, functional aids needed are predicted and designed. These aids can change as patient's abilities and functional goals develop.<sup>[10,16]</sup>

Constructional changes may be necessary to provide a safe and secure living place matching patients' new needs. These changes are generally expensive and difficult to apply but occupational therapist's efforts with collaboration and consultation of other experts can be effective in this filed. As Stiens *et al.* have mentioned, this section of home care program can include "ramps, automatic doors, overhead installed track lift systems, reserve power generators, and emergency response systems."<sup>[16]</sup> If the same changes can be made in the workplace, there might be a great step toward resolving occupational problems.

#### Home nursing and family help

Patients with spinal cord injury will spend most of their time with their families. Thus, family members have an important role in providing an effective care.<sup>[17]</sup> Involving

patient's family in the rehabilitation program after educating them may have potentially beneficial effects.<sup>[18]</sup>

On the other hand, providing care for an abundantly dependent patient may put lots of pressure on family members and occasionally harm familial relationships. This issue becomes clear as if we consider mean age of patients struggling with these injuries; an individual with zero dependence in his/her previous daily life is now completely disabled seeking help of others. Therefore, it is important to pay special attention to family issues when designing a comprehensive plan for home care and to prevent putting too much pressure on family members. Especially, in the first days of returning to their home, both patients and their families face a lot of pressure; thus, an outside support is necessary.<sup>[19]</sup>

Home nursing may provide a great help for patients with TSCI, performing activities of daily living such as bathing, dressing, transfers, and bowel/bladder management. Although this nursing care prevents excessive pressure to family members, the costs can be considerable.<sup>[20,21]</sup> Nursing care has its major effect on performance limitations rather than medical issues; thus, functional disability is the best predictor of the extent of nursing care needed.<sup>[22]</sup>

#### Social support

TSCI is a severe catastrophic life event, causing significant psychological trauma as well.<sup>[23]</sup> Social support can be effective in means of lowering the burden of psychological trauma, depression, disappointment, and elevating life satisfaction.<sup>[24-26]</sup> Unfortunately, social support programs are not easily available in developing countries and patients with TSCI buckle with lots of psychological problems.<sup>[27]</sup>

It has been proposed that participation in social activities is associated with a higher quality of life more than any other factors.<sup>[28]</sup> The WHO defines participation as "a person's involvement in a life situation."<sup>[29]</sup> According to a review by Barclay *et al.*, factors such as "having adequate personal care assistance, having appropriate social support, having adequate special equipment, and appropriate occupational therapy" can be effective in facilitating participation of a TSCI patient and consequently in increasing quality of life.<sup>[28]</sup>

TSCI Rehab project categorizes social support into following domains: “financial planning, discharge planning, discharge services, supportive counseling, educating about and managing referral to peer/advocacy groups, education about TSCI and other relevant topics, educating about and managing referral to community/in-house services, and team conferences. Every domain has its own branching.”<sup>[30]</sup> One of the important aspects of social support is to facilitate occupational opportunities for patients with TSCI. Although it has been shown that employment has some advantages on the quality of life of a TSCI patient,<sup>[31]</sup> only up to 35% of these patients are employed.<sup>[32]</sup> Occupational therapist can have a great role in facilitating work circumstances for a TSCI patient and introducing occupational opportunities matching their remained abilities.<sup>[33]</sup>

Nongovernmental organizations are of important role in the rehabilitation process. Providing home aids, establishing rehabilitation camps, educational and supporting programs for patients, and their families are among their activities.<sup>[10]</sup> By improving patients’ understanding of themselves and their abilities, providing sport programs, and voluntary groups, they can play their role in the process of rehabilitation.<sup>[19]</sup>

#### *Home-based primary care*

Home-based primary care means scheduled appointments of multidisciplinary medical team visiting a TSCI patient in his/her home. The services provided by this team may include – but not limited by – basic medical care, nursing, social service, physical, and occupational therapy.<sup>[11]</sup> Medical services and appointment frequencies may vary based on patients’ health condition and organization provides these services. In these programs, a nurse is usually responsible for maintaining health condition by providing nursing service, and occupational therapist is in charge of promoting functional capacity through training special skills, recognition of physical barriers, and finding solutions to resolve them, providing assistive devices, and offering necessary architectural changes at home.<sup>[34]</sup>

Sexual problems are among commonly neglected issues by a multidisciplinary team because of lack of required knowledge. Few studies have evaluated effectiveness of educating multidisciplinary team about sexual problems of TSCI patient and reported magnificent results.<sup>[35,36]</sup>

In home-based primary care, along with no need to transport patients between hospital and home (which prevents subsequent complications and harms), multidisciplinary medical team can closely evaluate real-life situation of patients and provide individualized solutions and recommendations about needed home aids and architectural modification. In addition, secondary problems will be detected sooner, and in case of emergencies, patients would be timely referred to hospital and subsequent costs will be reduced.

