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Ethical issues and dilemmas in spinal cord injury rehabilitation in the developing world: a mixed-method study

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STUDY DESIGN: Mixed-method study (small group discussions and online literature search).

OBJECTIVES: Identify the ethical issues and dilemmas faced by rehabilitation professionals involved in the service delivery to the persons with spinal cord injury (SCI) in the low income and lower-middle-income countries (LIC/LMIC) located in Asia.

SETTING: Small group discussions in three biomedical conferences in Dhaka, Bangladesh and Kuala Lumpur, Malaysia.

METHODS: Three small group discussions (30–45 min each) were held during three international conferences in 2019. The conferences brought together experts in the fields of neurology, rehabilitation, neurorehabilitation, and bioethics. A summary of SCI practice points and dilemmas were documented including goals of care, duties of rehabilitation professionals, health care worker-patient relationships, roles, and expectations of family members at different care settings.

RESULTS: There is a paucity of literature on this topic. The application of the principles of contemporary bioethics in the pluralistic societies of LIC/LMIC can be challenging. The ethical dilemmas faced by rehabilitation professionals working in LIC/LMIC are diverse and different from those reported from the Western and developed countries. Ethical issues and dilemmas identified were understanding patient autonomy in decision making, lack of insurance for SCI rehabilitation, financial challenges, challenges of providing emerging technology in SCI rehabilitation and SCI rehabilitation during disasters.

CONCLUSIONS: We have summarized the possible ethical issues and dilemmas which rehabilitation professionals in LIC/LMIC may encounter during delivery of SCI rehabilitation services. We hope it generates a discussion on an often-neglected aspect of SCI care in the LIC/LMIC and helps identify the complexities of ethical dilemmas unique to persons with SCI living in a developing country.

Spinal Cord (2022) 60:882–887; <https://doi.org/10.1038/s41393-022-00808-8>

INTRODUCTION

Spinal cord injury (SCI) is a devastating neurological injury. Depending upon the level and severity of the injury it can result in varying levels of disability and restriction of mobility. The cost of treatment of an individual with SCI is high and their quality of life particularly in the low- and middle-income countries (LIC/LMIC) is generally poor [1, 2]. Rehabilitation of people with SCI is challenging, time intensive and costly. Rehabilitation of SCI is typically a team-based task led by a rehabilitation medicine physician. Depending upon the available expertise and resources, the team may include physiotherapist, occupational therapist, rehabilitation nurse, nutritionist, speech language therapist, social worker, clinical psychologist, and other rehabilitation professionals, as necessary. Comprehensive SCI management and integrated rehabilitation have substantially improved in the developed countries. But there still are challenges in the continuum of team care starting from the site of injury, acute or critical care and rehabilitation at home or community level follow-up and inclusions [3, 4]. Most of the available literature on persons with SCI is on medical issues like pain, depression, fatigue, pressure ulcer, spasticity, bladder, and bowel dysfunction [5] and newer rehabilitation interventions like robotics and neuroprosthetics [6, 7]. The literature on dilemma and ethical issues and

dilemmas in SCI care and rehabilitation is scant and have been published from the developed world only [8, 9]. Recent recognitions of moral dilemmas related to care in rehabilitation medicine has increased interest in ethical aspects in persons with SCI. However, developments in ethical aspects of SCI did not keep pace with the technological and service developments. A discussion of ethical aspects of rehabilitation care in SCI is relatively new amongst clinicians particularly those based in the LIC/LMIC.

The contemporary bioethics as understood and practiced around the globe started in the USA in the latter half of the twentieth century [10]. The most common approach to clinical ethical analysis is principlism, which was proposed first by the “Belmont Report” [11] and then popularized by Beauchamp and Childress in their influential book on contemporary bioethics [12]. The four principles include respect for autonomy, beneficence, nonmaleficence, and justice. Although these principles were created in the Western society with their own culture and social issues, they are widely used and applied all around the globe in different contexts [13]. However, as Moazam pointed out that the application of Principlism without considering the local context and culture can be problematic and even counter-productive [14].

