

A qualitative study on psycho-social needs of the family caregivers of persons with spinal cord injury

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ABSTRACT

Background: Spinal cord injury is a high-cost long-lasting disability and a life-changing experience for family caregivers (FCGs). The current study aimed to explore the psycho-social needs of the FCGs of persons with spinal cord injury (PwSCI). **Materials and Methods:** An exploratory qualitative approach was used, and sixteen FCGs of PwSCI participated in the face-to-face interviews. All the interviews were audio-recorded, and session notes were added to the existing data and later transcribed. Thematic analysis was used to identify the main themes. **Results:** Three main themes have emerged, namely, awareness needs, resource needs, and personal care needs, from the data as a result of the qualitative analysis: The main themes have been categorised into nine sub-themes, such as want to know, alternative ways of contacting, the helpful or conducive environment of arrangements, sources to get money, pension certificate needs, resources for livelihood, resources for continuing the treatment, need my own time, and controlling of feelings. **Conclusion:** The findings of this research aid in designing or developing need-based tailor-made psychosocial interventions for the FCGs of PwSCI in India. Multidisciplinary team professionals involved in managing spinal cord injury and other stakeholders should understand the importance of meeting the mentioned psycho-social needs of FCGs of PwSCI and delivering such tailor-made psycho-social interventions in a timely.

Keywords: Family caregivers, psycho-social needs, qualitative study, spinal cord injury

Introduction

Spinal cord injury (SCI) is a frequent and devastating neurological illness that can occur suddenly and without warning. It has a major impact on individuals affected by physical, psychological, social, and vocational well-being.^[1,2] Persons with SCI (PwSCI) and their families are dealing with a life-changing event as a result of SCI.^[3] SCI has a prevalence rate of 236 per million people

in India, with an annual incidence rate of 15-20 per million.^[4] SCI affects around 1.5 million people in India, with 20,000 new cases being diagnosed each year. The majority (60-70%) are illiterate, poor peasants, and boys aged 16 to 30, showing a higher incidence rate among children under the age of five.^[5] In a developing nation like India, family support is important for afflicted persons. Family members do everything they can to assist the PwSCI recovery; however, adjusting tactics differ from family to family.^[6] Family carers (FCGs) play a vital role in PwSCI rehabilitation, and their quality of care is comparable to or better than expert treatment.^[7] Caregivers have significant adjustment challenges while caring for a PwSCI, which affects their interpersonal interactions, duties, community and leisure activities, occupational functioning, psychological well-being, and health-related quality of life.^[8]

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Caring for PwSCI varies from caring for people with other diseases and injuries because of the particular problems associated with SCI, such as bladder, bowel, pressure, and ulcer management,^[9] as well as the prolonged length of caregiving.^[10] A PwSCI ability to support them requires their ability to care for others, which is crucial. According to global research studies, FCGs with PwSCI experience isolation,^[11] burdens,^[12] low leisure pleasure,^[13] impaired capacity to locate and retain employment,^[14] and marital disruption.^[15] In view of the preceding, it is critical to recognise the enormous efforts of the FCGs in the recovery of the PwSCI and to meet their unmet requirements. Knowing the FCGs unique psychosocial requirements will help us build and deliver successful customised interventions. Primary care providers and family physicians are the first to be approached by the FCGs of PwSCI during the acute phase of the trauma, the current study findings help the primary care providers and family physicians to know the various psycho-social needs of the FCGs of PwSCI and facilitate accordingly for the better outcomes.

There is an increased demand for qualitative studies that investigate the needs of FCGs following SCI. Due to SCIs unpredictability, some family members end themselves in an “unexpected career,” as FCGs put it.^[16] There is a dearth of understanding of the emotional and practical challenges that FCGs face in India.^[17] There has been little study on how PwSCI and their FCGs adjust to new lives after an accident or how dyadic coping methods are employed to sustain relationships.

