Experience of healthcare professionals delivering care to persons with spinal cord injury in Cambodia

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Contents

Acronyms

ACC	Australia Awards Cambodia
ACCESS	Australia-Cambodia Cooperation for Equitable Sustainable Services
AF	Asia Foundation
CPTA	Cambodian Physical Therapy Association
FGD	Focus group discussion
ICRC	International Committee of the Red Cross
KhaPO	Cambodian Association of Prosthetists and Orthotists
MoH	Ministry of Health
MoSVY	Ministry of Social Affairs Veterans and Youth Rehabilitation
NGO	Non-government organisation
PRC	Physical Rehabilitation Centre
PWDF	Persons with Disabilities Foundation
SCI	Spinal cord injury

Executive Summary

Approximately 21 million people are living with spinal cord injury (SCI) worldwide with around 17% spinal cord injuries occurring in South Asia each year. Overall, SCI rates in low-middle income countries are higher than in high-income countries. Spinal cord injury is a complex condition which the initial traumatic injury is accompanied by flow-on secondary health issues that lead to severe implications for effective recovery and often lead to permanent disability. Persons with SCI experience significant barriers in daily life such as financial precarity, psychological difficulties, social exclusion, and access to healthcare services.

In Cambodia, there is only one specialised spinal cord rehabilitation centre, the Spinal Cord Rehabilitation Centre in the city of Battambang. Physical rehabilitation centres (PRCs) provide rehabilitation to persons with disabilities but only sometimes to SCI patients across Cambodia's 25 provinces and Phnom Penh. However, persons with SCI have less access to rehabilitation services due to the severity of their disability, lack of access and lack of resources at PRCs.

This research project explored the experiences of healthcare professionals working in the rehabilitation sector in relation to people with spinal cord injury. It also examined the experiences of family members caring for a person with a spinal cord injury. The research question was "*How accessible and effective is the current healthcare system for people with SCI in Cambodia and how might healthcare be improved?*" A qualitative methodology was utilised with in-depth interviews and one focus group being conducted.

The research found that SCI healthcare professionals interviewed were committed to providing the best care possible with very limited resources and knowledge. Many gaps in supporting SCI rehabilitation were identified including lack of qualified staff and an ageing workforce, shortage of medical supplies and equipment, limited awareness and community-based activities, poor referral systems, insufficient psychosocial support, inaccessibility, poverty, limited quality of services, short life expectancy, inadequate government budget allocation and lack of policies to support persons with SCI. The following 13 recommendations were made:

1. A needs analysis of the health system in relation to spinal cord injury (SCI) and rehabilitation needs to be conducted.
2. Better data needs to be collected on SCI from immediate injury to discharge and through interactions with PRCs.

3. The SCI centre should be relocated to Phnom Penh next to a major hospital (see Recommendations section for additional rationale and detail).
4. Specialised training should be given to those working with SCI including at hospitals, clinics and PRCs.
5. An improved referral system for SCI people should be put in place.
6. Extend PRCs and include regular outreach programs.
7. Mental health support for people with SCI and their carers should be established.
8. Create better access to catheter materials and medications required by SCI patients free of charge.
9. Home adaptions should be included in care of SCI patients.
10. Ensure accessibility to healthcare and PRC facilities is prioritised.
11. Raise awareness of the SCI centre.
12. Improve transportation access, this could include more financial support for travel.
13. Evaluation of all new programs to ensure sustainability and effectiveness.

These recommendations need the contributions of the community as well as the government and would benefit from NGO support.

Introduction

Literature Review

Approximately 21 million people live with spinal cord injury (SCI) worldwide, with the most common causes of SCI reported as falls, road traffic accidents and conflict/terrorism (Ding et al., 2022; World Health Organization & International Spinal Cord Society, 2013). Each year it is estimated that 0.9 million people experience SCI, with Southeast Asia accounting for approximately 5% of the global total (Ding et al., 2022). Overall, rates of change in the incidence of SCI in low and low-middle income countries are decreasing more slowly than in high income countries (Ding et al., 2022).

Spinal cord injury is a complex condition as the initial traumatic injury is accompanied by flow-on secondary injuries that can have severe implications for effective recovery if proper interventions are not delivered in time (Ahuja et al., 2017). The complex nature and severity of SCI means that people with the condition experience significant barriers in daily life including financial precarity, psychological difficulties, social exclusion, and difficulties in accessing healthcare services (Ahuja et al., 2017; Barclay et al., 2016; King & King, 2014). Furthermore, people with SCI are two to five times more likely to experience premature death compared to persons without SCI, with life expectancies much lower in Global South countries (Oderud, 2014; World Health Organization & International Spinal Cord Society, 2013).

Healthcare responses for SCI have shifted over time, with Mohan and Deb (2022) noting that the focus of care has become patient-centred, with treatment priorities typically focused on quality of life and successful integration of patients into the community. To ensure quality treatment outcomes, an understanding of the experiences of people with SCI from multiple perspectives is necessary to be able to articulate the factors which influence their quality of life and community integration. These experiences are diverse and nuanced, as research conducted by King and King (2014) with people living with SCI in Thailand demonstrated. Their work found that participants' experiences were influenced by the unique sociocultural factors that shaped their lives and therefore they made sense of their own experiences in different ways.

When considering barriers with relation to accessing healthcare for patients with SCI, the country of residence has been found to be a key factor in the experiences of accessibility and treatment outcomes (Bychovska et al., 2023). Studies within high income countries in the Global North such as Germany report high rates of use of and satisfaction with rehabilitation services (Martini et al., 2020) and in Switzerland studies have found that people with SCI commonly reported positive experiences of receiving healthcare for their condition (Ronca et al., 2020). Research has found that there are typically adequately stocked hospitals, sufficiently trained healthcare professionals and widespread integration of rehabilitation services and these resources inevitably increase the rate of social inclusion and community integration in Global North countries (Martini et al., 2020, Ronca et al., 2020). However, studies have also reported that there are discrepancies between standards of care within Global North countries for people experiencing poverty and/or living within rural areas (Bell et al., 2017; Ronca et al., 2020).

Research focused on the healthcare experiences of people with SCI in the Global South overwhelmingly report less satisfactory outcomes than those in Global North countries (Bychovska et al., 2023). Oña et al. (2023) utilised data from the International Spinal Cord Injury Survey and found that people in Global South countries with SCI were least likely to be able to access required healthcare in the initial treatment and ongoing management of their condition. Furthermore, research has found that people with SCI living in low- and middle-income countries face many challenges in accessing healthcare services, with these barriers to receiving initial and ongoing treatment occurring across multiple dimensions of everyday life (Dorjbal, et al., 2020). Consequently, these barriers negatively impact on the physical and psychological wellbeing of people with SCI and restrict their participation in almost all areas of life. Research evaluating the experiences of people with SCI in the Global South has identified multiple themes, summarised here using the following categories: hospital-based care, barriers to care, policy and legislation, education/knowledge base and sociocultural factors.

