

## Research Article

# Living with spinal cord injury in Mongolia: A qualitative study on perceived environmental barriers

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**Context:** Environmental factors play a key role in the lives of individuals with a spinal cord injury (SCI). This study identifies environmental barriers and their impacts on daily lives as perceived by individuals living with SCI in Mongolia.

**Design:** A qualitative study with semi-structured interviews was conducted. A topic guide for the interviews was structured around the components of the International Classification of Functioning, Disability, and Health.

**Setting:** Urban and rural areas of Mongolia.

**Participants:** A purposive sample of 16 persons with traumatic SCI.

**Interventions:** Not applicable.

**Outcome Measures:** Not applicable.

**Results:** Seven categories of environmental barriers were mentioned, such as poor access to the physical environment, absence of wheelchair-friendly transportation, negative societal attitudes, inadequate health and rehabilitation services, lack of access to assistive devices and medicines, limited financial resources for healthcare, and inaccurate categorization of disabilities in laws. These barriers were claimed to have an impact on physical and psychological health, limit activities, and restrict participation in almost all areas of life.

**Conclusion:** This study contributes to the identification of targets for interventions aimed at improving the lived experience of persons with SCI in a low-resource context. The findings reveal that while the Mongolian government already has laws and policies in place to improve access to the physical environment, transportation, assistive devices and employment, much more has to be done in terms of enforcement. Specialized SCI care and rehabilitation services are highly demanded in Mongolia.

**Keywords:** Lived experience, Developing country, International Classification of Functioning, Disability, and Health, Semi-structured interviews, Person-centeredness, Rehabilitation services

## Introduction

Environmental factors play a key role in the lives of individuals with a spinal cord injury (SCI).<sup>1,2</sup> SCI is a complex health condition that commonly leads to impairments (e.g. secondary complications), activity limitations (e.g. mobility), and participation restrictions (e.g. employment).<sup>2,3</sup> Environmental factors such as the built environment, societal attitudes, systems, and

services can act as barriers to people's participation in community life and autonomy<sup>4-8</sup> and thus contribute to disability.<sup>9</sup>

The situation in many developing countries is even more challenging than in high-resource countries. Previous studies demonstrated that a broad range of environmental factors are barriers in low and middle-resource contexts.<sup>10,11</sup> Specifically, the literature highlighted two major barriers related to environmental factors. Firstly, the limited availability of specialized healthcare and rehabilitation services as well as assistive technology, which can lead to SCI complications and

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functional limitations.<sup>12–15</sup> Secondly, the inaccessibility of the physical environment, which hinders participation in society.<sup>16,17</sup> The crucial issue in many developing countries is that such environmental barriers greatly contribute to mortality within a few years of SCI.<sup>18,19</sup> However, some countries have shown that strengthening services and policies, and reducing environmental barriers can result in an improved lived experience for persons with SCI.<sup>20,21</sup>

By focusing on Mongolia as a developing country,<sup>22</sup> the aim of this study was to identify environmental barriers and their impacts, as perceived by individuals living with SCI. To the best of our knowledge, there are no comprehensive data on environmental barriers following SCI in Mongolia. Existing studies of Mongolia focused on the pitfalls in rehabilitation services for persons with disabilities.<sup>23–25</sup> Furthermore, the Mongolian report for the Convention on the Rights of Persons with Disabilities (CRPD) stated that very little is known about the everyday life situation of persons with disabilities, thus limiting effective decision-making.<sup>26</sup> Given this backdrop, the present study investigates the lived experience of individuals with SCI in Mongolia. Findings may inform targets for intervention to reduce environmental barriers for persons with disabilities in Mongolia and can contribute to the literature about environmental barriers in low-resource contexts.

## Methods

### Design

An explorative qualitative study was conducted using semi-structured individual interviews.

### Sampling and recruitment

#### Sampling

We used a purposive sample, stratified by geographical area: urban (the capital city, Ulaanbaatar) and rural areas (provinces). The sample size was determined by thematic saturation. The data analysis was carried out in parallel to the data collection, and the recruitment was stopped once no new themes emerged from the analysis.

#### Eligibility criteria

Males and females with different levels of SCI were recruited. The following inclusion criteria were applied: people aged between 18 and 45 years, who experienced a traumatic SCI after the year 2001, living at home and speaking Mongolian fluently. The study excluded persons with degenerative or congenital diseases and persons over 45 years of age in order to focus on barriers in relation to SCI and not to ageing

or comorbidity. Indeed, the burden of chronic conditions and unemployment are very high among the population aged 45–65.<sup>27–29</sup> The decision to limit participation to individuals who were diagnosed with SCI after 2001 was to ensure that all participants had experience with the same healthcare system, which changed in the 1990s following the downfall of the Soviet Union.<sup>30</sup> Persons living in an institution were also excluded because the study focused on daily activities and participation.