On the other hand, unmet carer needs may impede effective care and negatively influence the health of both care receivers. Carers-unmet needs to motivate FCGs to invest more time in themselves.^[7] Given the distinctions in the Indian socio-cultural background as compared to Western nations, previous research investigations would require evaluation outcomes that are not universal. There is minimal research on the psycho-social needs of FCGs in the Indian setting; keeping this research gap in mind, the current study seeks to learn more about the psycho-social needs of FCGs from their own perspectives.

Materials and Methods

Design

The current study used a qualitative approach to capture the study variables suitably. The considered approach was selected since it aids in discovering and examining participant experiences related to the study variables.^[18] In the Indian context, the specific psycho-social needs of FCGs of PwSCI have not been explored in detail so far. Hence, the researchers decided to use an exploratory qualitative approach and in-depth face-to-face interviews to assemble data to analyse the psycho-social needs of the FCGs of PwSCI.

Setting and participants

The research was conducted at the Department of neurological rehabilitation, a tertiary care centre in South India. A total of

sixteen neurological rehabilitation FCGs of PwSCI were chosen as participants for the sampling. A convenience sample of sixteen FCGs of PwSCI was selected using the following inclusion and exclusion criteria for the research consecutively. Inclusion criteria include a) individuals aged 18 and above, b) the FCGs (Father, Mother, Brother, and Wife) who are giving main care to the PwSCI and will continue with the patient after discharge. c) The carer must be fluent in at least one of the following languages: English, Kannada, Telugu, and Hindi, and d) those willing to volunteer to participate in the study. Exclusion criteria include a) carers who suffer from serious psychological or neurological illnesses and b) the primary carer was caring for another family member with psychiatric or neurological disease.

Data collection

Methods of data collection

Semi-structured questionnaire: The researchers have developed a semi-structured questionnaire to capture the socio-demographic characteristics of the PwSCI and their FCGs such as age, gender, education status, marital status, and socio-economic status, and clinical characteristics of the PwSCI such as diagnosis, causes, level of injury, and duration illness. These clinical characteristics have been collected from the PwSCI case files.

Interview guide: The researchers have developed an interview guide (IG) to collect data about the concerns and psycho-social needs of the FCGs of PwSCI. This IG was tested for both face and content validation. The updated IG after the face validation was given to professionals from various backgrounds for content validation. The IG was finalised in consultation with the sixteen FCGs of PwSCI. The contents of IG are mentioned in Table 1.

Interviews: Face-to-face in-depth interviews have been conducted with FCGs of PwSCI who met the inclusion criteria and gave consent. The interviews started to collect the socio-demographic

Table 1: Interview guide contents and probes

Contents:

- Concerns of the FCGs in process of caring towards the PwSCI
- Psycho-social needs of the FCGs in process of caring towards the PwSCI
- Any other concerns or needs of the FCGs in process of caring towards the PwSCI
- What will help the FCGs in process of caring towards the PwSCI need
- Any other information of the FCGs in process of caring towards the PwSCI

Probes:

E.g.; If the FCGs talk about their concerns (Probes: informational, financial, vocational, emotional, sexual, rehabilitation, and environmental barriers, etc.)

E.g.; If the FCGs talk about psycho-social needs (Probes: social support, welfare, physical care, personal, treatment, referral, assistive devices, etc.)

E.g.; If the FCGs talk about the PwSCI neurological condition (Probes: types, symptoms, symptoms management, nature, prognosis, recovery, etc.)

E.g.; If the FCGs talk about the pension certificates (Probes: registration process, purpose, benefits, issues in receiving, etc.)

details of the FCGs. Then, the researcher started the interview using the above IG contents, wherever required and used appropriate probes to assist the participants in collecting the required information [See Table 1 for Probes]. Each interview lasted for about 45 to 60 minutes. The data collection was carried out from February 2021 to May 2021.

Ethical statement

Ethical clearance was attained from the Institute Human Behavioural and Ethics Committee. The subjects were elucidated about the research and its procedures before gaining written informed consent.

