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Research Article

IMPACT OF LOCKDOWN DURING THE NOVEL CORONA VIRUS DISEASE 2019 (COVID-19) PANDEMIC ON PERSONS WITH SPINAL CORD INJURY LIVING IN THE COMMUNITY: A STUDY FROM INDIA

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ABSTRACT

Objective: To assess the impact of COVID-19 lockdown on persons with spinal cord injury (PwSCI).
Study design: Survey
Setting: Department of Neurological Rehabilitation in a tertiary care hospital located in southern India.
Method: Persons with spinal cord injury-PwSCI (traumatic or non-traumatic) who underwent in-patient rehabilitation between 1st February 2018 and 1st February 2020 were included in the study. Their clinical details were obtained from hospital records. A telephonic interview was conducted between 18th and 25th May 2020. A questionnaire was used to conduct the interview and responses were recorded. Thematic analysis of qualitative data was done.
Results: 35 PwSCI participated in the study. The mean (SD) age of participants was 31 (15) years, most participants were men (n=23). Out of 35 participants, 14 (40%) individuals were diagnosed with traumatic SCI. Most individuals were unmarried (n=19) and unemployed (n=21). Eighteen PwSCI did not have access to treatment and therapy during lockdown. Most participants (n=19) had basic knowledge about COVID-19, (n=12) PwSCI had concerns related to COVID-19 pandemic. Twelve (n=12) participants reported the pandemic is affecting their mental health. The areas of concern were varied and related to availability of health services including teleconsultation, mental health issues like anxiety and fear, access to preventive measures, and lack of employment.
Conclusions: COVID-19 pandemic has significant impact on the lives of PwSCI. All the stakeholders have to collaborate to minimize the impact of COVID pandemic on PwSCI.

INTRODUCTION

The outbreak of novel Coronavirus disease 2019 (COVID-19) was declared as public health emergency of international concern (PHEIC) on January 31st, 2020 and as a global pandemic on March 11, 2020 by the World Health Organization (WHO). It was first reported from Wuhan city, China. In India, the first case of COVID-19 was confirmed on January 31st 2020 and the number of cases has been substantially increasing by the day since then.

People around the globe are witnessing unprecedented changes in their lifestyles due to the implementation of the various measures taken by the respective Governments amid the COVID-19 pandemic [1]. This crisis is affecting families, health care systems, the global economy, and having an impact on the vulnerable population of people with neurological conditions like Parkinson's disease [2] and spinal cord injury (SCI) [3]. In India, the prevalence of SCI is around 236 per million and the incidence of SCI is about 15-20 per million per year [4].

As a part of preventive measures against the COVID-19 pandemic in India, the Government of India imposed a nationwide lockdown on 24th March 2020 which was extended up till 30th June 2020 in five phases due to an increasing number of positive cases. During this period, public services (except essential) were prohibited, travel by air and rail were suspended and travel by road was restricted. Most hospitals suspended their outpatient services, thereby; regular follow-up care of patients also got affected due to travel restrictions.

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There is a dearth of literature about how the lockdown has affected vulnerable individuals in the community across the globe. Hence, it was necessary to study the problems faced by PwSCI (persons with spinal cord injury) living in the community during this period. Keeping this as the objective, the current study has looked into the concerns of the PwSCI during the COVID-19 lockdown in a developing country.

METHOD

The study was conducted in the Department of Neurological Rehabilitation at a tertiary care hospital in India. A review of hospital records of the patients discharged between 1st February 2018 and 1st February 2020 was done. Individuals who underwent inpatient rehabilitation for spinal cord injury (traumatic or non-traumatic) in the above mentioned period and aged between 15 to 60 years were included in the study. Basic socio-demographic data and contact details were collected from the inpatient records.

As the outpatient services were closed and PwSCI could not travel due to lockdown, a telephonic interview was conducted between 18th and 25th May 2020 by one of the investigators. Dropped phone calls were excluded from the study due to network connectivity issues. The data obtained during the telephonic interview consisted of socio-demographic details like age, education, occupation, marital status, economic status, and the clinical profile like duration of illness and associated co-morbidities. A semi-structured questionnaire was prepared by the researchers to obtain the data along with the questions to assess the objectives of the current study, like:

1) Do you have access (availability) to treatment-related materials (medication, materials needed to manage bladder (perform clean intermittent catheterization), orthotics, mobility aids, and assistive devices) and regular therapy (physiotherapy, occupational therapy and psychotherapy etc)?
2) Have you or any of your family members been diagnosed with COVID-19 (positive test)?
3) What do you know about the symptoms of COVID-19 and the preventive measures to be followed?
4) Any concerns related to the COVID-19 pandemic?