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Received: 8 August 2021 Revised: 25 April 2022 Accepted: 26 April 2022

Published online: 6 May 2022

SCI management and rehabilitation presents with a particular set of ethical dilemmas and challenges which need to be considered carefully during service delivery and interaction with the patient and the care givers [8]. These have been discussed in the international SCI literature as early as 1987 [15]. However, there is no discussion or documentation of the ethical issues related to SCI management and rehabilitation of the persons based in the LIC/LMIC. There is evidence that the demographics, clinical profile, and functional outcomes of persons with SCI in the low resource developing countries are different from those reported from the developed world [16–18]. Therefore, as professionals based in LIC/LMIC we believe that the ethical dilemmas and challenges of these persons with SCI will also be different.

We conducted this study to highlight the ethical issues which rehabilitation professionals in the developing countries, particularly Asian countries may encounter during delivery of SCI rehabilitation services and suggest some possible solutions. The aim is to initiate a discussion on this often-neglected aspect of SCI care in the developing world and to identify the ethical dilemmas unique to persons with SCI living in a developing country.

METHODS

This was a mixed-method study combining results from three small group discussions with an online literature search. The three international meetings, where small group discussions were held included Asian Spinal Cord Network Meeting, 2019, Malaysia, Asian Bioethics Conference 2019, Dhaka, Bangladesh and International Conference on Neuromodulation 2019 Dhaka, Bangladesh. These conferences brought together experts in the fields of neurology, rehabilitation, neurosurgery, neurorehabilitation, and bioethics over a course of 2–4 days. The small group discussions lasted from 30–60 min. It was moderated and the minutes of the discussions/meetings were recorded by the principal author. There was no specific layout plan for these meetings. All participants were encouraged to share their experiences and express their concerns regarding the ethical issues in the rehabilitation management of persons with SCI. Participants were also asked to recommend possible solutions to these ethical dilemmas. Most of the participants of these meetings were physicians from the LIC/LMIC including Bangladesh, India, Myanmar, Nepal and Sri-Lanka who were actively working with persons with SCI in indoor and outdoor settings.

Online literature search was carried out on Medline, PubMed Central and Google Scholar using keywords “bioethics”, “dilemmas”, “spinal injuries”, “spinal cord injury”, “persons with disability”, “neurological rehabilitation”, “developing countries”, “biomedical ethics”, “paraplegia”, “tetraplegia” and “quadriplegia”. Boolean operators (“AND”, “OR” and “NOT”) were used to combine search terms. Search was limited only to English language manuscripts with no time and manuscript type limits. The literature search was last done on 15th Sept 2020.

RESULTS

All participants had experience of managing patients with SCI either in the acute, sub-acute, long-term, rehabilitation and follow-up phase. The work experience of the participants in their respective fields ranged from 7–20 years. The most common causes of SCI in the LIC/LMIC reported by the participants were road traffic accident, fall from height, gunshot injury, inflammation and infections which is like the data reported in the literature [4, 16]. Participants mentioned that the initial care of SCI in their countries was inadequate and there were few centers providing a comprehensive multi-disciplinary SCI rehabilitation. Table 1 presents a summary of SCI practice points along with the dilemmas and ethical issues being faced.

DISCUSSION

SCI is a complex and disabling condition associated with high mortality and morbidity. The noticeable improvements in SCI services and outcomes over the years have mostly occurred in the

high-income regions of the world. Patients with SCI in the LIC/LMIC still face medical, social, cultural and economic challenges [19]. Ethics are reflections of the societal and cultural norms, which is also related to the time and place. While some principles are advocated as universal principles [20], their on-ground application differs according to the context.

For example, a great emphasis is placed on personal autonomy and individualism in the Western countries. A person with SCI may independently choose the treatment and rehabilitation plan she/he considers appropriate without any external influence or involvement of the family members [8]. However, this concept of autonomy has been critiqued as it does not consider other cultures outside the Western societies [21]. In addition in most of the developing countries, particularly Asian and Eastern cultures, “a person does not exist as an individual but as a member of the family, community or society” [22].