Data analysis

All the interviews were recorded, and session notes were added to the existing data. The transcripts were eventually imported and coded using Atlas.ti (ATLAS.ti 9 Desktop Trial; <https://atlasti.com/free-trial-version/>), and the raw texts were read and reread several times in order to become acquainted with the facts. The text portions representing FCGs psycho-social needs were reviewed and appraised throughout the coding process, and new codes were produced. After a thorough discussion of the emerging codes and themes, two peer research researchers who were not involved in this study were approached for aid in preserving consistency and sorting out the codes. The researcher performed the subsequent coding procedure for the remaining data set based on the findings of the primary coding.

The researcher reviewed the entire data set again to generate new useful codes and reduce unnecessary ones. After being exported to a Microsoft Excel file, the scripts were rigorously examined, and the themes were properly named. The created codes were then allocated to the relevant themes. These codes were reviewed again with the two peer research scholars who were not part of this study to confirm that the codes and assigned themes were consistent. The modifications were then debated and determined. Data analysis was carried out for each of the sixteen interviews. The findings of the FCGs of PwSCI psychosocial requirements were arranged into three main themes and nine sub-themes that came from the codes.

Results

Socio-demographic characteristics

Many of the PwSCI were male, got married ($n = 11$, 68.75%), belonged to low socio-economic status ($n = 12$, 75.00%), and half of them were studied up to higher secondary ($n = 08$, 50.00%), nearly half of them ($n = 07$, 43.75%), were self-employed. Many of the FCGs were female ($n = 09$, 56.25%), got married ($n = 10$, 62.50%), had a spouse by relation to the PwSCI ($n = 07$, 43.75%), and did not have prior caregiving experience ($n = 15$, 93.75%). The PwSCI and their FCG's mean age standard deviation was 35.6 ± 4.52 , 34.67 ± 3.727 years. All of the socio-demographic characteristics of the sixteen PwSCI and their FCGs are depicted in Tables 2 and 3, respectively.

Table 2: Socio-demographic profile of PwSCI

Variables	Frequency, (%) (n=16)
Gender	
Male	11 (68.75)
Female	05 (31.25)
Education	
Illiterate	02 (12.50)
Up to secondary	08 (50.0)
Higher secondary	05 (31.25)
Graduation	01 (06.25)
Marital status	
Single	05 (31.25)
Married	11 (68.75)
Having children	
Yes	06 (37.50)
No	10 (62.50)
Occupation	
Unemployed	05 (31.25)
Employed	04 (25.00)
Own business	07 (43.75)
Socio-economic status (SES)	
Low	12 (75.00)
Middle	02 (12.50)
High	02 (12.50)
Domicile	
Rural	12 (75.00)
Urban	04 (25.00)
Mean age of the PwSCI (Mean±Standard deviation)	35.6±4.52 years

Clinical characteristics

Many of the PwSCI ($n = 09$, 56.25%) were diagnosed with non-traumatic SCI, paraplegic level of injury ($n = 10$, 62.50%), of the 09 non-traumatic PwSCI, ($n = 06$, 37.50%) developed the illness due to the inflammation, the cause for the illness was due to falling in 03 (18.75%) patients, followed by road traffic accidents in 4 (25.00%). Half of the PwSCI ($n = 08$; 50.00%) have had the illness for 2-6 months, and the mean duration of the illness was 0.57 ± 0.31 years. The clinical characteristics of the sixteen PwSCI who have participated in this study are depicted in Table 4.

Psycho-social needs of the FCGs of PwSCI

The psycho-social needs of FCGs of PwSCI were arranged under relevant themes as a result of the qualitative research data analysis, which yielded three main themes: Awareness needs, Resource needs, and Personal care needs. The main themes have been categorised into nine sub-themes such as want to know, alternative ways of contacting, the helpful or conducive environment of arrangements, sources to get money, pension certificate needs, resources for livelihood, resources for continuing the treatment, need my own time, and controlling of feelings [see Table 5]. Below is a full portrayal of each code under several sub-themes, and FCGs quotes have been mentioned in a Supplementary File.