During the telephonic interview, the respondent's socio-demographic details and responses to the questionnaire (listed above) were recorded verbatim.

In addition, the investigator enquired about the challenges being faced by them, due to the lockdown. Their response was recorded and a thematic analysis was done to bring out their concerns. The data was analyzed in Microsoft Excel software 2007 version. For continuous variables (age, duration of illness) the mean, standard deviation (SD) are reported. For categorical variables, the data is presented as frequency and the percentage. Verbal consent was taken from the respondents to conduct the interview and record it.

RESULTS

The contact details of 50 patients who fulfilled the inclusion criteria were obtained from our records. Of these, we could establish telephonic contact with 35 PwSCI.

Table 1 Sociodemographic and clinical profile of the participants (n=35)

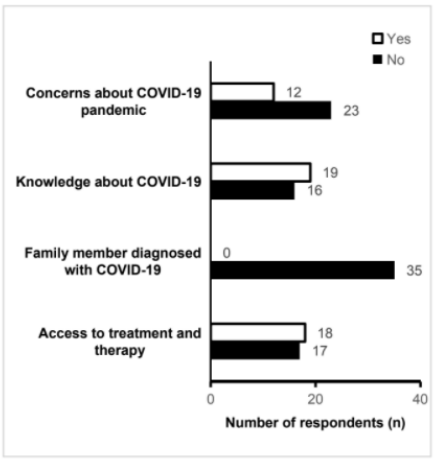
Variables		Frequency (n)	Percentage (%)
Gender	Male	23	65
	Female	12	34
Education	Illiterate	4	11
	Up to class 12	21	60
	Graduation	10	28
Marital status	Unmarried	19	54
	Married	16	45
Occupation	Farmer	6	17
	Own business	2	5.8
	Employee	6	17
	Unemployed	21	60
Socio-economic status	Low	17	48
	Middle	13	37
	High	5	14
State	Karnataka	18	51
	Other states	17	48
Diagnosis	Traumatic SCI	14	40
	Non-traumatic SCI	21	60
Co-morbidity	Yes	8	22
	No	27	77
Age in years [mean(SD)]		31(15)	
Duration of illness in months [mean (SD)]		11 (5.6)	

The mean (SD) age of the respondents (n=35) was 31(15) years, most participants were men (n=23). Most individuals were unmarried (n=19) and unemployed (n=21) and were from lower socio-economic strata (n=17). Among the respondents, 14 individuals were diagnosed with traumatic SCI. Among those with non-traumatic SCI (n=21), the most common etiology was transverse myelitis (n=7), followed by infection (tuberculosis, n=4), cervical spondylotic myelopathy (n=3) and vascular myelopathy (n=1).

History of co-morbidities (diabetes mellitus/ hypertension/ alcohol dependence syndrome and nicotine dependence syndrome) was present in eight participants. The mean duration of illness was 11 months (SD 5.6).The sociodemographic and clinical profiles of the respondents are shown (Table 1).

During the lockdown, 17 PwSCI did not have access to the materials which are used in the long term management following SCI (medicines, dressings for pressure ulcer, materials needed to perform clean intermittent catheterization, mobility aids) and therapy.16 participants expressed lack of knowledge about COVID-19 including symptoms and precautions to be taken. Twelve PwSCI wanted to know about COVID-19 pandemic and enquired about the route of transmission, course of the pandemic, duration of the pandemic, availability of treatment including vaccine, quarantine and hospitalization facility (figure 1).

	No	Yes
Access to treatment and therapy	17	18
Family member diagnosed with COVID-19	35	0
Knowledge about COVID-19	16	19
Concerns about COVID-19 pandemic	23	12



Thematic analysis of data has been shown (Table 2). The following statements of the PwSCI exemplify their concerns in relation to:

Table 2 Thematic analysis of the data

Variables		No of positive (yes) responses
Treatment or health	Difficulty in reaching hospital for follow up	19
	Worried that I may get infected during travel to the hospital for follow up	6
	Could not achieve the functional recovery as expected	4
	Worried about current health status	9
	I would like to talk to the physician about my current condition and medication	11
	I was not able to buy medicines or other materials (related to bladder management, mobility aids)	12
	Concerned about readmission in the hospital	5
	Difficult to consult the physician	4
	Difficult to continue therapy services	11
	I was not able to practice walking outdoors	6
Job/work	I was unable to reach workplace	7
	My family members were not able to start the business/shops	13
	Difficulty in applying for new job	2
	Job application status is pending	3
Finance	Any financial issue	23
	I have taken debts to take care of my family	13
	I have taken debts to continue treatment	4
	I am using my savings to take care for my family	4
Family	Difficult to manage the needs of my family	14
	Other family members have health issues	6
	Difficult to manage behavior of my family members	8
Travel	Not able to visit ill family members	4
	Family members were unable to come home (migrant workers)	6
Miscellaneous	Difficulties related to disability certification	7
	Not receiving disability pension	4
	Worried about vocational aspects	6
	Worried about the continuation of education	4
	Lack of safety gear (masks, gloves, sanitizers) and information booklets	11