Family is considered an important part of the decision-making process and are actively involved in all medical decision making. Many family members and relatives are available with the patient throughout their stay in the rehabilitation wards. They actively participate in the medical decision making and often are seen communicating on the behalf of the patient. This is particularly seen in children and elderly with SCI. This is due to the societal norms, where taking care of the children and elderly is considered social, moral and religious responsibility of the parents and children respectively. Many a times decisions are taken and communicated to the rehabilitation team on their behalf are, mostly without involving them.

In addition, after discharge from the hospital, for most patients with SCI family members are the primary caregivers for majority of the patients with SCI. This may result in a conflict with the physician or the rehabilitation team if they emphasize on the patient’s autonomy and do not involve family and relatives in the decision-making process. The concept of autonomy is not only related to the decision-making process while the patient is admitted to the hospital. Autonomy, at least in the Western view also determines how much independence or caregiving by the family is desired ultimately by the patient. As mentioned previously due to the hierarchical structure of the society and the socio-cultural norms patients usually do not decide about these issues and have to depend upon the family, caregiver and parents to make this decision.

Medical paternalism is generally looked down upon in the West. Patient autonomy and choice are now an integral part of patient care pathways. There has been a steady shift in patient counseling and consent toward supporting patient autonomy over medical paternalism [23]. However, some have argued the extremes of autonomy and paternalism are not compatible in a responsive, responsible and moral health care environment, and thus some compromise of these values is unavoidable [24]. Soft medical paternalism is still practiced in most of the LIC/LMIC where the patients often allow, actively ask or even expect their physicians to make decisions on their behalf. This may appear problematic to many bioethicists, but it should be considered as more of a cultural norm than the ethical dilemma.

The core ethical principles of beneficence (do good), nonmaleficence (do not harm), autonomy (control by the individual), and justice (fairness) [12] also apply to the decision making and service provision in SCI rehabilitation. There have been some remarkable advances in the SCI management and rehabilitation in the few decades and all of these are only available in the Western and developed countries [7, 25]. Due to the access to the internet, patients in the LIC/LMIC are often aware of these advances and may ask the rehabilitation medicine physician to recommend these latest technologies. This becomes a dilemma when the patient has resources to secure funds from the government which are not routinely available to all persons with SCI. The principle of beneficence supports recommending these novel technologies,

Table 1. Rehabilitation practice points and dilemmas related to SCI care and rehabilitation in the developing countries.