Awareness needs: The caregivers have expressed the following needs under the main theme of awareness needs: want to know,

Table 3: Socio-demographic profile of the FCGs

Variables	Frequency, (%) (n=16)
Gender	
Male	07 (43.75)
Female	09 (56.25)
Marital status	
Unmarried	06 (37.50)
Married	10 (62.50)
Education	
Illiterate	02 (12.50)
Up to secondary	05 (31.25)
Higher secondary	06 (37.50)
Graduation	03 (18.75)
Occupation	
Unemployed	08 (50.00)
Employed	04 (25.00)
Own business	04 (25.00)
Socio-economic status (SES)	
Low	12 (75.00)
Middle	02 (12.50)
High	02 (12.50)
Relationship with the PwSCI	
Spouse	07 (43.75)
Sibling	04 (25.00)
Parent	04 (25.00)
Other family member	01 (06.25)
Duration of caregiving (DOCG)	
Less than a month	03 (18.75)
1-6 months	08 (50.00)
7-12 months	03 (18.75)
More than a year	02 (12.50)
Previous caregiving experience	
Yes	01 (06.25)
No	15 (93.75)
Hours per week providing the care	
<60	02 (12.50)
60 to 90	09 (56.25)
>90	05 (31.25)
Any health issues	
Yes	06 (37.50)
No	10 (62.50)
Mean age (Mean±Standard deviation)	34.67±3.727 years

alternative ways of contacting, and helpful environment of arrangements.

Wanted to know health status and recovery process

All the FCGs of PwSCI have emphasised that they wanted to know about the illness condition and expressed that they should know about other illness components, such as symptoms, nature of illness, management, prognosis, and recovery. They also expressed that one of the needs under this theme was urine cleaning, draining process, and maintaining the urine dairy. Many of the FCGs have communicated that they want to know when their PwSCI will recover and how long it will take. They were also inquiring to know when their PwSCI can able to walk like before. Some of them were asked the researcher about their length of stay, and the FCGs have also stressed the necessity

Table 4: Clinical Profile of PwSCI

Variables	Frequency, (%) (n=16)
Diagnosis	
Traumatic SCI	07 (43.75)
Transverse myelitis	04 (25.00)
Myelopathy	02 (12.50)
Neuro myelitis optica	03 (18.75)
Type of spinal cord injury	
Traumatic	07 (43.75)
Non-traumatic	09 (56.25)
Cause	
Fall	03 (18.75)
Road traffic accident	04 (25.00)
Inflammation	06 (37.50)
Infection	03 (18.75)
Comorbidity	
Yes	05 (31.25)
No	11 (68.75)
Level of injury	
Paraplegia	10 (62.50)
Quadriplegia	06 (37.50)
Injury location	
Cervical	06 (37.50)
Thoracic	04 (25.00)
Lumbar	03 (18.75)
Sacral	02 (12.50)
Coccygeal	01 (06.25)
American Spinal Cord Injury Assessment (ASIA) type	
ASIA-A	04 (25.00)
ASIA-B	03 (18.75)
ASIA-C	07 (43.75)
ASIA-D	02 (12.50)
Number of hospitalisations	
One	12 (75.00)
Two	02 (12.50)
More than two	02 (12.50)
Time since discharge from the previous in-patient rehabilitation (n=04)	
<3 months	02 (12.50)
4-6 months	01 (06.25)
>6 months	01 (06.25)
Duration of Illness	
Less than a month	03 (18.75)
2 to 6 months	08 (50.00)
7-12 months	03 (18.75)
More than a year	02 (12.50)
Duration of In-Patient Stay	
Less than a week	03 (18.75)
1 to 2 weeks	05 (31.25)
3-4 weeks	04 (25.00)
>4 weeks	04 (25.00)
Mean duration of Illness (Mean±Standard deviation)	0.57±0.31 years

of symptom management techniques like bowel incontinence, bladder incontinence, pressure ulcer, and the additional needs mentioned in Table 5.