Several studies have documented the experience of hospital-based care for people with SCI in low- and middle-income countries (Chhabra et al., 2018; Dorjbal et al., 2020; Fuseini et al., 2018; Stillman, 2014). A study conducted in Mongolia by Dorjbal et al. (2020) that investigated barriers to healthcare for people living with SCI found that patients experienced gaps in their healthcare due to an absence of adequate hospital-based care services and workers. Participants mentioned they experienced having unskilled hospital workers suggesting and utilising inappropriate treatment methods and management techniques for SCI (Badenhorst et al., 2022; Dorjbal et al., 2020), with patients in South Africa reporting frequent difficulties in finding healthcare professionals that could appropriately manage their condition (Badenhorst et al., 2022). The literature also discusses the impact of adequately trained hospital-based healthcare professionals on how informed patients with SCI are about their condition, with studies reporting that patients are often unaware of the importance of initial and follow-up care for the injury (Badenhorst et al., 2022; Fuseini et al., 2018) due to healthcare professionals being unaware of these requirements.

Hospitals and pharmacies have also been found to lack a stock of important required medications for the initial response and ongoing management of SCI (Dorjbal et al., 2020). It was reported this increased the occurrence of secondary health conditions and pain. In Latin America, studies found healthcare professionals faced difficulties with initiating required responses to, and ongoing management of, SCI because of a lack of pivotal infrastructure such as technology and medical equipment within hospitals and externally based care clinics (Marchesini et al., 2020).

Furthermore, research conducted in Ghana discovered that crucial and time sensitive surgical treatments are frequently delayed due to the lack of medical supplies and difficulty sourcing trained medical staff. These delays can last from days to weeks for patients needing surgical treatment (Fuseini et al., 2018). Physical accessibility difficulties within hospitals have also been identified as impacting on the experiences of care for people with SCI. It has been reported that hospital examination rooms can lack required space for wheelchairs as well as not stocking the required assistive devices to ensure patients can safely move from their device to the examination room table. Where assistive devices are available, clinical hospital staff may be inadequately trained in the use of such machines, thus restricting the kinds of healthcare received as well as the quality thereof (Dorjbal et al., 2020; Stillman, 2014).

Much of the research exploring the experiences of people with SCI in low- and middle-income countries accessing healthcare commonly report that there are also barriers that arise before they can receive hospital-based and rehabilitative treatment for their condition such as inaccessibility due to characteristics of the built and natural environments, cost of treatment and sociocultural factors (Dorjbal et al., 2020; Fuseini et al., 2018; Khan et al., 2018; King & King, 2014; Liu et al., 2023; Marchesini et al., 2020; Oderud, 2014; Oña et al., 2021).

Physical environments will often be difficult (or impossible) to negotiate for wheelchair users (Dorjbal et al., 2020; Oña et al., 2021) with buildings lacking usable elevators where there are multiple flights of stairs, and even the patients' homes being difficult to move around (King & King, 2014). Public and private transport operators can be unable to or unwilling to assist in transporting people with SCI (Dorjbal et al., 2020; Oña et al., 2021). In some countries people with mobility aids are often charged more than abled passengers (King & King, 2014).

Studies have also shown that a primary barrier to accessing healthcare services for SCI is a lack of financial resources to pay for treatments (Marchesini et al., 2020). Individuals experiencing poverty in low- and middle-income countries are especially marginalized with respect to economic barriers to healthcare services for SCI (Oderud, 2014). Initial surgeries and required medications are delayed because of the patient's inability to make required pre-payments (Fuseini et al., 2018) and it is not uncommon for people in Global South countries to seek out alternative forms of healthcare such as herbal medicine or spiritually-based care due to an inability to afford medically-based treatment (Fuseini et al., 2018).

Sociocultural factors in Global South countries also impact the experiences of patients with SCI accessing healthcare. Research has identified stigma within society but also among healthcare professionals as a barrier to patients receiving required treatment for their condition (Dorjbal et al., 2020; Fuseini et al., 2018; King & King, 2014). In countries within Africa and Asia, unique barriers with relation to stigma and cultural practices arise. Liu et al. (2023) found that even across different provinces within the same country there are diverse cultural approaches to the initial treatment and ongoing management of SCI. Cultural preferences for spiritually-based healing in countries such as Ghana (Fuseini et al., 2018) have been found to increase the likelihood of patients disengaging with hospital-based care. In Thailand, King & King (2014) reported cultural beliefs that the "disabled body represents the operation of kam (karma), and hence blameworthiness. This justifies stigma and discrimination by the community." The cultural belief that disability is a form of punishment for previous bad deeds is shared in other countries and means that people with SCI may disengage from seeking treatment due to the stigma attached to them, which makes it difficult for healthcare professionals to provide needed care.

There is little existing research on the experiences of healthcare professionals in delivering care for patients with SCI in hospital-based and rehabilitative contexts. A scoping review conducted by Dalle et al. (2022) found that there are few studies exploring the management of SCI. Notably, a survey of Mongolian health professionals identified a key issue with the experiences of healthcare professionals in delivery services for SCI was the dearth of statistical data about the occurrence and prevalence of SCI within the country, as well as weak healthcare guidelines and standards from government (Khan et al., 2018). Studies have revealed that healthcare professionals find that overall, social policy and legislation regarding disability is ineffective and fails to provide equitable access to healthcare services for those with SCI (Mohan & Deb, 2022).

Although the studies discussed here have explored the experiences of people with SCI in low- and middle-income countries, there has been little investigation of the experiences of hospital-based care among people with SCI in Cambodia. Most studies conducted within Cambodia have focused instead on the outcomes of hospital-based care (Choi et al., 2017; Chua et al., 2018; Still, 2019). Data relating to occurrences and prevalence of SCI in Cambodia are scarce, and this lack of data has affected the ability to adopt strategies to prevent and adequately treat SCI (Chua et al., 2018). The available data shows that the two most common causes for SCI in Cambodia are work-related falls and road traffic injuries, most of which result from motorcycle accidents (Choi et al., 2017; Chua et al., 2018). There has been little research as to the outcomes of SCI care and this has been reported to be due to the limited resources the Cambodian healthcare system has for postoperative follow up (Chua et al., 2018).

Attempts are being made to fill this gap, e.g. a study conducted by Choi et al. (2017) sought to evaluate the outcome of surgical treatments for SCI patients in a Cambodian hospital. It involved 80 patients, 60 of whom were followed up with post-surgical treatment and found that 32% reported an improvement in their condition with respect to overall wellbeing. The study found that the most common post-operative complications tended to be secondary conditions such as wound infections, pressure sores and the impacts from the wrong level of surgery being conducted (Still, 2019). The little data available highlights the urgent need for further research exploring the experiences delivering SCI-based treatments within hospitals in Cambodia.

Cambodian Context

The setting of the proposed research is Cambodia, and the proposed participants are the people who provide care, rehabilitation and supporting policies for people with SCI. Spinal cord injury (SCI) is characterized by a high probability of ongoing need for healthcare services. It presents a high financial burden for individuals and families, and a high demand for healthcare services.

There is only one specialized spinal cord rehabilitation centre in Cambodia, the Spinal Cord Rehabilitation Centre in the city of Battambang (third largest city in Cambodia, about 300 km northwest of Phnom Penh). Eleven Physical Rehabilitation Centres (PRCs) provide rehabilitation to SCI patients across Cambodia’s 25 provinces and Phnom Penh municipality (2 in Phnom Penh, 9 in provinces, including one in Battambang: PWDF, 2021); however, they do not provide a specialized service for SCI patients, as they are a minority of their clientele (PWDF, 2021).