Treatment or health

1. I have missed my follow-up consultation as advised due to travel restrictions. I have queries related to medications and I am not noticing any recovery.
2. In my village, there is only one physiotherapist who is not been able to travel to my home for therapy due to lockdown.
3. I am staying in a remote area, the prescribed medicines are currently unavailable.

Vocation

1. I own a petty shop which is the only source of income to run the family. Due to the lockdown, I have not opened the shop for 45 days.
2. My husband is a car driver, our family depends on his earnings. Since the lockdown began, he has not gone anywhere.
3. My parents are daily wage workers and our family depends on their earnings. They were not able to find opportunity to work because of lockdown.

Financial status

1. In our family of 6 people, my father who is a farmer is the breadwinner. He has no monetary savings to run the family.
2. Because my husband could not work during the lockdown, we have taken debts from relatives to meet my medical expenses and run the family.
3. I have to take care of my parents and I am repaying the debt that I had taken to establish my shop. Due to the lockdown, I am unable to open my shop, now I am using the money I had saved for the continuation of my treatment.

Family

1. My family member has a chronic illness, due to lockdown, we could not continue the treatment.
2. My primary caregiver is my husband, he is finding it difficult to manage his work and to take care of my needs. He is experiencing physical and mental fatigue.
3. My primary caregiver is my wife, she is ill and unable to perform household chores. I have a family member with a disability. I am wheelchair-bound, hence, there is no one to take her to the hospital or help us at home.

Travel

1. My brother-in-law is a migrant worker in another state. We are concerned about his health and return to our village. My parents are distressed thinking about his return.
2. My parents went to visit my elder brother, to see their grandson. My elder brother resides in another city. My parents have not been able to return home due to a lack of transportation.
3. My grandfather recently fell ill and I am concerned about him. I was not able to visit him due to the travel restrictions.

Miscellaneous problems

1. I have applied for a disability identity card (certificate) but I have not received it. I do not know whom to contact. If I receive it, I will get financial assistance and this will be of great help to my family.

2. In my locality, we do not have access to sanitizers and masks for the prevention of infection. I am worried that I may get infected if I go out.

DISCUSSION

The unprecedented nature of lockdown has affected everyone, especially, people living with disability. The current study may help us understand the concerns of the PwSCI amid the COVID-19 pandemic in a developing country. To the best of our knowledge, this is the first study analysing the impact of lockdown during COVID-19 pandemic in rehabilitated PwSCI. The altered physiology following SCI can alter or mask the symptoms/signs of COVID-19 this poses a significant challenge for appropriate management [5, 6]. Early screening for COVID-19 and its timely diagnosis is important in persons with SCI. In our study, 16 (45%) PwSCI expressed a lack of knowledge about the presenting symptoms of COVID-19 and the preventive measures to be followed. The COVID-19 infection might affect the nervous system [7].

The existing disability in PwSCI may increase if they have additional neurological manifestations due to COVID-19, hence, prevention of infection is important. In our study, 11 (31%) participants did not have access to protective measures like masks and hand sanitizers. During the telephonic interview, the respondents were educated about the symptoms, signs of COVID-19, and preventive measures to be taken.

In addition, 12 PwSCI expressed concerns about the COVID-19 pandemic. They were provided relevant information along with contact details of helplines, which would aid in obtaining further information on a real-time basis and provide any assistance (if need be). In low and middle-income countries, most (67%) rehabilitated persons with SCI use reusable catheter for clean intermittent catheterization [8]. During rehabilitation at our center, PwSCI are taught bladder management with clean intermittent catheterization using Nelaton or Foley's catheter.

Majority of our follow-up patients with SCI need assistance of a family member or a therapist for their regular exercise program. In our study, due to lockdown 12 (34%) participants did not have access to prescribed medicines, catheters or mobility aids and 11 (31%) were finding it difficult to continue therapy.