Table 5: Psycho-social needs of the FCGs of PwSCI

Main themes	Sub-themes	Findings
Awareness needs	Wanted to know health status and recovery process	Illness components
		Continuation of exercises
	Alternative ways of contacting	Post-discharge concerns
		Follow-up facilities
Helpful environment of arrangements	Therapy sessions	
	Staying in the ward	
Resource needs	Sources to get money	Decision about discharge
		Monthly household expenses
	Pension certificate needs	Treatment costs
		Pension monetary
		Mobility aids
Resources for livelihood	Job/self-employment opportunities	
Resources for continuing treatment	Pursuing the education	
Personal care needs	My own time	Neuro or trauma care hospitals
		Rehabilitation centres
		Performing caregiver tasks
	Controlling of feelings	Timely daily activities
		Break from caregiving
		Managing negative emotions
		Solving day-to-day issues

Alternative ways of contacting/reaching out

The need for teleconsultation has increased during the COVID-19 pandemic; these services were very effective during the pandemic in continuing the healthcare services and treatment. Some of the FCGs have stated the significance of alternative ways of reaching out to the healthcare professionals' needs for the PwSCI, such as the need of/up facility over the phone need to learn exercises by video calling need to get medicines to slip, need to ask doubts about exercises, and need to remember the exercises. One of the vital comments from these needs was initiating telemedicine services for the follow-up services for the PwSCI due to coronavirus pandemic restrictions and to reduce the indirect treatment costs. Most of the FCGs communicated that they were not able to go outside to get the medications, and it was difficult to continue the therapy services due to the pandemic restrictions. The FCGs were concerned about the costs involved in the transportation to bring the PwSCI to the follow-up services as they cannot travel in public transportation; they considered this would be a helpful aspect to continue the treatment.

The helpful environment of arrangements

Given the nature of the illness condition, many of the FCGs have expressed their need for a helpful environment of arrangements during the rehabilitation admission. FCGs frequently have to make decisions regarding a variety of issues, and they have voiced worry that this prevents them from thinking clearly. As they were not aware of the recovery of the clinical condition, and worried about the functionality of the PwSCI, they have verbalised the following treatment needs such as wanting to prolong our stay in the hospital, and needing permission to stay in the ward, need to take decision about discharge.

Resource needs: The caregivers have expressed the following needs under the main theme of resource needs sources to get money, pension certificate needs, resources for livelihood, and resources for continuing the treatment.

Sources to get money

In view of both the direct and indirect treatment costs, many FCGs of PwSCI have expressed the following sources to get money for buying medicines and CIC tubes, meeting monthly household expenditures, frequent hospital visits, and treatment costs. In a developing country like India, many PwSCI, and their FCGs come from low socio-economic backgrounds; hence, they cannot afford the treatment and find difficulty in meeting the subsequent associated costs. Considering the lack of availability, accessibility, and affordability of adequate healthcare facility services and rehabilitation centres for SCI management, most of the FCGs were not able to meet the treatment costs.

Pension certificate needs

As many of the PwSCI find it difficult to continue the previous job or get a new job post-injury, they find it challenging to meet the family's needs. As the primary FCG has to look after the PwSCI activities of daily living, they could not be to go for a job or continue the job; hence, the FCGs express the need for the pension certificate needs. This helps them to meet the needs of the continuation of treatment, medication, and transportation. Most of the FCGs have expressed their need for the application of the disability pension certificate to receive the pension amount. The FCGs have stressed the importance of needs such as pension amount, more pension money, pension certificate, benefits of the certificate, need of a wheelchair, and a three-wheeler vehicle.

