

ORIGINAL ARTICLE

Challenges in comprehensive management of spinal cord injury in India and in the Asian Spinal Cord network region: findings of a survey of experts, patients and consumers

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Study design: Online survey.

Objectives: To understand the prevailing scenario of the comprehensive management of spinal cord injuries (SCI) in India and in the Asian Spinal Cord Network (ASCoN) region, especially with a view to document the challenges faced and its impact.

Setting: Indian Spinal Injuries Centre.

Methods: A questionnaire was designed which covered various aspects of SCI management. Patients, consumers (spinal injured patients discharged since at least 1 year) and experts in SCI management from different parts of India and the ASCoN region were approached to complete the survey.

Results: Sixty patients, 66 consumers and 34 experts completed the survey. Difference of opinion was noticed among the three groups. Disposable Nelaton catheters were used by 57% consumers and 47% patients. For reusable catheter, 31% experts recommended processing with soap and running water and 45% recommended clean cotton cloth bag for storage. Pre-hospital care and community inclusion pose the biggest challenges in management of SCI. More than 75% of SCI faced problems of access and mobility in the community. Awareness about SCI, illiteracy and inadequate patient education are the most important factors hindering pre- and in-hospital care. Inadequate physical as well as vocational rehabilitation and financial barriers are thought to be the major factors hindering integration of spinal injured into mainstream society. Strong family support helped in rehabilitation.

Conclusions: Our study brought out that SCI in India and ASCoN region face numerous challenges that affect access to almost all aspects of comprehensive management of SCI.

Spinal Cord (2018) **56**, 71–77; doi:10.1038/sc.2017.102; published online 12 September 2017

INTRODUCTION

Management of spinal cord injury (SCI) was revolutionized during the second world war.^{1,2} The establishment of services for comprehensive SCI management and ongoing technological advancements has made improvement in outcomes and quality of life possible. However, numerous factors in low- and middle-income countries (LMIC) still pose a big challenge to SCI comprehensive management and inclusion in the community.³ Thus, a large number of SCI in LMIC are still deprived of the benefits of advancements of knowledge and technology available to their counterparts in high-income countries.

Moreover, there is often a substantial delay in initiating management. In a previous study, causes and overall consequences of delay in initiation of comprehensive management of SCI were studied.⁴ It was evident that the delay added to the complexity of management, resulted in a higher incidence of complications, longer hospitalization, added costs and adversely affected outcomes.⁴

Rathore *et al.*⁵ identified the challenges faced in traumatic SCI management in Pakistan. Others have investigated the challenges in

individual components of SCI management like the inadequacy of pre-hospital care in LMIC.⁶ Scovil *et al.*⁷ highlighted inadequate community integration and health problems of spinal cord injured after discharge in Nepal. Chhabra *et al.*⁴ pointed out that the lack of infrastructure and trained manpower in India are important challenges. Hansen *et al.*⁸ brought out the challenges of vocational rehabilitation in Bangladesh.

Even though the challenges in comprehensive management of SCI are quite obvious in less-resourced settings, there is hardly any published literature on overall challenges for comprehensive management of SCI. Hence, we conducted this study in order to understand the prevailing scenario of comprehensive management of SCI in these less-resourced settings with a view to document the challenges and its impact. In order to get a comprehensive understanding, the patient's and consumer's perspective were also studied in addition to that of the experts. The term consumer has been used for people with spinal cord injury who have been discharged from the hospital since at least 1 year. The term expert has been used for people with specialized skills and knowledge in SCI management.

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The study had been presented as a poster in the Associations of Spine Surgeons of India session at Spine Week 2016 in Singapore. The same has been published as proceedings of the meeting in *Asian Spine Journal*. (Associations of Spine Surgeons of India 2016. *Asian Spine J.* 2016 Jun; 10(suppl 1): S1–S31).

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Received 22 September 2016; revised 1 July 2017; accepted 10 July 2017; published online 12 September 2017

METHODS

A questionnaire was developed especially for this purpose. It covered various aspects of SCI management like pre-hospital care, acute care, comprehensive rehabilitation, bladder management, the availability of infrastructure, community inclusion, prevention, components posing challenge, factors hindering management and strengths of the society helping overcome the challenge.

The questionnaire for experts had 54 multiple choice questions in all. For 34 questions only one option could be chosen, whereas for 20 questions multiple options could be chosen. Thirty-four experts in SCI management from different parts of India and the Asian Spinal Cord Network (ASCoN) region were approached to participate in the survey.