The Spinal Cord Rehabilitation Centre in Battambang provided treatment to 1628 patients with SCI (1302 males and 310 females) from 2014 to 2019 (PWDF, 2020, unpublished). There is a lack of comparable data from PRCs as they are managed at the individual PRC level and only a summary report without a specific SCI breakdown is sent to the Persons with Disabilities Foundation (PWDF). However, causes of SCI such as motor vehicle crashes have been increasing (PWDF 2021). The figures above indicate that rehabilitation services in Cambodia are limited, and PWDF (2021) notes that comparison with other countries and by gender implies that many Cambodians with SCI do not access the rehabilitation services they need, and that this is especially the case with women. This can further contribute to the disability-poverty cycle which has been observed in Cambodia in relation to disability as a result of motor vehicle crashes (Sann, 2017).

It is also unclear whether the PRCs are oriented to provide the services needed, given that SCI patients make up a minority of their clientele, and whether there are barriers to access that can and should be addressed. This research is aimed at utilizing the insights and experiences of family carers, healthcare workers and policy makers to inform more effective and accessible healthcare for people with SCI in Cambodia. The direct involvement of people with SCI is not planned at this point, for ethical and practical reasons, but may be pursued in the future. This omission will not detract from the value of the research, since disability and related rehabilitation is not an individual experience but also impacts the family, particularly when social support is low within a country (King and King, 2014).

Research Design

Study objectives

Research question

The main research question and sub-questions were:

RQ: How accessible and effective is the current healthcare system for people with SCI in Cambodia and how might healthcare be improved? Sub-questions include:

- What barriers or challenges do SCI patients experience in accessing healthcare services from the perspectives of family carers and healthcare workers?
- What improvements do family carers and healthcare workers think could be made to healthcare services to address these barriers and challenges?

- What improvements do policy makers perceive to be the most practical and feasible to introduce?

Outcome measures

The data was collected to provide a greater understanding of spinal cord rehabilitation care within Cambodia and allow this information to flow into services and policy implementation.

Study design

A qualitative methodology was used with data collected via in-depth interviews, semi-structured interviews and one focus group. Interviews were conducted in-person for all but one participant who was interviewed via Zoom. This methodology allowed for participants to share their rich experiences in the area of spinal cord injury treatment.

Study population

Participants

Participants recruited for this project had knowledge and experiences that related to the research question: How accessible and effective is the current healthcare system for people with SCI in Cambodia and how might healthcare be improved? In total, 16 participants were interviewed and 8 other participants were involved a focus group discussion (FGD).

Interviews: Battambang Spinal Rehabilitation Centre provided a letter of support to conduct the research with participants, and 9 were interviewed. 4 healthcare workers were recruited through the Provincial Rehabilitation Centres (PRCs). These 13 participants included doctors, nurses, physiotherapists, physical therapists, social workers and occupational therapists. 3 managers/policy makers were recruited from the Disability Action Council and the Ministry of Social Affairs, Veterans and Youth Rehabilitation (MoSVY) and interviewed to get an understanding of current policy, legislation and funding for spinal cord disability.

Focus group: 8 people formed the focus group, comprised of 7 family members of past and present patients of the Battambang Spinal Rehabilitation Centre, who were joined by a member of the SCI association who had originally been recruited for an interview but joined the FGD instead.

Consent approach

An information sheet and consent form approved through the ethics process was sent or given to potential participants before the commencement of data collection. Only upon each participant's voluntary informed consent to participate did the interview or focus group commence.

Participant withdrawal

Participants were informed that they could withdraw from the research at any time. No participants withdrew.

Procedures

Recruitment

Participants were emailed and informed through the Telegram app, which is widely used in Cambodia. An information sheet and consent form was sent to all potential participants. Participants provided informed consent through email and Telegram return of their signed consent form. The recruitment email comprised of the information sheet, the consent form and some questions that were used to capture demographic characteristics. When participants did not have access to email as in the case of family members, they were contacted by the representative of the SCI association who gave the participants information about the project and the phone number of the principal investigator if they wished to participate. process.

Schedule of measurements and data collection

Upon receipt of informed consent from participants, an interview was scheduled, and verbal consent was obtained again before the interview commenced. All but one interview were conducted face-to-face with one being conducted via Zoom. The interviews were recorded and then transcribed verbatim ready for data analysis. The transcripts were translated into English and a selection back-translated to confirm the accuracy of the translation. There was only one interview per interviewee of around 30 to 90 minutes. Transcribed and recorded files were saved according to interview number and country. The same procedure is used for the FGD.

Data collection and techniques

Interpersonal communication techniques such as listening, encouraging, clarifying, reflection of feelings, open questions, paraphrasing, and summarising were used to guide the interview process. The in-depth and semi-structured interviews along with the focus group allowed participants to give rich, detailed accounts of their experiences and thoughts.

Safety and adverse effects/events

There was some risk of discomfort in response to questions about spinal cord treatment and care and personal experiences. Participants were free to skip any of the interview/ FGD questions or pause or end the interview/ FGD at any time. In the event of uncomfortable feelings evoked during the interview/ FGD, participants had the option to seek support from the Transcultural Psychosocial Organisation (TPO) Cambodia where they would be offered one free counselling session, or with the QUT Health Clinics. This information was provided on the information sheet. Although a couple of participants became visibly upset during the FGD, these options were not taken up.

Analysis

Thematic analysis was conducted by both researchers independently using the six-phase approach outlined by Braun and Clarke (2021). The transcripts were transcribed verbatim, translated to English and then read by each researcher in order to gain familiarity with the data. Both researchers then read the complete data set once before commencing coding, resulting in emerging patterns. Patterns were then discussed, and a list of codes was generated. The researchers then identified patterns and connections between codes to develop themes. These were reviewed, followed by a final analysis of the themes. These themes along with verbatim quotes from participants are included in this research report.

Data management and record keeping

Confidentiality and privacy

All published work will omit the identity of participants. Those interviewed are referred to by a pseudonym in this report. Personal names in the transcribed raw data have been replaced with pseudonyms. Only the research project team has access to information such as the participants' names and contact details.

Data security

Electronic data is stored in the Research Data Storage Service provided by QUT and it is protected with a password. Hard copy data is stored in the principal investigator's filing cabinet which is locked.

Secondary use

The de-identified data will be used for a journal article and/or future collaborative research including conference presentations. Raw data will not be accessible to anyone.

Dissemination of results

A policy workshop presenting the preliminary findings was held in Phnom Penh on 6 December 2023. Thirty-two participants from the MoSVY, PWDF, PRC, SCI centre, MoH, ICRC, CPTA, KhaPO, ACCESS, SCI association, the Asia Foundation, AAC, and caregivers participated in the workshop. The discussions in the workshop have informed this report, and the report's acceptance will mark the end of the research, following which a summary of the research findings will be sent to the participants via email. The research will also be used to produce a peer-reviewed journal article, possibly a conference paper.

Results and Discussion of Findings

There is limited in-depth understanding in the Cambodian context of the experiences of service providers working with people who have experienced SCI. There is also a lack of empirical evidence on the experience of carers who bear the burden of care for patients once the leave hospital or the Battambang Spinal Cord Rehabilitation Centre. This exploratory research aimed to fill this gap and provide up-to-date data to the government and rehabilitation sector in Cambodia.