Practice points in SCI rehabilitation	Possible ethical dilemmas and issues
(a) Selection of patients for indoor rehabilitation: usually, the rehabilitation medicine physicians (Physiatrists) evaluate and recommend admission for the patients with SCI. This decision is guided by medical knowledge, clinical examination, and medical needs of the patient.	Health care resources are limited in LIC/LMIC. Despite recommendation for admission for long-term SCI rehabilitation, the administration might weigh the potential benefit and cost of admission/re-admission of a patient with SCI. They may prioritize a curable infectious disease over an incurable long-term disability like SCI thus raising the issue of injustice.
(b) Patient-rehabilitation professional relationship. Unlike acute and short-term illnesses and disease, the relationship between a patient with SCI and their rehabilitation professional is long term and must be based on mutual respect and open communication. Patient has the right to know about the nature of the disease and the outcomes.	SCI in most cases is complete and incurable and there is no option for independent walking for the patients. Breaking this bad news about the condition and prognosis of the patient is usually done by the physiatrist. A dilemma may arise regarding withholding the actual prognosis from the patient in order to prevent reactive depression or patient losing hope. In addition, many patients when talked about the actual prognosis start exploring alternative and complementary medical therapies and engage in unproven therapies.
(c) Goal setting and team dynamics: rehabilitation physician as the team leader take the leadership role of SCI treatment, sets the initial and long-term goals of rehabilitation in consultation with the patient, family members and the rehabilitation team members.	At admission patient can be at variable levels of decision-making capacity. This capacity can be negatively influenced by factors like low literacy rates, language barriers, post-operative pain, fatigue, depression or associated head injury. Medical paternalism is still prevalent in majority of the health care settings in the LMIC. The rehabilitation physician often decides about the rehabilitation plan of the patient in what he/she perceives as the best interest of the patient without involving the patient. This can be particularly problematic in patients with low literacy rates who might have difficulty expressing themselves or understanding the permanent nature of the disability associated with SCI. In addition, due to a general lack of training in ethics in the LIC/LMIC, rehabilitation team members may be biased by their own value system depending on background training previous experiences, religion and social culture.
(d) Decision-making capacity of the patient and rights of patient family members: the team treating the patient should respect the patients' rights on decision making. although the patient and family may be unaware of the long-term consequences of current disability.	Patient capacity to participate in goal setting and decision-making process varies significantly due to lack of knowledge regarding the ways that disability may impact their life choices. There is also less awareness or even non-existence of local statutory regulations on mental capacity as is available in some countries, e.g., Mental Capacity (Amendment) Act 2019 in UK.
(e) Challenges of the emerging technology in SCI rehabilitation: patients with SCI routinely search the internet for possible cures and the new technological advancement in the field of SCI available only in the high-income countries.	Most of the emerging technologies for SCI rehabilitation are not available or accessible to patients in LMICs. However, the patients with resources often ask for a medical recommendation to go abroad to avail them on government/public expense. It would be unethical to recommend an expensive treatment for a selected few while basic rehabilitation services are not available to the majority.
(f) Insurance and health care cost for SCI: acute care and rehabilitation of patients with SCI is costly and is a major financial burden specially on families with low resources. In some countries it is covered by medical insurance, while in other patients have to bear the cost from their own pocket.	Some participants highlighted that the SCI patients undergoing rehabilitation face restrictions on insurance coverage. The insurance covers the cost of the acute surgical management and hospital stay, but not for the long-term rehabilitation needs of the patients including the mobility aids and orthotics.
(g) SCI management and rehabilitation during disasters: the impact of natural disasters like earthquakes and tsunamis in the LMIC can be much worse than in the high-income countries. These disasters can suddenly result in a large number of patients with SCI.	Addressing the needs of SCI patients is particularly challenging when disaster strikes a LIC/LMIC with under-developed rehabilitation infrastructure. The focus of medical services is on providing acute medical and surgical care. During triage at the disaster site a patient with SCI might not be prioritized for evacuation and management. In many cases patients with SCI receive acute surgical care including spinal fixation but there is no mechanism or support for long-term SCI rehabilitation.
(h) Economic constraints: SCI rehabilitation usually requires prolonged hospital. It is expensive and requires a lot of resources. Delayed or no rehabilitation can result in complications like pressure ulcers, respiratory and urinary tract infections.	Many SCI patients based in the LIC/LMIC may not have enough resources to afford the cost of both the surgical management and long-term rehabilitation. They usually exhaust their resources on acute surgical management. When they report to a rehabilitation medicine physician, they are unable to enroll in the comprehensive indoor rehabilitation program due to lack of finances. Many go back to their homes (sometimes located in far flung areas), only to return with multiple preventable complications.

but it violates the principle of distributive justice as it only favors the provision of service to those with connections and resources to secure funds. In addition, none of these have been tested or used in the LIC/LMIC, the outcomes are not clear, and safety not established.

Considering the principle of nonmaleficence recommending these technologies might not be an appropriate choice in such cases.