Sixty patients from two Indian centers and 66 consumers from various parts of India were approached to participate in the survey and complete the modified versions of the same questionnaire containing 35 and 37 questions, respectively (see Supplementary Data for accessing the questionnaires). It was different than the one for consumers as it contained questions directed to patients regarding the injury and details regarding the pre-hospital, in-hospital and counseling facilities before discharge from the hospital. The questionnaire for patients explored the factors that play an important role in accessing management from the patient's perspective, including those that hindered acute management, surgical intervention, bladder management as well as prevention and management of complications during hospitalization. The questionnaire for consumers on the other hand also covered the perception of consumers regarding the factors hindering management of SCI, especially community inclusion and vocational rehabilitation. The data were analyzed separately for patients, consumers and experts, and presented as descriptive statistics.

RESULTS

Sixty patients, 66 consumers and 34 experts completed the survey. Thus, 75% patients, 83% consumers and 68% experts to whom the questionnaires were sent responded. Patients participated from two centers from India, consumers from 14 states of India and experts from 9 countries of the ASCoN region (including India) (see Table 1). The experts', patients' and consumers' opinions were almost similar with respect to availability of facilities including pre-hospital, acute and rehabilitation care for most of the aspects of SCI management (see Table 2). However, there was a difference of experts', patients' and consumers' opinions in availability of first-aid at-site, trained staff for evacuation, ventilator facilities, conduction of periodic meeting for assessment of achievements of goals and availability of vocational counseling.

Figure 1 depicts the experts' perspective of availability of disciplines involved in SCI management. Vocational counselors, peer counselors,

sports counselors, social workers, trained staff for evacuation, orthotists, occupational therapists and psychologists were the disciplines least available in that order. Physicians, nurses, nurse aid/ward aide and physiotherapists were the disciplines generally available.

Experts', patients' and consumers' perspective on the availability of various facilities for physical, psychosocial, sexual, vocational rehabilitation, pre-discharge planning and follow-up is depicted in Figure 2.

Fifty-seven percent consumers and 47% patients used disposable Nelaton catheters (see Figure 3). Thirty-nine percent experts and 32% consumers recommended processing of reusable catheters with soap and running water. Majority of experts (46%) recommended a clean cotton cloth bag for storage of a catheter at home. While 77% experts suggested that concomitant medical therapy was administered for voiding dysfunction, only 23% patients claimed to have received it.

The patients and consumers identified awareness about SCI/ illiteracy/inadequate education as the most important factors hindering pre-hospital care. The same were also the most important factors hindering all aspects of management of SCI. Mind-set and social beliefs were identified as the least important factors in this regard (see Table 3).

According to the consumers' perspective, pre-hospital care and community inclusion are the two biggest challenges in the Indian setup (see Figure 4). The majority of consumers reported that access (54%) and mobility (48%) were the most common problems faced by more than 75% of people with SCI in the community.

Experts were of the opinion that inadequate vocational rehabilitation and financial barriers are the two most important factors that hinder the integration of people with SCI into mainstream society. These were followed by inadequate physical rehabilitation, problems of access in the workplace as well as the environment and lack of availability of assistive technology in that order of importance. The experts, patients and consumers unanimously pointed toward the strong family and spouse support as being the most positive factor that helped overcome the challenges (see Table 4).

DISCUSSION

The revolution of SCI management brought hope to a large number of people suffering from this devastating ailment.¹ However, for quite a while the benefits of these advances in management were largely available in the high-income countries where numerous SCI centers

Table 1 Geographical representation of patients, consumers and experts

Item	Patients	Consumers	Experts
Number	60	66	34
Inclusion criteria	Completion of in-hospital care	Discharged from hospital at least since 1 year	Dealing with SCI patients
Geographical regions – participants	Indian Spinal Injuries Centre (ISIC) – 40 All India Institute of Medical Sciences (AIIMS) – 20	Chandigarh – 2 Gujarat – 4 Haryana – 6 Jharkhand – 2 Karnataka – 4 Madhya Pradesh – 2 Maharashtra – 8 New Delhi – 16 Punjab – 4 Telangana – 4 Uttar Pradesh – 8 Uttarakhand – 2 West Bengal – 4	Bangladesh – 3 China – 1 India – 15 Malaysia – 1 Nepal – 7 Pakistan – 2 Sri Lanka – 3 Thailand – 1 Vietnam – 1