### Recruitment

Two organizations in Mongolia helped identify potential participants and invited them to take part in the study. The National Traumatology and Orthopedics Center<sup>31</sup> provides acute care surgery for SCI at the country level. The Universal Progress – Independent Living Center<sup>24</sup> is the largest non-governmental SCI support organization, with members from all provinces of the country. The research team received the contact information of the people who declared their interest to participate and contacted them (phone call) to schedule the interview.

Ethical approval for this study was obtained from the Research Ethics Board of the Mongolian National University of Medical Sciences (No.16/3/2016-16). All participants signed an informed consent form before the interview.

### Data collection

Data collection was carried out from September to December 2016 by the first author.

### Questionnaire

Participants filled out a questionnaire to provide demographic and medical information, such as sex, age, time since injury, cause and level of traumatic SCI, living area and conditions, level of education, and current employment situation.

### Semi-structured interviews

We structured the topic guide around the components of the International Classification of Functioning, Disability, and Health (ICF),<sup>9</sup> which in the context of functioning, provide a rich list of the environmental factors. The ICF has been used in several studies as a framework to provide a comprehensive understanding of the lived experience of persons with chronic conditions.<sup>32,33</sup> Appendix 1 presents the topic guide.

### Data analysis

All interviews were audiotaped and transcribed verbatim in Mongolian. Each interview lasted approximately

60–90 min. The transcripts of twelve interviews (six from each geographical area) were translated into English by a professional translation center to allow a second researcher to act as a second reviewer for the analysis.<sup>34</sup> All instances relevant to environmental factors and their impacts in daily life were coded following the principles of thematic analysis.<sup>35</sup> To ensure that codes within a category were meaningfully related to each other and that there was a clear conceptual differentiation between categories, the categories and their supporting data were constantly compared to each other. When the data in support of a category was too diverse, the category was broken down into separate categories. When the data were very similar, two categories were merged. Disagreements on the coding of the twelve translated interviews were discussed until agreement was reached, and the coding scheme was refined. On the basis of the decisions made, the first author then coded the remaining four interviews that were not translated into English.

## Results

### *Characteristics of the study participants*

Table 1 shows demographic and medical characteristics of the 16 participants. Nine males and seven females between 25 and 45 years of age participated in this study. Half of them were recruited from six different districts in Ulaanbaatar and the other half from rural areas in eight different provinces. The majority of the interviewees had paraplegia. The main causes of SCI were road traffic injuries. All of the participants lived with family members. Ten were unemployed.

### *Perceived environmental barriers*

The analysis highlighted that individuals with SCI in Mongolia face several environmental barriers in their daily lives. Identification of the barriers across the two geographical areas and sex was similar. These perceived barriers were grouped into seven categories: (i) poor access to the physical environment; (ii) absence of wheelchair-friendly transportation; (iii) negative societal attitudes; (iv) inadequate healthcare and rehabilitation services; (v) lack of access to assistive devices and medicines; (vi) limited financial resources for healthcare; and (vii) inaccurate categorization of disabilities in laws. The barriers identified by the participants are described below, along with their perceived impact on the participants' lived experience. Table 2 contains representative quotes.

### **Poor access to the physical environment**

All participants were wheelchair users and reported that the access to buildings (e.g. entrances and restrooms)

and the outdoor environment (e.g. streets) was the largest barrier for mobility and other daily activities, such as personal care and housework.

- (a) *Entrances and exits of buildings:* The participants stressed that thresholds, heavy doors, and the inadequacy or lack of ramps and lifts led to challenges in entering or exiting private and public buildings. Therefore, they have to rely on family members, neighbors, and strangers (e.g. to carry them up and down the stairs) (Table 2, Q1–3). Most participants stressed that the absence of ramps is due to a lack of policy implementation. Policies exist, but contractors prefer to pay penalties, which are low, instead of building according to the rules (Table 2, Q4). In relation to the presence of thresholds, some participants explained a cultural barrier to their removal: Mongolians believe that the removal of thresholds could bring bad luck. For this reason, most public places have one (Table 2, Q5).
- (b) *Restrooms:* Another major barrier was the absence of wheelchair-accessible toilets and bathrooms (e.g. very small size or located in separated inaccessible buildings). Hence, urban participants living in an apartment needed to be carried to sit on a toilet seat or in a bath (Table 2, Q6–7). Many rural participants live in a Mongolian traditional dwelling (yurt) without a modern restroom. So, they managed this challenge with the help of their caregivers (Table 2, Q8–9).
- (c) *The outdoor environment:* The participants stressed that sidewalks were inadequate and sometimes lacking. Mobility was therefore very difficult for urban participants, and the situation was even worse for those living in rural areas, where the roads have a dirt surface (Table 2, Q10–11). Furthermore, the majority of the participants stated that they did not go out during the winter due to cold weather and snow (Table 2, Q12). Moreover, the participants emphasized that the inaccessibility of the physical environment was an obstacle for continuing education, employment, and engaging in leisure activities (Table 2, Q13–15).