Resources for livelihood

The FCGs were more expressive and concerned about the vocational needs; they stressed how the PwSCI and FCGs vocational (employment or education) components would impact after the injury. Some of the FCGs were told that they would need help in need, some jobs for me need loans to start a livelihood, and some jobs for the patient's children need to continue my job need to continue their education. Some of the FCGs were concerned about continuing their employment; some needed new employment or livelihood options, whereas the other FCGs had expressed concerns about continuing their education during caregiving.

Resources for continuing the treatment

In this study, FCGs have pointed out the importance of needs about the local resources for continuing the treatment and where they can find such resources for the continuation of the PwSCI treatment, which plays a significant role in the outcomes of the recovery. Most of the time, the FCGs and PwSCI enquired about the local therapy and rehabilitation centres to continue the treatment at a lower cost. Some of them have stated that they would prefer to go to nearby hospitals for follow-up due to financial issues and travelling challenges. Continuation of exercises and regular treatment adherence is the key factors for

better recovery of the PwSCI. The FCGs have expressed the following needs: nearby neuro or trauma care centres for f/up, nearby physiotherapy centres, nearby occupational centres, and nearby welfare officers address about nearby NGOs about nearby rehabilitation centres.

Personal care needs: The FCGs have expressed that the following needs under the main theme of personal care needs are needing my own time and controlling feelings.

My own time

Unlike other illnesses, the FCGs would usually be with the PwSCI. Hence, the FCGs will not get time to perform their activities of daily living or daily routines on time. FCGs are frequently required to do duties for which they have not been trained. They disregard their own health by devoting so much time and energy to caring for the sick. They also limit their social activities to ensure that they are always with the PwSCI. The status of neurological disabilities (SCI) worsens over time as they cause numerous symptoms and functional impairments that frequently raise demands on FCGs. PwSCI are fully reliant on FCGs for daily tasks such as bowel and bladder functions, transfers, locomotor function, and self-care. Some of the FCGs have expressed their needs, such as needing another person for shifting, needing to sleep on time, needing some break from this caregiving, spending time for myself, attending social functions, and eating on time.

Controlling of feelings

Most of the FCGs have stated that they would indulge in providing care to the PwSCI at the cost of their own mental health needs, and an added factor could be due to lack of time. The amount of time spent caring for the PwSCI is related to FCGs suffering. FCGs give remarkable uncompensated care that takes large amounts of time and energy over months or years and necessitates the completion of emotionally taxing activities. When care requirements change, they are continually forced to solve issues and make decisions, but they feel unskilled and spontaneous as they scuffle to adjust to new roles and responsibilities. Although FCGs prioritise PwSCI demands, their own needs are frequently overlooked. The FCGs have expressed the following needs: not getting any idea to solve these problems, do not have any close people to share my problems with, the need to control my anger; do not know how to control these tensions.

Discussion

The psycho-social issues of the FCGs of PwSCI during the rehabilitation phase are unique and need to be explored. The current research highlights the psycho-social needs of the FCGs of PwSCI in India. Three main themes developed from the data as a result of the qualitative analysis: 01) Awareness needs, 02) Resource needs, 03) Personal care needs.

We need to comprehend the bidirectional correlation between the FCGs and the majority of the psycho-social difficulties that

develop as a result of the PwSCIs health state. These two are not distinct entities; one influences the other. The difficulty of caring for people with SCI is individualised and contextual in nature. As a result, capturing the FCGs psychosocial requirements demands specific care. Many stakeholders, including professionals in SCI care and non-governmental organisations, are considered to satisfy the requirements of PwSCI and their family members following injury. Moreno A *et al.*, 2017, highlighted an integrative approach towards SCI needs by including stakeholders such as PwSCI, their FCGs, and healthcare professionals in their scoping study protocol.^[19]