Table 2 Percentage of respondents declaring availability of various individual components of SCI management

	Patient	Consumer	Expert
<i>Pre-hospital care</i>			
First-aid at-site	10	13	42
Trained staff for evacuation	3	6	70
Two or more institutional transfer before reaching definitive institution	63	56	69
Time taken to reach definitive institution more than 1/2 months	22	16	26
Deterioration in neurological status while transfer to definitive institution	19	28	21
<i>Acute hospital care</i>			
Acute management facilities for spinal cord injury	33	32	40
Protocols for acute care	NA	NA	8
Ventilator facilities	40	52	84
Administration of anticoagulant prophylaxis	47	45	45
<i>Rehabilitation care</i>			
Trained rehabilitation staff for management of spinal cord injury	42	32	53
Initial assessment followed by goal planning for treatment	33	32	41
Periodic meeting once weekly for assessment of achievement of goals and progress	18	31	30
Periodic meeting once monthly for assessment of achievement of goals and progress	82	6	7
<i>Sexual management</i>			
Sexual counseling for patients	23	33	37
Sexual counseling for spouse	12	22	10
Educational material (video demonstration) for sexual counseling	13	19	5
Fertility clinic services	3	4	8
<i>Community inclusion/vocation</i>			
Vocational counseling	59	46	30
Employment after discharge			
<10%	NA	4	65
11–30%	NA	16	15
31–70%	NA	27	16
>70%	NA	54	4

were set up. The LMIC were slow to respond to the needs of the society in this regard.^{2,5} This could be attributed to various reasons. SCI has a comparatively lower incidence as compared to other ailments. Since its management is much more expensive for the same investment, a much larger population can be covered for management of other ailments with more obvious results.⁵

It has been mainly in the past two decades that the LMIC have focused on setting up services for SCI management and dedicated SCI centers. The number of such centers available are, however, often inadequate to meet the needs of the population.^{3,7} In addition, there have been numerous other challenges that have prevented people with SCI in these countries to get the benefits of optimum treatment as per established standards.⁹ These challenges have affected almost all aspects of SCI care.⁴ This study was conducted in order to document these challenges and their impact.

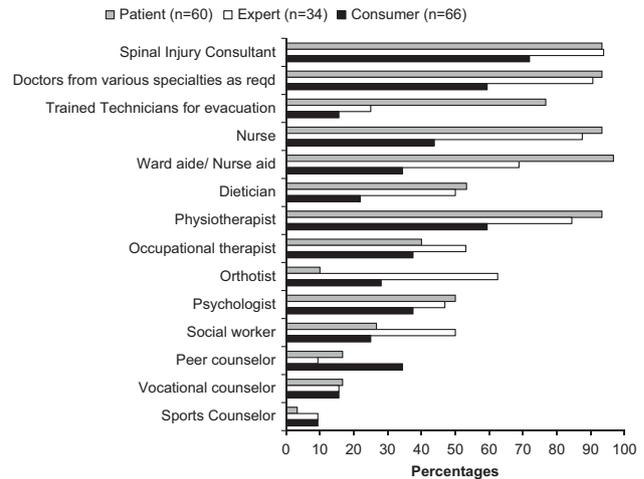


Figure 1 Opinions of respondents regarding availability of various healthcare professionals involved in SCI management.

Including the experts, patients and consumers in the survey helped in getting a better perspective of the actual prevailing scenario. The potential benefits of consumer involvement in such research is well established.¹⁰ With lack of adequate information on fulfilled and unfulfilled needs, studies that evaluate consumer perspectives can be useful in obtaining information as to whether or not services are meeting their requirements. It was felt that experts may have a better perception of the facilities available in their institution, especially for acute management, whereas the patients and consumers from their own experience and that of their peers might have a better perception of most other aspects like pre-hospital care, rehabilitation, psychosocial aspects pertaining to management and ease of accessibility of the facilities. In addition, consumers were expected to be in a better position to assess how the outcome translates into practically getting them back into a normal lifestyle and the other issues pertaining to community inclusion.