At total of 16 interviews were conducted with staff at the Physical Rehabilitation Centre for Persons with Spinal Cord Injuries in Battambang, allied health workers at selected PRCs, and government/NGO managers/policy makers. In addition, the FGD was conducted with 7 carers of people living with a spinal cord disability and a member of the SCI association.

The Results and Discussion of Findings is divided into four findings sections:

1. Interviews with 9 staff from the Battambang Spinal Cord Rehabilitation Centre
2. Interviews with 4 staff from Physical Rehabilitation Centres
3. Focus group discussion with 7 family carers and an SCI association member
4. Interviews with 3 managers/policy makers

Battambang Spinal Cord Rehabilitation Centre

Battambang Spinal Cord Rehabilitation Centre is situated in the Northwest province of Battambang. It is an inpatient 24 bed specialist centre.

The medical staff consists of:

- One manager
- One doctor – part-time
- One physiotherapist – part-time
- One assistant of physiotherapist
- Seven nurses

Services:

- Services provided at the centre are free and include two meals a day, bed, mattress, catheters, and medication. A carer must also stay with the patient for the duration of their stay.
- Support for transportation (10,000 Riels as per government policy) applies for all types of disability and regardless of travel distance.
- Training for carers in caring for a person with spinal cord injury.

"Here we have to cooperate." Staff commitment

Staff at Physical Rehabilitation Centre for Persons with SCI in Battambang showed both commitment to each other and to the patients in the rehabilitation centre. Given that the staffing of the centre is small this was an invaluable asset, however, it also showed the vulnerability of the staffing situation as if one nurse was sick or on leave there was no other nurse to cover their shift. The nurses worked a 24-hour shift in twos and also relied on the assistance of the patient carers when tending to patients. The quotes below highlight their commitment to each other.

> *"There are only a few of us and without good cooperation and teamwork, it could be such chaos."*
>
> *"We want to start and finish together..."*

As well as their commitment to each other, staff often went above and beyond for the patients. Feeling sorry for patients was a major driver of their commitment. Some staff even purchased much needed items when the family could not afford to do so. This is clearly evident in the quotes below.

> *"I only come back because I pity the patients."*
>
> *"He even went out to buy it himself because he didn't want the patient to spend their own money."*

While this commitment was to be applauded the staff also talked about the issue of not being able to recruit staff to the centre. This was of great concern given the ageing of the staff employed, with all reaching retirement age in the coming years.

"Nobody wants to come." Staff shortages and an ageing workforce

Staff talked about their concerns at not having enough staff, the ageing of the workforce and the lack of access to training for this specialised area of care. Staff who retire are not replaced and there are doubts whether the number of current staff can provide treatment that meets quality standards for healthcare.

> *"His assistant was not trained." (Was formerly the cleaner)*
>
> *"Only two nurses per shift (24hrs) and if one is absent the other has to cover alone. So we couldn't monitor thoroughly."*
>
> *"Currently there is not much (training)."*

In addition, health professionals at the SCI centre have not received the capacity building recently. Staff used to have training to extend their knowledge and skills when the centre was under the management of an International NGO, but it does not happen now when the centre is under the direct management of the government. Staff talked about the need for suitably qualified people to be employed due to the specialised nature of SCI care. If staff are not trained, they can make mistakes that can negatively impact patients, including making their injury worse.

There was also concern about everyone getting to retirement age, as one participant stated:

> *"Yes, we are all the third generation and when we reach retirement age, we don't know what management or the government will do…………we can reach retirement age in the next 2 to 3 years."*
>
> *"For nurses, now is ok but all the nurses are old. I don't know what will happen in the future."*

In addition to this the staff interviewed talked about wages for staff being a barrier to other health professional coming to the centre. The pay is lower than for equivalent civil service jobs and there is a lack of secure employment, again in contrast to the civil service. Health professionals would not find the salary and conditions at the centre attractive, and in addition to civile service roles, a physiotherapist or doctor could earn more running his/her own clinic.

> *"For civil servants the salary is higher…..that is why they rarely give civil servant status here. Mostly are contractors that's why nobody wants to come……."*

While staff at the centre were highly committed this will not sustain it into the future. The ageing of the workforce, the lack of training and the lack of pay incentive leaves the centre in a vulnerable position going into the future and this needs to be addressed.

Another concerning issue was the lack of equipment and medical supplies at the Physical Rehabilitation Centre for persons with SCI at Battambang. The government provides insufficient medical supplies to fulfil the needs of use in the centre. In addition, there is a lack of necessary equipment to provide treatment to patients such as x-ray machines, laboratory facilities for blood testing and so on. Patients were sent to use the services at hospitals or private clinics at their own cost. Patients face not only financial challenges but also practical challenges travelling because patients with SCI need more space, which makes travel costs expensive. This puts another burden on patients and their families.

"Sometimes we have a supply shortage." Shortages of equipment and medical supplies

All staff interviewed spoke about a shortage of equipment including wheelchairs and medical supplies including medication and catheters required for patients. Current practice is for the SCI centre to ask an INGO for wheelchairs to support the patients with SCI because insufficient wheelchairs are provided by the government. This had adverse impacts on patients who would then have to pay themselves.

> *"When necessary the patient paid for the medication……..when we do not have and they were in bad pain or emergencies."*
>
> *"Just our materials are not sufficient."*
>
> *"Some patients didn't receive any wheelchairs at all when they are discharged……..For 10 we lack 5 wheelchairs."*
>
> *"The challenges here mostly from the lack of medical supplies such as catheters, normal catheters and permanent catheters, as well as the bag and other stuff such as drugs."*

This then puts the burden of supplying the equipment and medicine on families who are already struggling to make ends meet with many living in poverty.

It is also important to point out that there is no diagnostic equipment at the centre, so patients have to go elsewhere for these procedures.

"Some do not know that there is a centre for SCI." Lack of awareness of SCI centre results in poor referral systems

The SCI rehabilitation centre in Battambang is the only one in Cambodia and services the whole country. However, its existence is not widely known outside the province by people working within the medical system as well as the general population. It seems the SCI centre in Battambang is invisible to the public. Little service promotion is conducted to make the population aware of the SCI and its services. Most patients know about it through word of mouth. As a result, the referral system is poor.

> *"Because we did not raise awareness in the community or hospitals."*
>
> *"Mostly they do not know, and I usually tell people about the centre and its services."*
>
> *"There were advertisements, but people just didn't pay attention."*
>
> *"We did not advertise or raise awareness broadly about our services, and therefore, only a few people know about the centre."*
>
> *"Overall, people who know are just a few."*

It should be noted that the staff try to raise awareness about the centre through word of mouth and social media, but overall, this has little impact.

"Once they are out there, they are on their own." No community follow-up for patients

Currently there is no outreach to patients who have been discharged from the centre. In the past this was funded by an international NGO. COVID-19 has also contributed to the lack of follow-up. This can have negative consequences for most patients and carers who are unable to cope. The staff at the centre stated that:

> *"Now we don't have the activity anymore (outreach) only here with the current role in the centre."*
>
> *"We used to go out to patients but not now."*
>
> *"No, but before COVID they told us to do community follow-up to the patients' houses and provide a check-up. If they had an issue, we consulted them on it."*
>
> *"When they're home in the community, only the healthcare system is recommended."*

This was an issue as health centres and most hospitals were not accessible and lack staff with the knowledge to work with people with SCI. PRCs rarely saw SCI patients as they did not have the rehabilitation knowledge or necessary equipment, and were sometimes not accessible.