### **Absence of wheelchair-friendly transportation**

Transportation represents another important challenge for the participants. Inaccessible public and private transportation restricted many of the participants' access to activities outside the home. To overcome this barrier, they relied on the practical support of family members or friends as well as on private vehicles.

- (a) *Public transportation:* The participants reported that only a few adapted vehicles were available in Ulaanbaatar and none in rural areas. Moreover, accessibility might be challenging even in the

**Table 1 Demographic and medical characteristics of the study participants.**

Participant ID	Sex	Years of age	Date of injury	Cause of injury	Level of injury	Injury type	Living area	Educational or work status at/ before injury	Highest level of education at interviews	Current working situation
P1	Male	45	2001.09	Traffic accident	Paraplegia	Incomplete	Urban	PhD student	Post-graduate studies	Volunteer work
P2	Female	25	2010.08	Traffic accident	Tetraplegia	Incomplete	Urban	Student	Vocational education	Volunteer work
P3	Male	36	2008.03	Work accident	Paraplegia	Complete	Urban	Unemployed	Secondary school	Unemployed
P4	Female	29	2007.10	Traffic accident	Tetraplegia	Incomplete	Urban	Just after graduation	Vocational education	Unemployed
P5	Male	39	2009.12	Traffic accident	Tetraplegia	Incomplete	Urban	Employed	Vocational education	Unemployed
P6	Male	33	2001.07	Traffic accident	Paraplegia	Incomplete	Urban	Employed	Secondary school	Unemployed
P7	Male	36	2001.04	Medical error	Paraplegia	Complete	Urban	Student	Post-graduate studies	Self-employed
P8	Female	34	2003.07	Traffic accident	Paraplegia	Incomplete	Urban	Employed	Secondary school	Unemployed
P9	Female	40	2008.04	Traffic accident	Tetraplegia	Complete	Rural	Employed	University	Unemployed
P10	Female	28	2011.09	Traffic accident	Paraplegia	Complete	Rural	Employed	University	Unemployed
P11	Male	45	2003.01	Traffic accident	Paraplegia	Incomplete	Rural	Employed	University	Self-employed
P12	Female	31	2009.04	Hiking	Paraplegia	Complete	Rural	Employed	University	Unemployed
P13	Male	34	2003.09	Traffic accident	Paraplegia	Complete	Rural	Just after graduation	University	Self-employed
P14	Female	27	2010.09	Traffic accident	Paraplegia	Complete	Rural	Student	University	Unemployed
P15	Male	40	2001.11	Violence	Paraplegia	Incomplete	Rural	Student	Secondary school	Unemployed
P16	Male	36	2008.12	Traffic accident	Tetraplegia	Complete	Rural	Self-employed	University	Self-employed

equipped buses, mainly due to the drivers’ lack of technical preparation (Table 2, Q16–17). Those participants who had traveled by train or plane also had problems with accessibility (Table 2, Q18–19).

- (b) *Private transportation:* Transportation using private vehicles was highly preferred to public transportation. Some male participants drove illegally modified cars. However, they reported that such car adaptations were mostly performed by non-certified entities and thus had no warranties. They also reported that not all individuals with SCI held valid driver’s licenses due to the lack of driving schools with proper training and equipped vehicles (Table 2, Q20–21). In addition, private transportation is expensive, and some participants in remote areas had to give up their jobs, as they could not afford the cost of using alternative private transportation (Table 2, Q22).

**Negative societal attitudes**

Among the perceived barriers, the majority of the interviewees mentioned negative societal attitudes. They

experienced discrimination within their families (e.g. not being accepted by the girlfriend’s family), at work (e.g. not being hired because the recruiter did not believe they could perform the job), and in society at large (e.g. people believe that persons with disabilities are paying for previous bad deeds) (Table 2, Q23–25). Furthermore, the participants stressed how such negative attitudes impacted their psychological health and caused distress (Table 2, Q26).