Pre-hospital care

It is well established that pre-hospital care substantially improves the outcomes of SCI management.⁶ Implementation of emergency medical services in high-income countries have a positive impact on the chances of survival in people with SCI¹³ and has decreased the incidence of complete SCI.¹¹ Our study brought out that this aspect of SCI management has unfortunately received less attention in the ASCoN region. Only 3% patient respondents were evacuated by trained staff and 10% received first-aid at the site of accident. Sixty-three percent of experts reported that pre-hospital care was the most neglected aspect of SCI management. The findings are similar to that of other studies for Asian and other LMIC.^{4,12–14}

Institutional transfers

Studies have also established the importance of minimizing institutional transfers before reaching the definitive institution in achieving an optimal outcome.¹⁵ Our study revealed that this was far from optimal in the ASCoN region. Sixty-three percent of the patients reported that they reached a definitive institution after two or more institutional transfers.

Delay in initiating treatment

One of our previous studies³ had also indicated that late admission to the definitive institution leads to adverse consequences in people with

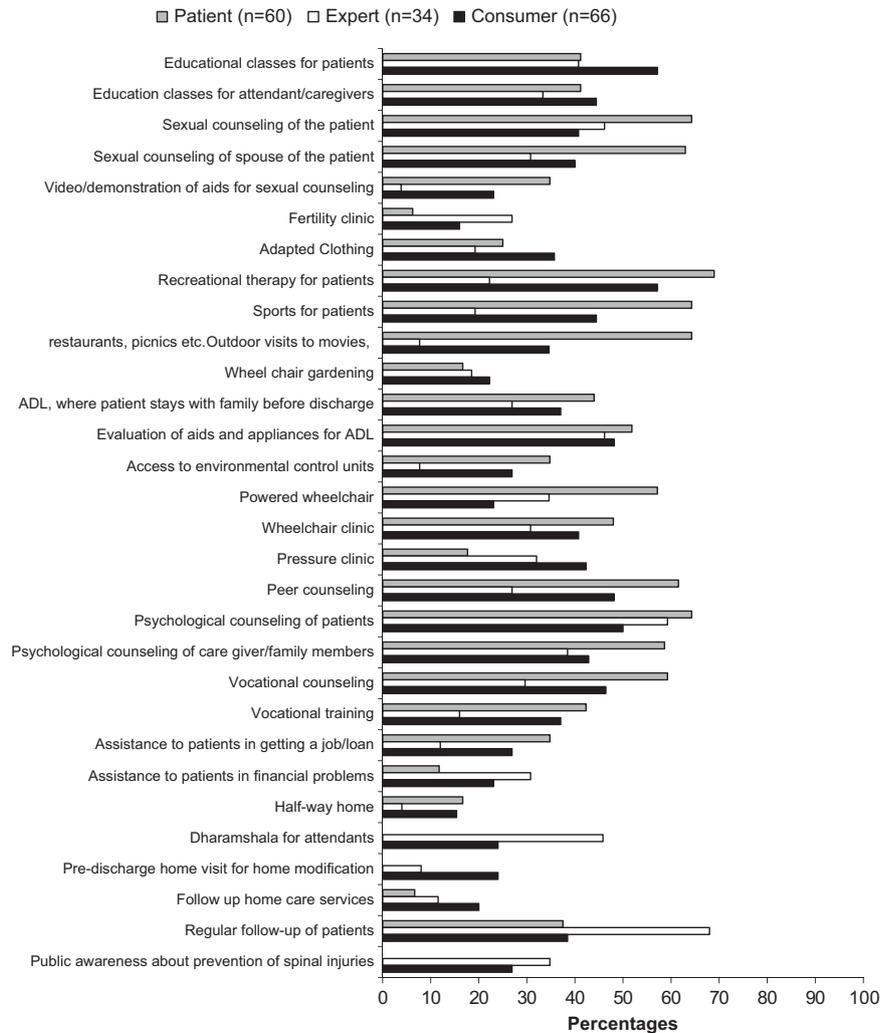


Figure 2 Opinion of respondents regarding availability of facilities for SCI management.

SCI. The compromised outcome of vertebral lesion and rehabilitation, increased incidence and severity of complications led to an overall compromised outcome, longer hospital stay and higher costs of hospitalization. In fact, we had used the terminology of neglected traumatic SCI for people with SCI who reach the definitive institution more than 30 days after the injury. In our study, 22% of patients took more than 1 month to reach the definitive institution.