"We refer them to the hospital." Lack of psychosocial support at centre

As well as not having outreach services the centre did not have the resources or skills for SCI patients who may experience mental health issues as a result of their injury. International literature shows that people who suffer a traumatic SCI with subsequent paralysis are in need of psychosocial support, in particular for depression and anxiety. While most staff were aware that some patients struggle with their mental health there was no access to this support at the centre other than the staff.

> *"When patients aren't well or sad, we always initiate conversations."*
>
> Interviewer: Are there any patients with mental distress?
>
> *"Yes, we talked to them and joked around so they could laugh and brighten up."*
>
> *"If they are just at home by themselves, their mental health could worsen."*
>
> *"Some case quarrel/fight between family or spouses but like I said we couldn't ask much since it is not our business."*
>
> *"We told the caregivers they aren't well or sick, their moods fluctuate and the caregivers have to support them."*

If the mental health needs of the SCI patients are not addressed, it could lead to longer term mental illness such as depression and anxiety. This would have a negative impact on both the patient and the families that support them.

“Because they can die from a pressure sore.” The challenge of care for people with SCI

One of the greatest (potentially life-threatening) issues faced by SCI patients is pressure care (skin care). When not attended to, pressure sores can develop and into serious injuries. All staff talked about this and how it can lead to readmission to the centre. They also spoke about the impact pressure sores can have on the lives of people with SCI and that of their carers.

> *“Due to the living conditions of or patients, they couldn’t follow-up 100% of what we taught them……..so the pressure sore returned.”*
>
> *“Mostly they come back due to the pressure sore.”*
>
> *“When they were careless and developed the pressure sore, they come back immediately back and forth.”*
>
> *“Mostly they come back due to pressure sores and wounds.”*
>
> *“These kinds of pressure sores escalate so fast because the patients don’t feel the pain and if the urine leaks and gets in there, it makes the wound even worse.”*

These quotes clearly highlight the constant struggle with care and in particular the need for constant skin care to prevent pressure sores.

“Many come back with urination problems.” The cost and issues of urinary care

The second big challenge faced by people with SCI is care of their urinary tract. Their injury can impair urinary tract function with many people needing to intermittently catheterise or have a catheter *in situ* permanently. Cost and availability were issues for many of the patients, as was the ability of carers themselves to care for this aspect of their family members’ lives. It takes skill and expertise to catheterise a person and while this was taught at the centre to carers before the person with SCI was discharged, many of the carers struggled.

> *“When we don’t have condom catheter, we use plastic bags.”*
>
> *“It is mostly infection of their bladder with painful urinating.” (readmission to the centre)*
>
> *“They can use for several months (catheter) if they clean properly. This type of patient has a hard time with urination and UTI (urinary tract infections).*
>
> *“Mostly from fever/infection and catheter blockage.”*

“They are very poor, they barely have money.” Many of the patients live in poverty

Most patients who accessed the centre lived in poverty and struggled to make ends meet. This impacts not just the patient but also the family. A carer might have to leave employment to care for their family member further entrenching poverty. As a consequence, medications and catheter materials may be too expensive and often were for many. Alternatively, the person with SCI could be left alone for extended periods of time while their carer went to earn money, this would result in increased risk of pressure sores and other negative medical consequences.

> “*Because they got no money and kept it untreated for too long, the infection could reach the bones.*”
>
> *“Imagine a couple in which the husband who has SCI and the wife has to be the caregiver and can’t go to work, so who’s gonna help them.”*
>
> *“Their family economic status are always poor and another thing is before they come to us, they already spent so much money.”*
>
> *“No caregivers because they need to work for money such as going to Thailand to work.”*
>
> *“Most patients when they come here spent every penny they had on treatment at other big clinics.”*

“It’s complicated with the means of transportation.” Cost and access to transport a challenge

As a result of the financial drain and many of the families living in poverty, transport became a major issue and often meant it was impossible for the person with SCI to attend a healthcare centre or hospital due to the prohibitive cost of transport and lack of accessible transport. Many with SCI, especially those with tetraplegia cannot take mainstream transport and special transport is expensive e.g. taxis.

> *“It’s hard for them because most patients are from poor backgrounds and not having enough money for taxi fares.”*

> *"For some they are very poor and barely have any money. Sometimes the reason for the delay in discharge is for those who are waiting to save enough money for transportation back home."*
>
> *"Everything costs money. The transportation from one province to another costs quite a bit of money."*
>
> *"We do (allowance for transport) but the allowance is very small which is KHR10,000 and it doesn't matter if they come from far away."*

This section clearly demonstrates the issues facing people with SCI, their families and the staff at the Physical Rehabilitation Centre for persons with SCI in Battambang. While the positive attitudes and the commitment of staff are to be applauded, there are many challenges that urgently need to be addressed if quality and sustainable care is to be delivered to people with SCI.

Findings from the Provincial Rehabilitation Centres

Four rehabilitation specialists from four out of eleven provincial rehabilitation centres (PRCs) were interviewed from across Cambodia. Three interviews were conducted face-to-face while one was conducted online using Zoom. The following themes emerged from the interviews.

"We do not have enough assistive devices." Equipment and access an issue at PRCs

The participants from PRCs spoke about the issue of having enough assistive devices for people with an SCI. They also talked about access to the centre and how this can be difficult, especially for people with tetraplegia. This finding is consistent with the perspective of the health professional PRC for persons with SCI in Battambang.

> *"We do not have wheelchair they can lay on."*
>
> *"No now, it was before that we provided them with lying wheelchairs because they couldn't sit up."*
>
> *"I don't have full equipment as you know that rehab has not fully equipped to support SCI.*

As noted in observations by the researchers, access to PRCs could be difficult for SCI people in wheelchairs.

The pictures below illustrate the difficulty that a person in a wheelchair would have navigating the PRC environment.

“Patients died because of very bad infections from pressure sores.” A constant theme

This theme was constant across service providers and the focus group discussion with carers of people with SCI. The quote used below highlights the difficult and the desperate need for good skin care, otherwise it can lead to death.

> *“From what I think, the doctors only provide treatments until the patients get better. Then they discharged the patients without giving any advice, unlike at the SCI centre, on the prevention of pressure sore as they only know how to provide treatment. When the patients didn’t know, they couldn’t prevent it and the pressure sore kept coming back and making it worse. For the pressure sore, the patients do not feel any despite how big the wounds are, and once the pressure sore extends to the bones, the patients start to develop infection and fever, yet they still don't feel any pain and just the fever which could lead to death.”*

The trouble with catheters

The participants in the PRCs also raised the same concern around the need for good urinary tract care as noted above. Across service providers and the focus group discussion, issues around catheters were always mentioned: from the inability to find them at pharmacies, to the cost and the lack of knowledge around their use from families to clinics.