**Inadequate healthcare and rehabilitation services**

The participants concluded that the current Mongolian healthcare system’s response to persons with SCI is inadequate, citing a lack of knowledgeable and skilled rehabilitation professionals. They did not receive appropriate information regarding their diagnoses and ways for self-management. Accordingly, they had to rely on peer support to get information about daily living with SCI (Table 2, Q27). Similarly, the participants could not get adequate information regarding sexual

**Table 2 Representative quotes.****Poor access to the physical environment**

Q1. "I live on the fifth floor and I cannot get home alone. It is a five-story old apartment with no lift or ramp. It is hard for me to get out and come back in. My wife has to ask someone to help me. I need two persons to help me to go up and down the stairs with my wheelchair. I would like to live in an apartment with lift and standard ramp. Nowadays, new apartments have lift, it is not a problem. However, there is no ramp in most of them." (P1)

Q2. "I rarely go shopping with my husband or mom. Maybe two times a year [laughed] to big malls like Grand Plaza, which have ramps and lifts. If they are busy, then I cannot go. [...] Of course, I do like to go shopping. I like to choose clothes for myself, but everything is so limited for people like me to go out. I only go to certain places such as the State Department Store and Max Mall because these stores have ramps and lifts." (P4)

Q3. "There are only few supermarkets that have a ramp. Maybe around three or four. That is quite difficult situation for me. In many cases, I could not buy what I wanted to due to the limited options in the accessible shops. Also, when I go to barber I cannot get in. There are only two barbers that have a ramp, and they change their location all the time. I just would like to be able to go to any barbershop that is open. I am not satisfied with this situation. There is no bank with a ramp in this province. Therefore, I cannot get bank services." (P13)

Q4. "There is a standard for ramps in Mongolia. There can only be 12 cm of elevation over 1 m. However, companies do not follow the standard. First, we need principles of liability. Because people and/or companies do not know the standard very well, so they make the ramps with sharp and steep slope. Some of them claim that they cannot make changes to follow the standard because it is a rental accommodation. That is why, we need strict policies and principles. In fact, Mongolian government makes requirement on companies to build their apartments according to the standard. There should be a specialist to monitor and check whether companies are following the standard requirements. Sometimes, the companies prefer to pay the penalty because it is small amount of money." (P10)

Q5. "For example, our school had many stairs and thresholds. We removed thresholds inside home, but when we go outside the threshold is a pretty big problem for us. You know, we have a culture related to the threshold in Mongolia. For example, when you enter a yurt [Mongolian traditional tent], do not step or sit on the threshold. Mongolian people like to have thresholds inside buildings or home, consequently thresholds are everywhere." (P2)

Q6. "I cannot enter the restroom at home with my wheelchair. It is very small which is typical for old Russian style apartments. I always need someone's help when I need to go to toilet. Sometimes, I use a portable toilet if there is no someone at home." (P5)

Q7. "We have a common bathtub. Bathtubs of old apartments are high and deep, but our bathtub's height is 10–15 cm. While sitting on a wheelchair, I manage to put my legs into the bathtub, then my wife supports me and I put my lower body on the edge of the bathtub, and thereafter again my wife supports me to smoothly get into the bathtub. When I finish washing my body, my wife comes in and does the exact same thing but in reversal sequence to get me out of the bathtub. True, it is impossible to have shower or take a bath all by myself." (P1)

Q8. "I did not go to the toilet since I got trauma. Because, I cannot go. It is impossible to use the toilets in countryside. You know the toilet in the countryside? Wooden and deep, I might fall down into it [laughed]. I always do it at home. My husband always helps me." (P9)

Q9. "We do not have a modern bathroom. It is pretty difficult to take a bath in the countryside. My father brings in water from outside. My mother usually arranges everything for me to take a bath. She prepares warm water and washes all my body on a bed. Generally, I can wash my upper body. Sometimes, we use a portable bathtub to take a bath. So, my parents just hold me from both sides and put me in the bathtub." (P10)

Q10. "Most sidewalks around apartments are not designed and constructed for persons with disabilities. There are lot of borders and thresholds everywhere, so it is much easier for me to use the traffic road. I saw some places started to have curb ramps, but it is not everywhere." (P1)

Q11. "Most roads where I live are dirt roads. I mean, we do not have paved roads or sidewalks in rural areas. It is very difficult to get around in a wheelchair because of stones and others obstacles in dirt roads. The only paved road is in front of the local government building in our province. When I cross a road, I can use only railroad crossings. You see, there are many obstacles whenever we go. Our environment is not accessible for us at all, which means, there is no chance to move around." (P10)

Q12. "Well, in summer time, it is much better. I can wait for one or two hours, until someone comes and helps me to get home. But, in winter it is much harder. People with SCI get cold very quickly. When it is  $-20^{\circ}\text{C}$  outside, there is a risk getting sick or start freezing. That is why, many wheelchair users do not go outside in winter time. I stay inside from November to March. In Mongolia, it is  $-30^{\circ}\text{C}$  and snowing a lot. The road is very slippery during the winter." (P3)