Acute hospital care

Facilities for acute in-hospital care were available in a third of all the facilities. However, acute in-hospital management is not as neglected as the other aspects of SCI management, probably since infrastructure required for acute management generally is almost the same as that for other trauma and is available at most multi-specialty hospitals. In our previous study also, only 10% of all the neglected traumatic SCI had received no acute management at all, whereas 72% of patients had been sent home after acute management.³

Multidisciplinary rehabilitation

A multidisciplinary rehabilitation team is required to provide optimal outcome in spinal injured.⁹ Our study brought out that all disciplines

are generally not available for SCI management in the ASCoN countries. The findings were similar to that of other studies from ASCoN and other LMIC, where multitasking is often required for care normally provided by other members of the team.^{5,16,17}

Comprehensive rehabilitation care

Comprehensive services of rehabilitation care optimize the outcome, but are generally not available at a large number of facilities in LMIC.^{4,18} This study also reported that important components of comprehensive rehabilitation care like occupational therapy, psychological management, sexuality and fertility management, assistive technology, wheelchair clinic, peer counseling, educational classes, vocational placements, pre-discharge home visit and follow-up home-care services were especially lacking in many of the centers and important principles of rehabilitation like goal planning and monitoring were not followed. For example, 90% experts felt that the patients do not get the benefit of pre-discharge planning.

Management of neurogenic bladder

This aspect of management poses a big challenge in the LMIC. Like previous studies bringing out constraints in access to investigations for

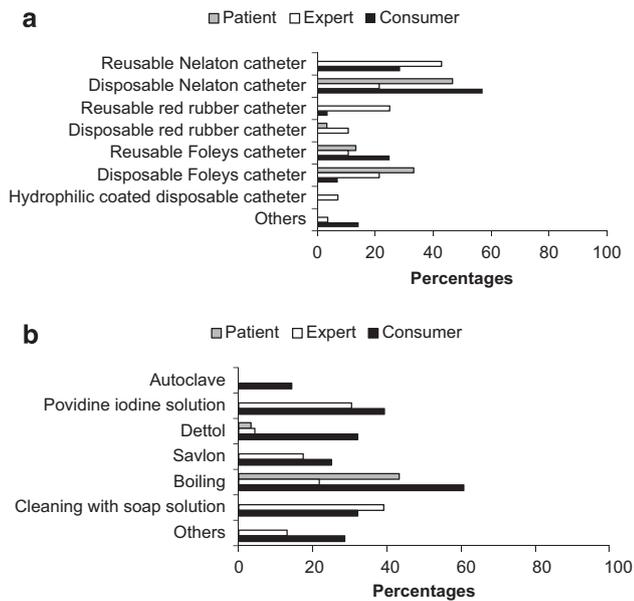


Figure 3 Expert, consumer and patient perspective. (a) Type of catheter used for CIC and (b) mode of processing reusable catheters.

Table 3 Factors (coded 1 through 9) rated by patients and consumers as 'most important' causes of hindrance of various components of SCI care

Component of SCI care	Patient	Consumer
Pre-hospital care	1	1
Acute management of patients during hospitalization	1, 2	1, 2
Surgical interventions of patients during hospitalization	1, 2, 3	1, 2, 3
Bladder management of patients during hospitalization	1, 2	1, 2
Prevention and management of complications of patients during hospitalization	1, 2	1, 2
Comprehensive rehabilitation of patients during hospitalization	1, 2, 6	1, 2
Sexual rehabilitation of patients during hospitalization	1, 9	1, 2, 9

Codes: 1: Awareness about SCI/illiteracy/inadequate education; 2: Not reaching the definitive institution specializing in management; 3: Financial constraints; 4: Psychological factors; 5: Availability of trained manpower; 6: Availability of infrastructure (comprehensive rehabilitation facilities); 7: Availability of technology (AT, free hand system, seating clinic); 8: Mind-set and Social Beliefs; and 9: Inadequate sexual rehabilitation.

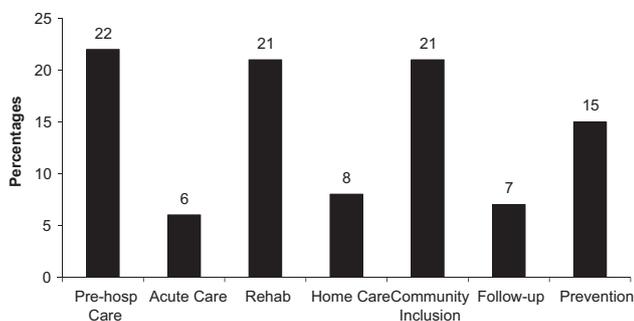


Figure 4 Challenges in management of SCI in the Indian setup: consumers' perspective.

neurogenic bladder evaluation,¹⁹ our study also brought out that up to 66% of patients did not undergo investigations like urodynamics. Knowledge²⁰ and access²¹ to simple and cheap methods of urodynamic evaluation are limited.