In the light of previous research, this is the first known qualitative study from India that investigated the psycho-social requirements of FCGs for the PwSCI. The current study emphasises the importance of the interaction of several aspects connected to the psycho-social requirements of FCGs for the PwSCI, such as personal, emotional, social, vocational, health services, and environmental. It is perilous to comprehend the function of the aforementioned components in order to give active supporting mechanisms of psychological therapies to the FCGs of PwSCI. FCGs serve a significant role in eliciting psychosocial demands and anticipating psychosocial concerns at various time periods, such as during rehabilitation and after discharge. A Switzerland-based qualitative study has reported the same form to the expert's observations and their professional roles with adequate knowledge about the psycho-social issues.^[20]

It is obligatory to understand the impact of psycho-social needs and how to meet them because unfulfilled needs are associated with a decrease the quality of life^[21]; thereby, they devote more time to their family's care as caregivers.^[7] Comparing the findings of the preceding literature with the current research discloses the awareness needs, which seem to be the most significant. A preliminary study from America with the inclusion of seventeen FCGs of PwSCI has stated about health informational needs and why it is regarded as the most important need.^[22] The same study has reported that the emotional needs of the FCGs were often unmet, and these findings are on par with the current study findings. A recent qualitative study from Canada has demonstrated the importance of educational training programs for the PwSCI and their family members on building relationships post-injury.^[23]

Many interventional studies across the globe have included psycho-educational intervention in their research studies to provide health information needs to the PwSCI and their FCGs.^[24] In tune with the current study findings, a descriptive survey from Australia with the inclusion of 179 FCGs of PwSCI has concluded that informational, and personal care are the most commonly reported services.^[25] In the current study, some of the FCGs have stated their need to either get new employment or continue the previous one. An editorial article from India mentioned the challenges of PwSCI and their FCGs at the community level and recommended addressing the issues related to vocational aspects and community-based rehabilitation.^[26]

The FCGs have reported about the alternative ways of contacting (telemedicine services) considering the coronavirus pandemic-2019; they have stated the significance of the alternative ways of contacting to ensure follow-up and continue the therapy sessions. The rehabilitation professionals have said that it would decrease the treatment cost and increases the quality of life of the PwSCI.^[27] The FCGs in this research identified the telemedicine needs for their benefits based on their observations and suggestions, such as ensuring regular follow-up, supervising the PwSCI exercises, conducting therapy sessions, clarifying doubts and raising awareness on the realistic condition of PwSCI, and to get an online prescription. A literature review from Ireland has concluded that providing interventions like problem-solving skills and family training to the FCGs of PwSCI is the need of the hour; this is resonating with the current study findings.^[28]

The need for resources for the continuation of treatment in this research is similar to the previous studies across global perspectives of the special attention rendered for referral services related to the management of clinical symptoms and secondary complications associated with SCI.^[29] However, the FCGs in this study have mentioned various resources for the continuation of treatment like neuro care hospitals, rehabilitation centres, occupational centres and physiotherapy centres, and government medical centres.

The FCGs spend a significant amount of time, effort, and resources taking care of persons with neurological disabilities as part of caregiving and the majority of the care is provided by informal carers.^[30] In line with the above cross-sectional study from India, the FCGs have stressed the importance of personal care needs that they need a break from caregiving, want to adhere to daily activities timely, and need alternative caregiver support. The current study identifies some unique needs, such as alternative ways of contacting, the helpful environment of arrangements, sources to get money, pension certificate needs, and resources for livelihood. Awareness needs (want to know about the illness details) were the most commonly reported needs from many studies from across the globe. Even in the current study, almost all the FCGs have stressed the importance of awareness needs. However, considering the socio-cultural background of the Indian FCGs have reported some unique needs. The utmost dominant needs were awareness, resource, and personal care needs, as per the FCGs of this study.

Strengths and limitations

Our information indicates that this is the first study to look at the psycho-social needs of Indian FCGs with PwSCI using only in-person interviews to determine the FCGs demands from their own viewpoints. The study was conducted in a tertiary care hospital run by the government of India; hence, the sample is diverse and represents subjects from across the country. Limited sample size and convenience sampling are two limitations of the current research.