Q13. "I still think about continuing my study [thinking ...]. My situation right now is dependent on my mom. If I wanted to continue my study in college, there will be issues on who will pick me up or drop me off at college etc. Even if my classmates could help me in getting a cab every day, the most difficult thing will be going to the restroom. So, because of these issues I cannot continue my study in college." (P4)

Q14. "I would not say I tried hard enough to look for a job. I think there are limitations everywhere starting from ramps at entrances to non-availability of restrooms specially designed and equipped for persons with disabilities. I do realize that it is quite difficult for people like me to stay for long time in workplaces. I think these are main difficulties to get a job." (P3)

Q15. "I used to play basketball almost every day. I gave up my sport after the injury. It is impossible to do this. If I wanted to play, I need to go out there. So, someone needs to help me to get there. The only hobby now is reading and surfing the internet." (P11)

**Absence of wheelchair-friendly transportation**

Q16. "Long buses with ramps were imported recently for us. But, those buses go within few lines only. Also, our bus drivers do not stop closer to the curb, so it is hard for us to get in. They never use the ramps. In fact, the government pays five billion tugriks to bus companies to let persons with disabilities take a bus for free. But, we cannot take the bus." (P7)

Q17. "There are no accessible buses for persons with disabilities in rural areas. Two years ago, minibuses started to serve in the province center. But, not so many passengers with disabilities use the minibuses, which are very small, so I cannot get in. Once I used the minibus to go to the capital city for my treatment. My mom was traveling with me. I could not sit in the first year, so we had to rent the whole minibus to transfer me in horizontal position. Later, when I started to sit, we did not rent the whole minibus, but I needed two seats. We spent a lot of money on transportation. It is approximately 1600 km and it takes almost 24 h to get to the capital city." (P15)

Q18. "It is very difficult. I am heavy with my wheelchair and the wheelchair does not fit in the train's narrow hallway. It is completely impossible to move on a wheelchair inside the train. Once, I traveled to China to have a spinal surgery. People had to put me on a mattress and haul me. There is no chance of me moving by myself. So, I just stayed inside my cabin during the whole travel. There was no way to get to the toilet. I had to go inside my cabin." (P5)

Q19. "There are no platforms. Actually, the government has made some changes, but they did not do it according to the standard again. The government supported to equip recently one coach in one train to access for wheelchair users. But, there is only one coach for many persons with disabilities. Moreover, the equipped train goes in only one direction. Our government really should solve this problem for us." (P14)

Q20. "It is better if you install hand control in your car. But, we do not have that kind of service. Only one guy from my work made a fabricated car for me. It is not made according to standards and it is illegal. But, there is no other way. Police do not have any concept about it. I think they are not aware that this kind of car even exists. [...] It is dangerous." (P7)

Q21. "I drove a car without a license for almost two years. Even, if I wanted to take driving courses they do not have that kind of service and the vehicle for us. [...] The law says that if a person is not considered as a healthy person, they are not allowed to take driving courses. I visited many hospitals to get legal paper saying that I am healthy, only I am a person with disability. But, doctors are afraid that if anything happens, police will take legal actions against them. I also visited many driving courses, asking to get a driving license. But they do not allow. My friend and I used to go out of the city and he taught me how to drive. Eventually, I learned how to drive illegally without official driving courses." (P15)

Q22. "[The] non-governmental organization offered me a job. I needed to go between the province center and soum [village] where I live. At the beginning, I used taxi for one and half year. I spent a lot of money. It was 10'000 tugrik [~ 4 USD] a day. Also, my parents could not move to live in the province center because they are herders. I could not live alone, even now. Then, I just gave up. [...] No. no buses or other public transportation between the province center and soum." (P9)

#### Negative societal attitudes

Q23. "I have a girlfriend now. The problem is that her parents, relatives and friends do not like me because I am a person with disability. My girlfriend told me that they all constantly persuade her to finish our relationship. They think I am infertile. I really get anxious and stressed about myself because of this." (P11)

Q24. "I am an economist. I take care of my family's financial needs by running my own publishing service company. Even though I want to work as an economist, Mongolian companies do not hire me." (P13)

Q25. "I think Mongolian society does not understand and accept persons with disabilities. Mongolians are very superstitious. So, they think people who make lots of sins get to become disabled or something like that. I have communicated with a lot of people, most of them think this way. So, because of our society attitudes, I do not go out much." (P16)