#### *Innovative models/methods*

##### *Transitional rehabilitation*

The idea of developing this model was to make sure that rehabilitation program would continue especially shortly after transition from hospital. Transition period is very stressful for patients and their families and necessitates comprehensive support. In this model, rehabilitation strategies are designed based on patient’s needs and goals to decrease hospital stay, reduce costs, and in addition to proceed rehabilitation in patient’s real-life circumstance. This model consists of services such as nursing, physiotherapy, occupational therapy, and social work professionals provided by a multispecialty team. Discharging from hospital takes place 4 weeks sooner than regular discharge plan. Before initiating the program, rehabilitation objectives are defined with participation of both patients and caregivers, though further modification and reevaluation are possible. Duration of the program is 4–8 weeks and frequency of visits depends on needs and living condition of the patient.<sup>[12]</sup> Introducing this model to a patient living in a remote area can be challenging. As Wallace and Kendall have reported, transitional rehabilitation in remote areas faces five types of challenges including: (1) identification, education, coordination, and funding of local care providers; (2) Family involvement in rehabilitation; (3) contact with social and community supports; (4) specialist’s support to problem solve discharge needs; and (5) skill acquisition and transfer in a community environment.”<sup>[37]</sup>

Transitional rehabilitation should be a part of a long-term rehabilitation program for patients with TSCI. Monitoring the advantages and disadvantages should be performed even after finishing the program.

High tech devices have been commonly used in the home care programs of patients with TSCI. Modern wheelchair designs, brain-based command signals, and locomotor training are only some examples of utilization of modern technology in enhancing quality of life and functional capacity of patients with TSCI.<sup>[38]</sup> Although there have been trials assessing their efficacy, recommending these devices to every patient demands further understanding of their safety profile, availability, and cost-effectiveness. In following paragraphs, we will discuss some examples of technology-based interventions specifically designed to help patients with TSCI.

##### *Electromyogram biofeedback*

Although some paraplegic patients may be able to walk after injury, it would be with some abnormalities such as Trendelenburg gait. In a gait retraining study, using a permanent biofeedback tool both in clinic and home resulted in more progression in walking skills compared to using it only in clinic.<sup>[39]</sup>

### Functional electrical stimulation

Using functional electrical stimulation to improve gait skills in patients with incomplete spinal cord injury showed promising results. Increasing blood supply, preventing muscle atrophy, increasing walking speed, step width, and standing duration along with decreasing dependency to aids are among its advantages.<sup>[40]</sup> As Kirshblum *et al.* said, this technique had also positive effects on “upper-extremity use, bladder control, respiration, and cardiovascular and tissue health.”<sup>[38]</sup> Application of this technique as a part of home care strategy has been evaluated in some studies.<sup>[41-43]</sup>

### Telemedicine

In this method, high tech devices such as video conference are used to connect patients with TSCI and the medical team even when they are miles away. This is especially of value for patients living in distant areas from TSCI units. The telemedicine rehabilitation team can include a physician, nurse, physical therapist, dietitian, psychologist, and recreational therapist.<sup>[44]</sup> Furthermore, surveillance of noncomprehensive programs with smaller goals such as improving hand function can be achieved using this method.<sup>[45]</sup> Several studies revealed efficacy of this technique in different aspects of rehabilitation programs of patients with TSCI.<sup>[46,47]</sup> Although this model showed promising results, further investigations should be dedicated to prove its efficacy and cost-effectiveness compared to traditional methods.<sup>[48]</sup>

### Discussion

This review is an attempt to better introduce and classify different aspects of home care programs for patients with TSCI all around the world. Different fields of home care including home aids/modification, home nursing and family help, social support, home-based primary care, and novel models/methods have opened a new horizon toward a more effective rehabilitation. A great number of papers have been published in this field and yet there is an increasing trend to introduce more efficient strategies. There is still a long road to establish a safe, widely accepted, and cost-effective rehabilitation package in the setting of community and home for these patients.

Conducting clinical research in the field of TSCI rehabilitation is very difficult. Sample heterogeneity and small size, ethical problems of not delivering rehabilitation services to control group, impossibility of patient blinding, and lack of an appropriate measurement tool along with financial problems are some difficulties.<sup>[49]</sup> Hence, nearly all investigators in TSCI home-based rehabilitation have only introduced and described their findings, and there are no comparative studies performed. Thus, future studies should be dedicated to intelligently designed clinical trials to evaluate and compare clinical effectiveness of different strategies. Financial concerns are another aspect of home care that has been neglected in previous studies. Hence, there is a need to conduct cost-effectiveness studies to find the most affordable strategy.

It should be considered that rehabilitation of an individual with spinal cord injury is not just a combination of separated parts coming together, but it includes all aspects of life of a biopsychosocial person with a catastrophic disability. Hence, studies investigating the effectiveness of complete packages of rehabilitation components are mandatory.

### Conclusion

Recently, rehabilitative management has become the main gadget to promote residual function of patients with TSCI. In this regard, home-based rehabilitation programs have shown potential benefits. These programs are widely variable in terms of the service they provide for patients with TSCI. Thus, findings of different studies in this field should be used to design a comprehensive integrated strategy with consideration of patient’s personal, physical, financial, social, and other limitations.

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### Conflicts of interest

There are no conflicts of interest.

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