> *"In one case with a health centre, even just managing the catheter, they said they didn't know how to do it and referred the patients to the referral hospital. I went to support him myself at 8 PM. This was voluntary as well because his wife called for my help as the patient suffered since 5 PM and I told them to go to the health centre. When the health centre staff saw the patient in the wheelchair for paraplegia, they said they didn't know how to manage the catheter. At 8 PM, I went there myself and inserted the catheter suddenly, the bag filled fast. I got back home at 9 PM that night and this was all voluntary with my own resources. Another thing with the transportation is the taxi said they couldn't transport the patient because the patient smelled due to the leaks. The local authorities didn't know how to help either but the centre does not discriminate. For any persons with SCI, no one really pays attention to them."*

The quote above is a stark reminder of the challenges faced in relation to catheterisation for both the person with SCI and their families. In this case the action of the participant who went beyond what was required of him in his job resolved the problem for the person with SCI.

Corroboration of themes between Battambang SCI Centre and PRCs

Many of the themes from the Battambang SCI Rehabilitation Centre were echoed by PRC participants, these included:

- Lack of training and awareness around SCI.
- Lack of specialised equipment needed for SCI care.
- Poverty experienced by most SCI patients and their families.
- Difficulty with transport including accessibility and cost.
- Lack of awareness of the SCI Rehabilitation Centre, especially in the community.

Findings from Focus Group Discussion of Family Carers of People with SCI

In order to get a greater understanding of the challenges faced by the families of people with SCI a focus group discussion was conducted with family carers. There were seven participants that included five women and two men. The women were all wives of men with an SCI, while one man was a husband and carer to his wife and the other man was the brother and carer of a person with SCI. All caregivers had experienced staying at the PRC for persons with SCI in Battambang with their injured family member.

The focus group discussion had to be stopped on one occasion as three of the women became upset. They were asked if they would like to stop but were adamant that they wanted to tell their stories. There was a lot of nodding of heads during the discussion as participants agreed with each other and also offered each other mutual support and encouragement.

"When it is too much, I cry….." Burden of the carers

All carers who participated in the FGD cared for loved ones who had profound degrees of paralysis due to a spinal cord injury. The burden of care for their family members was obvious from their responses. It should be noted that carer burden has been covered in the international literature but mostly focuses on high-income countries, and there remains a dearth of literature that focuses on carer burden in low and low-middle income countries such as Cambodia.

The participants highlighted the impact that constant around the clock care had on them, their family and the economic situation. The following quotes highlight this theme.

> *"Sometimes when you are unwell and you can't afford to medicine, it's very stressful for you because you're sick yourself and have to look after your husband. I've been having low blood pressure and chronic dizziness….."*

> *"I was being called all the time and sometimes didn't get to sleep or do anything else because we were busy being attentive to them. …….they couldn't eat by themselves so they just stared at the food until we helped out."*

> *"I've been through all the difficulties and struggles but I never let my husband see me cry."*

> *"Sometimes I felt I'd had enough and I shouted at my husband."*

"He curse me out." The emotional and mental strains

This burden of care also created emotional stress between the families especially between the carer and the person with a SCI. However, as mentioned earlier, there is little to no mental health support for these families.

> *"They do feel different from us as they're suffering, stressed, moody and very hard to deal with. For example, if I went somewhere for a little long, he would say I went to*

> *meet men, or if he wanted to eat something and I couldn't meet his expectations, he got very angry."*
>
> *"My husband bangs his head on the bed when he is angry. He said he was struggling so I told him if he wanted to do that make sure he dies or don't even dare do that."*
>
> *"He would call me if I was away for 3-4 hours and curse me out."*
>
> *"If I am three hours away, she would get really angry.*
>
> *"There's no point in taking turn answering cause we all have the same answers."*

"So, I don't get to do anything really." Inability to earn an income

This constant emotional burden on families was exacerbated by poverty and the need to earn an income. Participants talked about their inability to work and earn an income due to their caring responsibilities. All participants were low-socio economic status before the accidents causing the injuries to their family members. The inability to work further entrenched their positions in poverty.

> *"Before I did rice farming but as soon as I left the house my husband told the kids to fetch me back because he had a problem with urinating or his catheter got stuck, so I didn't get to do anything really."*
>
> *"We struggled to generate income, it will be better if we have a job we can do at home while looking after our spouse."*
>
> *"Before, when I was selling my snacks, I was able to get him some breakfast or food but my joints are very bad and I couldn't earn an income."* (pain in joints was from the heavy tasks of caring for her husband)

"Every day I depend on my child who is 22." Financial stress of care

The financial stress of not being able to work, plus the loss of income of the person with SCI put huge financial pressure on the families. This was exacerbated by the cost of transport, medicine and catheter materials, as was noted earlier. For some the financial strain led to them having to borrow money; while some spoke of borrowing from families, others had to turn to other avenues of monetary support that left them open to high interest rates and an inability to pay the loan back..

> *"All kinds of challenges and struggles including financial…………My husband's wheelchair and cushion are old and wearing out."*
>
> *"I loaned from someone……I just said I loaned from others and I haven't paid them back."*
>
> *"I don't loan but I borrow from my child."*
>
> *"We live far away and we are insufficient financially."* (participant explaining inability to buy enough catheters for her husband)
>
> *"All of us experience the same thing here."*

Other issues mentioned by the family carers

Many of the other themes highlighted by the family carers corroborated what was heard from the service provides at Battambang SCI Rehabilitation Centre and the Provincial Rehabilitation Centres:

- Supply issues in relation to catheter materials (plastic bags used as substitutes and medication.
- Inability to pay for medical supplies.
- Inability to access clinics and hospitals due to transport and costs.
- Lack of community support.
- Carers feel they are invisible within the system.
- No respite for caring duties.

Findings from Interviews with Policy Makers

Three policy makers were interviewed to get a better understanding of policy landscape and the future of service provision and social support for people with SCI and their families.

"Service referral is a challenge." Lack of referral pathways

Across all the participants a lack of a clear referral pathway was mentioned. Poor service referral was also been discussed above by the service providers. This was most likely exacerbated by a lack of knowledge of the PRC for persons with SCI. This lack of referral pathway could cause negative impacts for people with SCI and their family including the need to spend more money and lack of care leading to death.

> *"If we have guidelines and policy. The policy to be delivered to the health centre, then the health centre should understand about the condition of SCI so they can follow that guideline."*

> *"There was a crisis with the lack of social service workers in the community so the pathway or the referral system is not yet functioning and caused the problem for people with disabilities, elderly, or children with disabilities could not access to services. "*

"No, we do not have a specific policy for each type of disability yet." No specific policies for supporting persons living with SCI

Part of the issue relating to lack of care as seen by the participants was the lack of specific policy that was related to people who had a spinal cord disability. All policy makers confirmed that there is no clear policy to support patients with SCI as they require special support even through they are discharged from the PRC for persons with SCI. The government has policies to provide social assistance and protection schemes to support persons with disabilities. This presents an issue as people with SCI have needs specific to them and their disability is most often profound. There are also medical issues that need attention including those mentioned previously by participants such as urinary tract care and skin care. Their condition is both a rehabilitation and a health concern. In most countries rehabilitation services fall under health ministries due to the on-going medical care some forms of disability including SCI need, whereas in Cambodia the responsibility lies with the Ministry of Social Affairs, Veterans and Youth Rehabilitation (MoSVY).