Q26. "I think our society looks at us as sick people who can do nothing. They think that persons with disabilities have no intellectual potential, I could feel and sense it. People stare a lot. Some people look at us like we are poor or they pity us. One day in a supermarket, when I laughed some people said 'Poor her, she is laughing'. I do not like to go out because I do not want to have this kind of bad feelings. Then, I get really depressed." (P8)

#### Inadequate healthcare and rehabilitation services

Q27. "Well, let's say from similar persons with SCI. They helped me to learn these things. When I was in a hospital, I met one guy on a wheelchair. Since then, I have got a communication with persons living with SCI. I get information from the Independent Living Center. My life has changed completely since meeting with my friends living with SCI at this center. Doctors have not provided me with much information. After the accident, doctors saved my life. After that my parents took care of me. Then, I needed consultation on how to live in future. Youths with SCI taught me a lot." (P14)

Q28. "Mongolian doctors at the clinics do not have any concepts about persons with SCI. They told me that I could not give birth. They wanted me to have an abortion. My mom did not approve the abortion. Also, I wanted to keep my baby. I did not visit any clinics again until my expected delivery date. I found one acquaintance of my mom and lobbied the doctor. Then, I had caesarean section birth. I knew few persons with disabilities who gave birth. So, I believed that I also could do it." (P4)

Q29. "I do not think it is possible for me to conceive naturally. I have not got diagnosed yet. I still think about it. There are persons with SCI who have had kids through artificial insemination. But, they do not share the information. I think few private hospitals in Mongolia do that service. But, it is a rare thing in our country." (P13)

Q30. "The government tries to take loans to build nursing homes for us. In fact, we do not need them, we need proper rehabilitative care. The Rehabilitation Centre is newly re-established. They do only treatments like massage and vitamins. That is all. They try to heal spinal cord injury by massage or acupuncture. They do not understand that these treatments do not have any effects. I spent so much money and time on useless treatments. From the beginning, doctors should have explained everything. I even went to see pastors and visited temples or churches with the aim to stand on my feet." (P11)

Q31. "We get pressure ulcers and doctors do not know how to treat it. It is so pitiful that so many persons with SCI could not survive the pressure ulcer and die. After I got injured, the trauma hospital's doctors said to my wife that patients with SCI live for maximum ten years due to pressure ulcers with a proper care. But, it is now past 15 years since I got injured. I am still alive and I guess I will live for some more years [smiled]. Actually, they cannot treat pressure ulcers in Mongolia." (P6)

Q32. "In this province, there are no doctors who are specialized in kidney and bladder. If you use a catheter in a wrong way, you could get bladder infection. Once I had a problem with a catheter, doctors could not change it either, and I had to travel to the capital city to get specialized doctor's service. Since then, I learned how to change my catheter on my own." (P13)

Q33. "In my opinion, health services are not really good in Mongolia. Most of persons with SCI need to go abroad for treatments. [...] I am very sensitive about one thing. Our doctors are not good on providing with information for us. They do not give any advice on how persons with SCI should live their life. I went to Japan, once I paid 100 USD for 30 min session with a doctor." (P7)



Q34. “[...] I have heard that a Chinese doctor came to Mongolia. So, I visited that doctor to get some consultation. The doctor said to me that I did not get proper treatment. Then, I decided to go to China to get treatment. When I stayed there in a hospital, the treatment for pressure ulcers was much better than in Mongolia. My relatives helped me in terms of money. We collected some money for this purpose.” (P1)

#### Lack of access to assistive devices and medicines

Q35. “It is difficult to find a good quality wheelchair [smiled]. The reporter Z used to import second-hand wheelchairs from USA. He imported two and distributed to persons with disabilities. Fortunately, I was one of the two lucky persons to get the wheelchair. It was free. Thereafter, lots of wheelchairs were imported to Mongolia, but most of them were from China and with very bad quality. I am still using the one I was given for free after choosing from several wheelchairs. It is manual. I guess, most of the wheelchairs here in Mongolia are manual. Even, if I find the automatic one, I am afraid that there is no specialist to maintain and repair. Also, the automatic wheelchairs are heavy. So, it would be even more difficult to move around, especially if there is a need to hold me while getting up and down. Also, mostly Mongolian market imports wheelchairs for clinical practice. In fact, we need a wheelchair in daily living.” (P1)

Q36. “In Mongolia, technologies are poorly developed. For example, I saw this chair on the internet in which you can sit and transfer to a bathtub without slipping. There are many types of equipment for persons with disabilities, right? But, Mongolian market does not sell those kinds of products. Few stores sell appliances for persons with disabilities, but they cost too much. So, we are unable to buy them.” (P7)