Table 4 Percentage of respondents declaring factors that help in overcoming the challenges

Factors	Patient	Consumer	Expert
Strong family support, i.e., joint family system	93	91	100
Strong religious beliefs	23	29	31
Strong support from the spouse	13	24	58
Strong community support	17	48	35
Alternative medicine/therapies	0	38	4

Unlike other studies from LMIC, where it was found that intermittent catheterization is either not initiated or initiated late, or that patients switched back to an indwelling catheter, our study suggests that people with SCI generally continue to use clean intermittent catheterisation (CIC) for bladder management.

Like in other studies that have brought out that due to the costs involved, the majority of patients in the LMIC are not able to afford disposable catheters,¹⁹ our study also revealed that the majority of consumers used reusable Nelaton or Foley's catheters (68%).

Though World Health Organization (WHO) recommends cleaning with soap and running water to process the reusable catheters,²² in our study consumers felt that only 32% of people with SCI use this technique. Various other methods like boiling (61%), povidone-iodine solution (39%), dettol (32%), savlon (25%) and autoclaving in pressure cooker are the modes of processing commonly used.

WHO recommends use of regularly washed cotton cloth bag for storing of reusable catheters.²² As per experts in our study, only 46% people with SCI do so, whereas many persons still continue to use other improper storing methods like povidone-iodine solution (14%), savlon (14%), dettol (9%) and others (18%), thus increasing the probability of genito-urinary complications.²³ The finding of our study that relevant concomitant medications are not adequately used is similar to that of other studies.²⁰

Our study also suggested that urinary tract infection is the complication that bothers patients with SCI, the most in the Indian setup. Other studies have also shown that the rate of genito-urinary and renal complications in patients with SCI in LMIC continues to be quite high leading to substantial morbidity and mortality.^{3,23}

Sexual and fertility counseling

A large number of consumers (67%) did not get adequate sexual counseling, and sexual counseling for the spouse was often left out (78%) in our study. Very few facilities had access to information brochures or other education material for sexual counseling. The finding was similar to that of other studies,^{4,19} which reveal that sexual counseling and management is one of the most neglected aspects of SCI management in the LMIC. As high as 80% of people with SCI and 90% of spouse do not get adequate sexual counseling.²⁴ Among the various factors for inadequate emphasis, the prominent ones are lack of awareness and cultural factors, discussion about sex being a taboo especially for females.²⁵ Fertility counseling and management are neglected even more.²⁵ Our study also brought out that facilities of fertility management are sparse (6%), and if available, affordability becomes an issue.

Assistive technology

Our study brought out the challenge posed by the lack of prescribing proper wheelchairs and making suitable assessment. Numerous other studies have also highlighted this issue,⁶ attributing it mainly to affordability despite the availability of low-cost alternatives.²⁶ The lack

of assistive technology services and availability of assistive devices was also brought out. Other studies have also revealed how affordability deprives the spinal injured of these devices,^{12,26} thus affecting their quality of life.

Home-care and follow-up services

All respondents felt that lack of appropriate home-care services posed a significant challenge for people with SCI. This is unfortunate since home-care services are particularly relevant for LMIC as significant challenges need to be overcome in getting back to a normal lifestyle after discharge, and only few people with SCI can go back to the hospital for a follow-up. The poor follow-up was also substantiated by our study. Sixty percent of the experts felt that less than 50% of patients came back for a follow-up. This had been mainly attributed in another study to financial constraints, difficulties in access to spinal injury centers and transport infrastructure unsuitable for wheelchair users.⁵

Accessibility, community inclusion and vocation

The majority of consumers in our study felt that more than 75% of people with SCI faced problems of access and mobility both in the community and at home. Other studies have also brought out how the issue of accessibility both within the community³ and at home⁷ poses a major challenge for people with SCI in the LMIC restricting their mobility substantially.

Consumers of the study were of the opinion that only 10–25% of people with SCI successfully return to a vocation. Other studies from less high-income countries^{8,27–29} also suggest that return to vocation after SCI is a big challenge. As per experts in our study, inadequate vocational rehabilitation is the main barrier for returning to vocation, followed by lack of awareness of government benefits, lack of opportunity and psychological factors.