Implications

The current study highlights the psycho-social needs of the FCGs during hospitalisation. These insights will help us to provide appropriate and comprehensive psychosocial interventions for the FCGs of PwSCI. Also, it will help us to modify the hospital administration procedures for rehabilitating and adequate psycho-social-vocational functioning of the PwSCI caregiver programmes within the neurological rehabilitation services.

Recommendations

The perspectives and experiences of the FCGs of PwSCI would be considered while creating customised psychosocial interventions and testing them in controlled environments based on the psycho-social needs of FCGs. The multidisciplinary team would incorporate the study's most recent findings into its management strategy in order to provide the FCGs with a promising course for intervention. Future studies can combine quantitative and qualitative methods with a sizable sample size to support their conclusions. Certain policy-level actions would be started in order to address some of the demands of the FCGs from their own perspectives.

Conclusion

The FCGs of PwSCI in India have unique, significant psycho-social needs that are atypical in nature, and these needs are common in most of the FCGs. The rehabilitation professionals understand in meeting the above-mentioned psycho-social needs during the admission, and post-discharge, which will enhance the psycho-social outcomes among the FCGs and helps in PwSCI recovery. This study highlights the development of tailor-made psycho-social interventions for the FCGs of PwSCI.

The primary care and family physician will get an insight into the psycho-social needs of the FCGs of PwSCI. Since they are in the first line of the acute phase of the trauma treatment, this information will help them to meet the psycho-social needs of the FCGs.

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Conflicts of interest

There are no conflicts of interest.

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Supplementary File

Awareness Needs

Wanted to know health status and recovery process

- *I am concerned about my son's recovery... How long will it take for him to walk and do his day-to-day activities on his own... at times, I even think about whether he will walk or not like before (.) we want to know about his current health condition, S, 48 years, Male.*

Alternative ways of contacting/reaching out

- *This COVID pandemic has made our lives very difficult; having a person with spinal cord injury at home during such a difficult time is a very painful situation (.) We also couldn't contact the local doctor; my husband has an infection and urine leakage. Considering such conditions, it would be better if we provided online consultation facilities, S, 32 years, Female.*

The helpful environment of arrangements

- *I am in dilemma whether to continue the rehabilitation or not, my brother has gone back to home to look after my mother(.), I am working person and I can't stay with my father in the ward to look after him, we will be grateful if you help us finding a care taker and give permission for them to stay with the patient, K, 41 years, Male.*

Resource Needs

Sources to get money

- *I am facing a lot of financial issues in managing the expenditures related to my wife's treatment, I am a security guard, and all my salary would go to meet the basic needs of us..., now this unexpected situation has changed our lives, and we need to sell the gold. Now I am worrying about the post-discharge expenditures, especially medicines on a regular basis; R, 58 years, Male.*

Pension certificate needs

- *I learned that patients like my mother would be eligible to apply for a pension certificate. Could you tell us the procedure for the same.... It will be of great help so that I can avail of the income tax benefit or if there are any other benefits with this certificate (.) S, 35 years, Female.*

Resources for livelihood

- *I am a married person and have a child, now I have to think about what kind of business or job I can do to look after my own family, how long I should depend on my brother for my financial needs...., so if you help me in this regard to find the resources I can plan such activities after the discharge, T, 39 years, Male.*

Resources for continuing the treatment

- *We are not aware of the good physiotherapy centers in our home town; if you could inform us about the physiotherapy centers..., we can continue practicing the exercises for the patient on a regular basis; J, 41 years, Male.*

Personal Care Needs

My own time

- *Being an employee, living in a joint family and looking after a person with a spinal cord injury during the evening is very difficult, and I feel like there is no break for me to spend time for myself....I have sacrificed my Sundays and holidays to take care of my injured brother, K, 32 years male.*

Controlling of feelings

- *Sometimes, I feel like running away from this caregiving or just me and my son will take poison and die ((weeping)), how many more days do we have to lead a life like this? I don't understand how to deal with these difficult situations and having no hope and no recovery, R, 29 years, female.*