Q37. “There is a special pole stick on my bed to ease a movement around the bed, also to support for sitting or lying on the bed. I use a very old style metal bed from Russia that enabled to equip with that pole stick. My old bed is comfortable enough to move around using that pole stick.” (P1)

Q38. “The law says that the welfare service should give away wheelchairs worth 150'000 tugriks [~61USD]. For that matter, the welfare companies buy wheelchair worth in that amount, which are usually very bad quality wheelchairs. If the government spent more money, the welfare companies would be able to import better quality wheelchairs. The welfare companies could import expensive wheelchairs, but in that case we ought to pay the difference. [...] The government announces tender and the company that wins the tender becomes responsible for the social welfare activities. I am not happy about those wheelchairs either. People with any shapes and size might use a wheelchair. When the wheelchair does not fit your size, it becomes another difficulty for us, for instance back pain.” (P13)

Q39. “The social welfare office provides support once in three years for special devices. There is a list of equipment that social welfare gives away for free [...]. We get wheelchairs, crutches, chairs, watches, also sphygmomanometers. Most of the equipment in the list are very not useful for us. I really need transfer devices.” (P16)

Q40. “It is difficult to sit on a wheelchair every single day. I have had pressure ulcers several times before, but now I am preventing it with a cushion. French doctors used to come twice a year. They gave me this cushion for free. So, I cannot find this cushion in Mongolia. I have to have it repaired and there is one guy who can repair my cushion.” (P11)

Q41. “The social welfare office provides about 20 types of the devices for persons with disabilities. Unfortunately, preventive cushions are not included. We really need such special utilities to prevent. If the government wants to support us, then provide the most useful and important devices or tools.” (P14)

Q42. “My brother sent me a special ointment from Sweden. After using that ointment for three days, my skin started to recover. That was a really good ointment. We need that kind of medicines. Unfortunately, we cannot find them in Mongolia. Mongolian doctors suggested one ointment. I used it a lot, unfortunately that ointment could not treat my pressure ulcer.” (P4)

Q43. “After a while, taking morphine did not really work and I started to take tramadol. But, I got allergy from it on my skin and later I started to see hallucinations.” (P9)

Q44. “Every day I need to take 100 mg morphin and 150 mg pregabalin. These are drugs with pretty high dose. It is very difficult to find them. I always order them from Korea. Even though these drugs are very expensive for me to afford, I really need to take them. If I do not take my drugs, I suffer from strong pain and cannot sleep. If I cannot order these strong ones, sometimes I take tebantin 300 mg. You can find tebantin here in Mongolia, but this does not work for me. When my drugs finishes, I have anxiety.” (P6)

Q45. “I use camel marrow to prevent pressure ulcers. I apply it on my skin in the areas where pressure ulcers usually develop. When you sit on a wheelchair for a long time, the area of your skin, where you might develop pressure ulcers, gets darkened. You massage those areas with camel marrow.” (P13)

Q46. “When the pain relief pills did not quite work in the hospital, the nurses used injections to make me asleep. They explained that I got pain shock due to the strong pain and if I refuse to get injections, maybe some vodka would help me to sleep. I drunk just 50 ml vodka and immediately fell asleep. Since then, I drink vodka when I need to sleep.” (P9)

#### Limited financial resources for healthcare

Q47. “I get quarterly allowance of 60'000 tugriks [~25USD] for medicines. I also get allowance for medical devices that I need to use, which is provided once in three years. It depends on what medical devices I need. For example, I get money for catheter bags. So, I get 740'000 tugriks [~302USD] once in three years. Other 64'000 tugriks [~26USD] for care and 140'000 [~57USD] for wood and coal once a year. The government supports for heating if a person lives in an apartment, or for wood and coal in a yurt [Mongolian traditional tent]. However, these monetary supports are insufficient for my life, but better than nothing.” (P4)

Q48. “Before, there were no supports on this allowance of the half-fare transportation expenses. The government has updated the social welfare policy for us recently. Now, it is stated that if a person with disability who lives in remote areas more than 1000 km from the capital city, you can get allowance for one way of the whole transportation expenses with the aim of accessing healthcare services. But, it is only once a year.” (P15)

Q49. “Well, state hospital service is free of charge for persons with disabilities. But, the state hospitals are always short of medicines and injections that I need. So, we have to get drugs and injections ourselves. Doctors say what they have and what they do not have, so we manage to get the necessary medicaments ourselves. Some medicines are very expensive and I cannot pay for it.” (P15)

Q50. “[...] it is quite a big financial burden for us to pay another half of the hospitalization expenses. Although my disability pension is higher compared to some others, I cannot afford the cost of sanatoriums. I guess the other people with lower pension must be in an even worse situation. Private hospitals cost a lot, even after discounts. Due to this reason, I cannot get proper treatments that I want.” (P6)