After SCI, for some patients particularly high tetraplegic life becomes difficult, sedentary with often chronic intractable pain

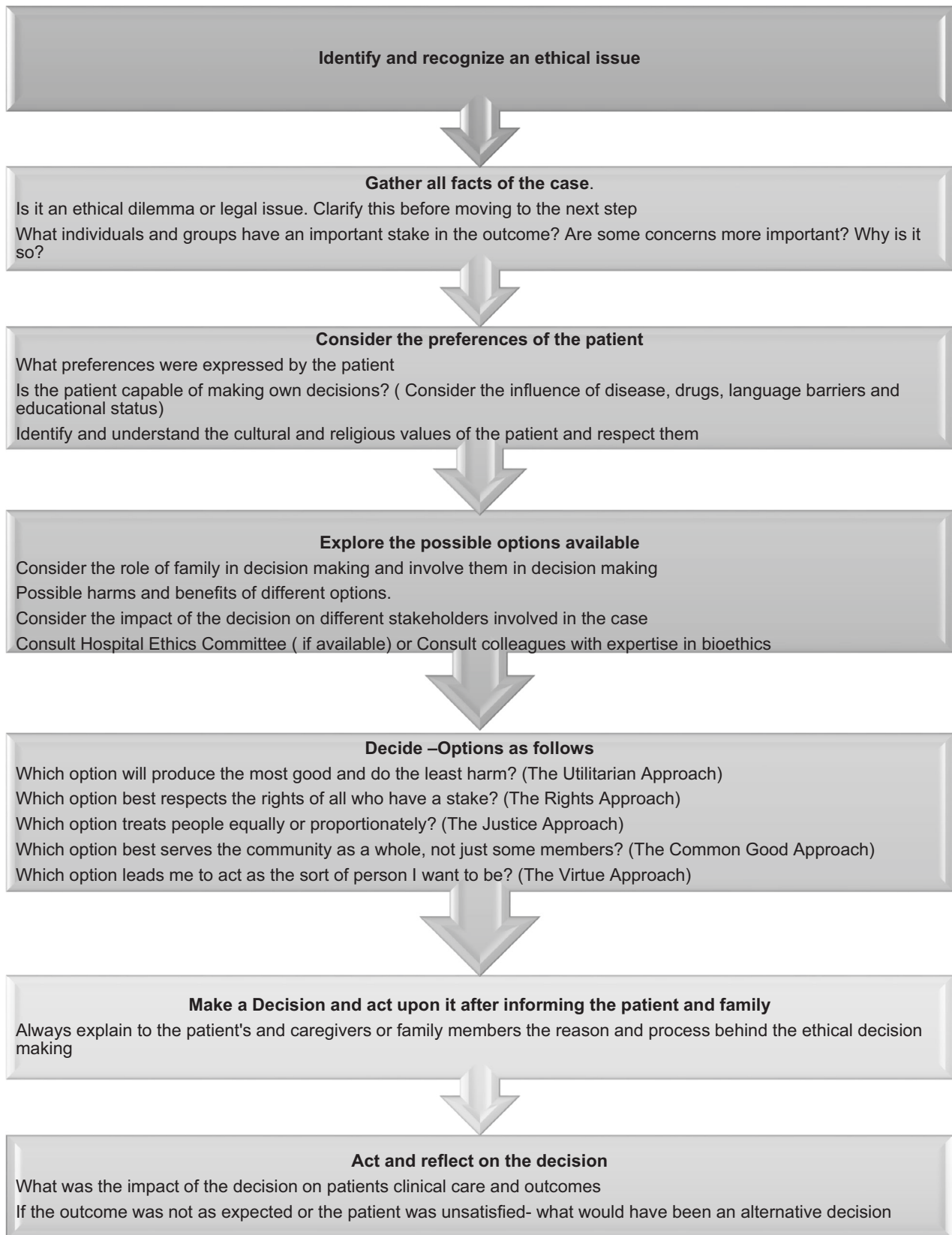


Fig. 1 A Framework for solving SCI related ethical dilemmas.

requiring costly medications and treatment. They may be totally dependent on their care givers, confined to a powered wheelchair, needing permanent artificial respiration and a complicated, computerized environmental control system. As autonomous beings, they may request an end to their prolonged suffering in form of medically assisted dying or euthanasia [26]. Euthanasia is a controversial issue in SCI, practiced in the Western world but unheard of in LIC/LMICs [26, 27]. Some participants of the workshops reported that few of their patients with cervical SCI expressed that they were exhausted and would like to end their lives. However, none requested active euthanasia and such expressions were attributed to low mood and depression. A request for active euthanasia will be likely be refused by a rehabilitation professional in a LIC/LMIC due to the religious beliefs, cultural issues or medico-legal issues. All participants agreed upon this.