Alternative medicine/cellular therapies

Although 38% of consumers in the study felt that the availability of alternative medicine helps overcome the challenges to SCI management in the Indian setup, this can often work like a double-edged sword. Very often the people with SCI keep pursuing alternative medicine with the hope of a 'cure'. This is especially true for cellular therapies. There had been a media hype about the positive outcome of this therapy. People with SCI often spend precious resources to avail such transplantations. In the meantime they do not pursue rehabilitation in the expectation of a 'cure'. Once it becomes evident that they would not improve in neurology, they become depressed.

Outcomes, morbidity and mortality

All respondents felt that the outcomes of most SCI in low-income countries are substantially compromised due to the various challenges. The observation is similar to that of other studies.³⁰ Cripps *et al.*³¹ also brought out that, 'LMIC have the highest one-year mortality rates'.

Prevention

Based on the consumers' perspectives, our study highlighted that the inadequate focus on prevention is one of the biggest challenges in SCI management. A report on global mapping of people with SCI reflects that there is insufficient data on incidence and prevalence.³¹ The absence of accurate data poses a challenge for the formulation of effective prevention programs. Implementation and enforcement of prevention programs is also inadequate, thus compounding the challenge.

Factors contributing to challenges in management

Consumers and experts indicated that pre-hospital care, physical as well as sexual rehabilitation and home-care services pose the most significant challenge for SCI management in the Indian setup. According to the patients and consumers, lack of awareness about SCI/illiteracy/inadequate education, financial constraints and spinal cord injured not reaching the definitive institution specializing in SCI management were the most important contributing factors hindering different aspects of management during hospitalization. The experts felt that inadequate physical as well as vocational rehabilitation and financial barriers are major factors hindering the integration of spinal injured into the mainstream of society.

Thus, our study provides some insights for experts, healthcare providers and policy makers in India as well as the ASCoN countries on the most significant challenges of SCI management and factors contributing to it. This and other subsequent studies will help in developing strategies to overcome the challenge.

Overcoming the challenge

The experts, patients and consumers unanimously pointed out that strong family and spouse support are main strengths of society that helps people with SCI overcome the challenge. Strong community support, strong religious beliefs, innovativeness and availability of cheap and abundant manpower were other factors, which had a positive influence in that order of importance.

LIMITATIONS

On comparison of responses, there were differences of opinion observed between the responses of the patients, consumers and experts. This could be mainly due to the fact that most of the patients were from two tertiary-level centers, which thus had more facilities, whereas the consumers had been treated in all types of centers. The experts were also mainly from tertiary-level centers.

Another limitation of our study was that the patients and consumers were from India, whereas the experts were from many other Asian countries as well. Evaluating patients' and the consumers' perspective from other ASCoN countries would be considered in a subsequent study. And finally, the questionnaire used for this study was not a validated questionnaire. Irrespective of its good face validity, we might have missed some important information related to the challenges in comprehensive management of SCI.

CONCLUSIONS

SCI in India and in other ASCoN countries face numerous challenges, which affect almost all aspects of comprehensive management. Pre-hospital care is one of the most neglected components. The number of SCI centers and the services available are often inadequate to meet the needs of the population. Acute care, bladder/bowel care and sexuality as well as fertility management all add to the challenges of SCI management in these countries. There is a higher incidence of complications in LMIC as compared to high-income countries. Facilities for comprehensive rehabilitation are generally not available, and there is a poor concept of multidisciplinary approach. Post-discharge follow-ups, home-care services and community inclusion and vocation are areas in which LMIC lag behind leading to further hindrance in SCI management. Numerous factors like lack of availability of trained manpower, inadequacy and inaccessibility of services, non-availability of multidisciplinary comprehensive care, lack of a barrier-free environment and financial barriers hinder comprehensive management of SCI and contribute to the challenge. Strong family, spouse and community support, positive attitude of the spinal

cord injured, innovativeness and availability of cheap as well as abundant manpower are the main strengths that help to overcome the challenges of SCI.

DATA ARCHIVING

There were no data to deposit.

CONFLICT OF INTEREST

The authors declare no conflict of interest.

ACKNOWLEDGEMENTS

We extend our gratitude to all the participants from India and the ASCoN region for their support and participation. There is no funding for this study.

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Supplementary Information accompanies this paper on the Spinal Cord website (<http://www.nature.com/sc>)