> *"…this is the problem that we need to develop and during this time we have one new assignment for the transition plan…"*

> "*SCI is very clinical like the hospital, so it should be under management by the MoH*"

"Some activities are reduced due to limitation of budget." Loss of budget in transition from INGOs to Government

As well as the issue of policy directly targeting the people with an SCI, budget was also mentioned as a concern by the policy makers. This was also mentioned by the service providers interviewed as part of this research. The interviews revealed that when the SCI centre had support of an INGO, activities that supported people living with SCI were conducted after discharge. This allowed for better care post-discharge and this outreach is common practice in many countries. These comments were also reiterated comments made by service providers interviewed.

> *"Before when we transport the patient to their home, we have the workshop technicians that go with us and they built toilet, they feel bed fit for the SCI patients so they could live easier."*
>
> *"They only have budget for taking care of the patient in the centre. For example, the medication, the food in the centre and some accessibility, maintenance in the centre but not outreach program."*
>
> *"for SCI (patients) we couldn't do the home follow-ups and they are fewer in number (compared to other persons with disabilities) and we do not have enough budget to do so."*

"Quality of service is still limited." Limited health knowledge of SCI

The lack of budget also led to the belief that the quality of services provided to people with a spinal cord disability needed attention. Additionally, they were also concerned about the lack of knowledge and expertise needed to work and treat people with a spinal cord injury in Cambodia.

> "*They have health problems and mental conditions and when they referred to the hospital, the hospital didn't understand about the situation of the SCI (patients) so they keep for a long time so they keep at the hospital for treatment for a long time." and "I think it's still low, not only in the centre but outside centre. "*
>
> *"It seems not many specialist doctors available in the country; no proper treatment could cause persons with SCI to death or serious conditions. After the centre was transferred to PWDF, that doctor resigned. After that, for around a year we didn't have a doctor."*
>
> *"I think that the attention given to the patients from the centre isn't fully sufficient due to the limited resources." and "…due to the limited budget, the provision of services may not be fully sufficient."*

"Lack of evidence base for the government." Limited knowledge, limited budget

However, the policy makers did note that without the data to understand the prevalence and the experiences of people with spinal cord injuries and spinal cord disability it was difficult to move forward. Currently, there is a lack of data on the prevalence on SCI and limited knowledge around the impact SCI has on people and their families once they are discharged from the SCI centre. Additionally, nothing is known of those people who acquire an SCI and do not go through the centre. As a result, knowledge of the needs of this cohort are very limited and they remain invisible.

> *"No data but when we debate budget to the Ministry of Finance and Economic, no evidence base for them but if the system show about how many people affected this month."*
>
> *"The managing body of the SCI centre, we didn't pay much attention to them because we focused more on PRCs than the SCI centre but it doesn't mean that we neglected the centre."*
>
> *"This is not only just PWDF but other donors as well that didn't pay much attention to the SCI centre and only focused more on the PRCs."*

Key Messages

Many of the key messages that arose for the findings align with the literature related to the Global South and to Cambodia more generally. The section below unpacks the key points from this research.

A lack of data on prevalence of SCI and the lives of people with SCI

Currently, there is a lack of data on prevalence of SCI and the lives of people with SCI after discharge makes it difficult to understand the nature of all the issues. This makes it difficult for policy makers and service providers to accurately legislate and provide for the required assistance and needs for people with a spinal cord disability and their families. A report prepared on SCI part of the Disability Rights Initiative in Cambodia (a joint programme between UNDP, UNICEF and WHO) noted there was no reliable prevalence data; they did however state, *"a conservative estimate that is consistent with international trends indicates that over 300 people sustain a SCI annually in Cambodia, based on numbers and frequency of* *new cases reported during the hospital visits or on later contact."* (Kleinitz et al., 2017 page 14).

Data from hospitals or health clinics where people present with a spinal cord injury is not reliable and it is difficult to gauge the prevalence of people presenting with this type of injury and then follow them through the health system. This is important, as not all SCI will result in spinal cord disability. Disability data within Cambodia also does not disaggregate this data, so an accurate number cannot be achieved.

There is clearly a lack of knowledge around the treatment and care of SCI

There is a lack of knowledge around the treatment and care of SCI at all levels of the healthcare and rehabilitation systems including referral pathways. This theme was mentioned by both service providers at Battambang Spinal Cord Rehabilitation Centre and participants at the Provincial Rehabilitation Centres as well as the policy makers interviewed. This finding is in line with the current research in the Global South.

Studies have documented the experience of hospital-based care for people with SCI in low- and middle-income countries (Chhabra et al., 2018; Dorjbal et al., 2020; Fuseini et al., 2018; Stillman, 2014), with much of the literature exploring the lack of experience of healthcare professionals in dealing with SCI patients. The literature also discusses the impact of adequately trained hospital-based healthcare professionals on how informed patients with SCI are about their condition, with studies reporting that patients are often unaware of the importance of initial and follow-up care for the injury (Badenhorst et al., 2022; Fuseini et al., 2018) due to healthcare professionals being unaware of these requirements. Currently, as little is known about the care SCI patients receive at hospitals and health clinics in Cambodia, this gap in knowledge could be leading to more severe consequences from their initial injury.

In addition, to staff at Battambang SCI Rehabilitation Centre taking about a lack of knowledge around SCI care was the concern of other medical professionals not wanting to come and work at the centre. Staff stated that they thought this was mostly to do with the low wages received by the staff and lack of job security, since they were not employed by the government and hence did not enjoy the accompanying salary and security. Given that all the staff were near retirement age, this is an issue that needs addressing immediately to ensure there are adequately trained staff to care for the patients at the centre.

Lack of specialist equipment and medical supplies and accessibility

These issues of a lack of special training are also complicated by the lack of special equipment and medical supplies. A lack of access to medicine, catheter materials and assistive devices was reported across all the cohorts of participants. For the patients and their families, this was causing harm and contributing to making their lives challenging. The centre and families reported not having access to enough medicine. This has been reported in the literature where it was stated that hospitals and pharmacies were found to not stock or have important required medications for the initial response and ongoing management of SCI (Dorjbal et al., 2020). It was identified that the failure of hospitals to stock essential medications increased the occurrence of secondary health conditions and pain. In Latin America, studies found healthcare professionals faced difficulties with initiating required responses to, and ongoing management of, SCI because of a lack of pivotal infrastructure such as technology and medical equipment within hospitals and externally based care clinics (Marchesini et al., 2020). This finding echoes the issue of the centre where diagnostic treatment is not available and patients have to find their way to another facility to get required tests such as medical imaging.

In addition to medications, participants reported a lack of catheter products for SCI patients both at the centre and when they were discharged. This caused issues around urinary tract infections that can lead to death.

There is a lack of physical and informational access for people with SCI and their families.

Physical and informational access also complicated these challenges. Service providers and the carers spoke about difficulties with physical access to health clinics and PRCS. Again, this is a common theme in the literature. Physical accessibility difficulties within hospitals have also been identified as impacting on the experiences of care for people with SCI. Literature has reported that hospital examination rooms can lack required space for wheelchairs as well as not stocking the required assistive devices to ensure they can safely move from their device to the examination room table. Where assistive devices are available, research has reported clinical hospital staff to be inadequately trained in the use of such machines, thus restricting the kinds of healthcare received as well as the quality thereof (Dorjbal et al., 2020; Stillman, 2014). However, assistive devices such as those mentioned above have not been made available to the staff at the rehabilitation centres.