Persons with SCI are considered vulnerable population due to the nature of their disability. Special care must be taken while conducting research in this group to avoid any ethical conflicts. The International Campaign for Cures of Spinal Cord Injury Paralysis has established a panel to review methods for clinical trials for SCI. They recommend undertaking clinical trials with prospective blinded design maintaining highest ethical standards, obtaining adequate and a clear informed consent [28]. It is important to note that many of the issues identified by the experts were not specific to SCI alone. Patients with other neurological disabilities and rehabilitation professionals residing in these countries can also face the same ethical challenges.

Another potential issue faced by women with SCI is of discrimination. Men are usually the main bread earners in the LMIC located in this region and may get preferential treatment by the family. There is anecdotal evidence that women with SCI do not get the same level of attention and care in the long term after discharge from the hospital. For example, the Oct 2005 earthquake in Pakistan resulted in hundreds of patients with SCI, mainly paraplegia. Irhsad et al. documented the long-term gendered consequences of SCI on women [29]. The findings show that 3 years after the disaster, paraplegic women are socially, emotionally, and financially isolated. The small stipend they received was a significant source of income, but also led to marital distrust, violence, and abuse. In contrast, men received full social and emotional support [29].

The ethical challenges faced by health care professionals dealing with SCI are also complicated by the fact that hospital ethics committees do not exist or have not been appropriately established in some developing countries [30]. In some places they are only exist on paper without performing any actual task. Therefore, the professionals are unable to obtain timely ethical consult and solution to a dilemma arises during SCI rehabilitation. A proposed framework for solving ethical dilemmas arising during SCI rehabilitation is presented in Fig. 1.

There are certain limitations which warrant mention. The focused group discussions were not based on a structured format and the discussions varied in different meetings. The minutes were recorded by one person using a paper and pen instead of recording the conversation and transcribing it verbatim. It might have resulted in some of the point of views being missed from the final compilation. The dilemmas and ethical issues identified are from the physicians and rehabilitation professional perspectives only. No persons with SCI or their care givers were part of the discussions. There is a possibility that those who are living the experience may identify or prioritize different ethical issues than the ones mentioned here.

CONCLUSION

This is one of the first report to document the ethical issues and dilemmas unique to SCI rehabilitation in the LIC/LMIC located in

Asia. It appears that these ethical issues are common, unique to these areas, underreported and do not receive much attention. They can adversely affect the patient motivation to participate in the long-term rehabilitation program and the relationship between the SCI patient and the rehabilitation professionals involved. There is a need to formally document the ethical dilemmas and challenges faced both by the persons with SCI and their rehabilitation providers using well designed studies. In addition, a discussion of ethical issues related to SCI care and rehabilitation must be a part of the training curriculum of different rehabilitation professionals.

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ACKNOWLEDGEMENTS

We gratefully acknowledge the experience sharing of all participants of the group discussion.

AUTHOR CONTRIBUTIONS

TU gave the idea for the study. He was responsible for collecting responses from the participants and summarizing them for this manuscript. He carried out the revisions and gave approval for the final version of the article. MAS performed the initial literature search. He contributed to writing the first draft, extracting and analyzing data, interpreting results. He gave approval for the final version of the article. FAR performed the literature search, extracted data revised the first draft. He gave approval for the final version of the article. MS contributed to revising the first draft, extracting, and analyzing data, interpreting results, and gave approval for the final version of the article.

COMPETING INTERESTS

The authors declare no competing interests.

ETHICAL APPROVAL

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

ADDITIONAL INFORMATION

Supplementary information The online version contains supplementary material available at <https://doi.org/10.1038/s41393-022-00808-8>.

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