The pandemic has led to the worsening of a sedentary lifestyle. Six (17%) participants were not able to practice outdoor walking, which might lead to secondary complications. PwSCI residing in India, especially in rural areas, face challenges of uneven terrain and lack of barrier-free environment. These factors, when combined with the inability to visit specialized SCI center due to lockdown can further delay the detection and appropriate management of complications in these individuals. In the present study, 19 (54%) PwSCI reported inability to report in the hospital to discuss their current medication and health status. Eleven (31%) individuals with SCI, expressed their desire to consult the treating doctor over telephone, to discuss concerns related to medication and functional status. The Italian Society of Physical and Rehabilitation Medicine has recommended use of tele-rehabilitation services for outpatient consultation [9]. PwSCI were advised to consult us through teleconsultation services available in the institute for the last 8-10 years. Though respondents wished to have a follow-up consultation at the hospital, they were worried (n=9) about getting infected with COVID-19 if they were to visit the outpatient services. Telemedicine services may reduce the travel burden, other expenses and need for physical presence in outpatient clinics [10], thereby, preventing potential exposure to infection. Tele-rehabilitation services utilize lesser resources by minimizing the barriers of distance, time, and cost [11].

Previous research finding in community-dwelling rehabilitated persons with SCI residing in south India suggest that physical independence and social integration is adequate but low economic self-sufficiency as compared to other developed countries [12]. In our study, 13 (37%) participants reported family members were not able to open their shop or business due to lockdown. As the PwSCI were dependent on the income of their family members, the lockdown had a negative impact on this vulnerable population. About 48% of the participants (n=17) incurred debts due to the monetary constraints during the lockdown.

A study conducted in Australia, reported return to work in about 35% of the individuals with SCI [13]. Seventeen participants (48%) were from low socio-economic status and 7(20%) participants were not able to reach their workplace. A recent cross- sectional study done in Bangladesh reported that the median (IQR) monthly income of each family member was US$30 (US$19-US$48) prior to injury and dropped to US$0 (US$0–US$18) following injury[14]. In the present study, most participants were residing in rural areas and the total annual income of their family was less than US$262 (US$22 permonth). Fourteen (40%) PwSCI reported difficulty in managing the needs of their family. Moreover 11 (31%) PwSCI were not receiving disability pension which amounts to nearly US$26 per month. The response to COVID-19 must be inclusive so that persons living with disability can continue their education and work [15]. In the present study, PwSCI expressed their worries about continuing the previous employment or finding a new job and return to education.

Twelve PwSCI reported that the pandemic is affecting their mental health. They described an increase in anxiety, fear of getting infected, inability to concentrate, and restlessness. Fear, uncertainty, and stigmatization are commonly reported mental health issues during infectious disease outbreaks [16]. Providing information about the pandemic may reduce the psychological impact on individuals [17] Counselling was done over the telephone to alleviate these concerns of PwSCI. All the SCI health care professionals and advocacy groups should come together in an organized and approachable manner to proactively diminish the direct and indirect effects of COVID-19 on the SCI population [3].

The present study has several limitations. We used a telephonic interview for assessment, however, as the lockdown was mandated, a face-to-face interview was not feasible. The questions used in our study are not standardized or validated for research. The cohort of participants are from a single neurological rehabilitation center, however, they are residing in various states across the country.

The study was conducted during the lockdown and the restrictions are being relaxed gradually. In this scenario, it is likely that the concerns (problems) expressed (faced) by PwSCI may not resolve immediately. The findings of our study may not be generalized to the entire SCI population; however, similar issues may exist in other parts of our country and rest of the world.

CONCLUSION

COVID-19 pandemic has a significant impact on the lives of PwSCI. The areas of concern are varied and range from basic access to preventive measures, healthcare services, and caregiver support, to the continuation of education and employment. Health care professionals, advocacy groups, non-government organisations, and Governmental agencies have to collaborate to minimize the impact of COVID-19 in PwSCI.

Implications

Tele consultation services to be initiated by the other allied health professionals (physiotherapists and occupational therapists) to continue the care for the PwSCI.

Teleconsultation services in district hospital are the need of the hour.

The care giver support groups can have teleconsultation with the different stakeholders who have involved in the continuum of care for the PwSCI.

Future recommendations

There is a need to look at the coping strategies and resilience among the PwSCI and their care givers during the pandemic, and also explore how they are managing the stress and psycho-social issues which arise during this pandemic with the existing resources. After care (post discharge) services plays a crucial factor for the well being of the patients with neurological conditions.

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Conflicts of interest

The authors declare no conflicts of interest.

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