Much of the research exploring the experiences of people with SCI in low- and middle-income countries accessing healthcare commonly reports barriers to the built and natural environments, in addition to cost of treatment and sociocultural factors (Dorjbal et al., 2020; Fuseini et al., 2018; Khan et al., 2018; King & King, 2014; Liu et al., 2023; Marchesini et al., 2020; Oderud, 2014; Oña et al., 2021).

Physical environments will often be unable to handle wheelchair users (Dorjbal et al., 2020; Oña et al., 2021) with buildings lacking usable elevators with multiple flights of stairs, and patients in 2014 have reported experiencing difficulties simply moving around in their own homes (King & King, 2014). In previous years, INGOs such as Humanity and Inclusion did provide some assistance in making homes more accessible for people with disability. Public and private transport options were also said to be mostly inaccessible due to type of vehicle and affordability and in some cases transport workers were either unable to or unwilling to assist in transporting people with SCI. This issue has been well documented in the literature. (Dorjbal et al., 2020; Oña et al., 2021). In certain cases, countries can often charge extra for people with mobility aids compared to abled passengers (King & King, 2014).

Poverty remains a key issue for people with SCI and their families.

All participants talked about the financial strain of caring for a person with a spinal cord disability. Almost persons with SCI are breadwinners and all of their carers have to stop working and take care their family members who are persons with SCI, so the amount of household income has dramatically reduced. The high level of poverty amongst persons with SCI has been attributed to education and employment (Krause, et al., 2014). Basic care costs have detrimental impacts on cost of living and cost of healthcare for persons with SCI which may lead to a high mortality rate. They have limited access to healthcare services since they cannot afford them (Oderud, 2014). Most participants as carers reported that they fell into debt because they needed money just for daily expenses and the cost of healthcare. Poverty remains a major consequence for persons living with SCI in low- and middle-income countries (Oderud, 2014). A social protection scheme and additional support for training and employment should be in place for persons with SCI and their families.

There is a lack of policy direction.

The current policies exist to support persons with disabilities in general but do not specifically address persons with spinal cord injuries. Sub-decree ១៣៧ អនក្រ បក signed on June 2011 that the policy is to support persons with disabilities in general for 20,000 Riels per months for between three to 12 months depending on the level of poverty. In addition, the government offers free of charge rehabilitation services for persons with disabilities with 3,000 Riels for meals per day and 10,000 Riels for transportation per time. The amount of money is insufficient to cover food and transportation because most persons with SCI are already living in poor conditions and cannot these expenditures, in particular transportation costs, which are expensive. Health Equity Funds provide financial support to households in poverty through the IDPoor system, which includes issuing of Equity Cards, and enables access to healthcare services free of charge. However, it is challenging for persons with disabilities to have access to the IDPoor system in some communes. MoSVY recently launched (October 2023) a disability identification card for persons with disabilities; however, it is still challenging for people with disabilities to receive the card. The commune focal points identified 288,690 people with disabilities in Cambodia; MoSVY has issued 222,148 ID cards for persons with disabilities (MoSVY, n.d). Legal frameworks play significant roles in supporting the live of persons with SCI, maintaining their community participation (Trezzini & Phillips, 2014). Hence, the government should develop policies and regulations to support persons with SCI.

PRCs including the SCI centre in Battambang are under the management of MoSVY except the physiotherapy service under MoH while persons with spinal injuries need medical services which logically belong under the MoH. Discussion between these two ministries (MoSVY and MoH) of handover strategies for these services is underway, with technical support from INGOs. It is expected that SCI treatment and care may be better when PRC services relevant to SCI are under MoH.

There is a lack of funding for treatment and social care

The government has allocated insufficient budget for SCI treatment and social care. The PRC for persons with SCI in Battambang was established by Handicap International then handed over to PWDF. It has been noticed that number of activities has reduced; for instance, the community-based activity and capacity building to assist staff in the PRC care for persons with SCI. Similar to previous experiences of such transfers, the handover of PRCs from INGOs to the government have been followed by a loss of human resources and a significant drop in activities (PWDF & HI, 2021). Accordingly, the budget allocation for operating these centres has markedly decreased. This pattern has also been observed in South Africa in the area of disability and rehabilitation, marked by a lack of budget allocation, spare parts, assistive devices and medical supplies (Sherry, 2014). This leads to limited quality of healthcare and a reduced quality of life after discharge from the hospitals and PRCs.

None of the PRCs under supervision of PWDF have community-based programs to support persons with disabilities due to lack of budget, whereas the PRCs implemented these activities when they were being supported by INGOs. Some of this activity has been resumed on a small scale in the PRC in Takeo. Without such programs (country-wide), persons with SCI become invisible in the community due to lack of follow-up after discharge, so further assistance to them cannot be provided unless the SCI association has funds available. More attention should be given to the budget allocation for the healthcare treatment and social care.

Recommendations

These recommendations are based on existing research and the thoughts of the research participants.

1. A needs analysis of the health system in relation to spinal cord injury (SCI) and rehabilitation needs to be conducted.
2. Better data needs to be collected on SCI from immediate injury to discharge and through interactions with PRCs.
3. The SCI centre should be relocated to Phnom Penh next to a major hospital – this will allow for around the clock medical care and access to diagnostic testing (radiology and haematology for example). Much needed equipment would also be more readily available.

   Rationale:

   Hospital-based SCI units provide access to multi-disciplinary teams that can provide care that results in better treatment outcomes. These units are associated with better quality of life outcomes, lower rates of health complications and an overall reduction in time spent admitted to hospitals. (NSW Agency for Clinical Innovation, 2020).

   Early access to hospital-based specialized care for spinal cord injury decreases mortality rates and the number and severity of secondary health complications that can arise in SCI. This is a result of the availability of multidisciplinary treatment teams as well as the access to various diagnostic services embedded within hospitals (Abedi et al., 2022; Parent et al., 2011).

Complication rates are higher in SCI patients compared to other rehabilitation patient groups. Complications include urinary tract infections, respiratory complications, pressure ulcers (sores) and pain. These are frequently reported and often occur together (Gedde et al., 2019). The ability for hospital-based care to provide easy access to healthcare professionals that can treat these conditions quickly which means their treatment outcomes are significantly improved (Fenton-White, 2020).

Specialised hospital-based spinal cord units have been found to also have economic benefits, as the positive treatment outcomes means that patients engage with healthcare services less frequently than patients with SCI who do not receive treatment from these clinics (Illis, 2004). Hospital-based treatments allow for efficient and optimized delivery of the management of spinal cord injury resulting in both positive health and economic benefits (Talavera-Mosquera et al., 2022).

4. Specialised training should be given to those working with SCI including at hospitals, clinics and PRCs.
5. An improved referral system for SCI people should be put in place.
6. Extend PRCs and include regular outreach programs.
7. Mental health support for people with SCI and their carers should be established.
8. Create better access to catheter materials and medications required by SCI patients free of charge.
9. Home adaptions should be included in care of SCI patients.
10. Ensure accessibility to healthcare and PRC facilities is prioritised.
11. Raise awareness of the SCI centre.
12. Improve transportation access, this could include more financial support for travel.
13. Evaluation of all new programs to ensure sustainability and effectiveness.

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