**Inaccurate categorization of disabilities in laws**

**Q51.** "As per Mongolia law, employers must employ one person with disability for every 25 ordinary people working in the workplace. However, I think it does not get implemented as it states. Unfortunately, persons with disabilities employed are the ones who have very light injuries such as missing one finger on hand or hearing disabilities. I do not think wheelchair users have been hired by any companies. The most problematic issue is 'ability to work'. The law states three levels of the disability. If the disability is above 70% – it means 'ability to work' is completely lost. For example, I lost 90% of my ability to work. 50%–70% is partly lost. Below 50% person is stated to have the ability to work. This is wrong, because people think that a person with SCI has completely lost his abilities to work. Depending on the level of injuries, persons with disabilities can perform different tasks. So, the legal terminology should be corrected. In reality, most employers think that persons with disabilities cannot do any work, so they refuse to employ us. It should be changed according to the international standards or terminologies." (P1)

**Q52.** "[...] the reason is that our country does not have a system of evaluating the level of injuries. There should be a category for serious and light injuries. So, we have such inefficient system, our government should revise financial regulations. For example, financial supports should be distributed according to the level of assistance required." (P12)

reproductive health (Table 2, Q28–29). They also received treatments and recommendations that were not useful for their conditions (e.g. suggestions of acupuncture and massage therapy as a cure for SCI) (Table 2, Q30). The lack of knowledgeable and skilled care contributed to the development of secondary health conditions (e.g. urinary tract infections) (Table 2, Q31–32).

Overall, the perceived inadequacy of healthcare and rehabilitative services led some participants to seek treatment and consultation abroad (Table 2, Q33–34).

**Lack of access to assistive devices and medicines**

The lack of access to assistive devices (e.g. wheelchairs and support surfaces) was identified as a large barrier to mobility and pressure ulcer prevention. In addition, the challenge in accessing adequate medicines to treat pressure ulcers and pain was often reported.

- (a) *Scarcity of assistive devices:* The participants reported difficulty in finding assistive devices for mobility, such as standard wheelchairs and transfer devices. They mainly obtained standard wheelchairs with support from donor organizations, the Internet, or persons living in developed countries (Table 2, Q35). Concerning the lack of transfer devices, some of them found alternatives, which greatly improved their mobility (Table 2, Q36–37). According to the participants, the scarcity of standard assistive devices is also due to the current government policies. For instance, individuals with SCI receive little money to buy wheelchairs, thus they are limited to only poor quality options (Table 2, Q38–39). Seat cushions were occasionally provided by donor organizations, but they were not readily available in the market for purchase and not reimbursed by the government (Table 2, Q40–41).
- (b) *Inadequate medicines:* Although a few local pharmaceutical companies import some medicines to treat pressure ulcers, the participants reported that they were not effective or had many side effects. Thus, some participants acquired better-quality ones from abroad. However, these medicines were expensive for them. The participants who took higher doses of pain drugs experienced considerable stress attempting to source them from other countries (Table 2, Q42–44). Due to shortages of effective medicines, there was a frequent use of home remedies (Table 2, Q45–46).

**Limited financial resources for healthcare**

The social welfare benefits support healthcare needs, transportation for persons in remote areas who need to access healthcare service in urban areas, salaries for caregivers, and housing. Nonetheless, the participants reported that they often faced problems in handling



healthcare expenditures because those benefits were insufficient (Table 2, Q47–48).

The health system also provides free medical treatments for persons with disabilities in state-owned facilities and covers 50% of treatment costs in private hospitals. However, medicines are not always available in the state hospitals, and private hospitals are still unaffordable for many (Table 2, Q49–50).

### Inaccurate categorization of disabilities in laws

Some participants cited the improper categorization of disabilities in the Mongolian laws. The Labor Law categorizes the ability to work of persons with disabilities according to the severity of their disability and dictates that companies must hire one person with a disability for every 25 employees. Since the ability of individuals with SCI to work is usually considered to be severely impaired, the participants reported that employers prefer workers with lower disability levels (Table 2, Q51–52).

## Discussion

This study provides insights into how individuals with SCI in urban and rural Mongolia perceive barriers in the environment and can contribute to the identification of targets for interventions.<sup>36,37</sup> Our findings are comparable to those from other low-resource contexts and are discussed below in light of the World Health Organization's report International Perspectives on Spinal Cord Injury (IPSCI). The IPSCI report aims to enhance the experience of persons living with SCI through its recommendations for improving services and developing and refining policies.<sup>2</sup> The use of IPSCI throughout the discussion enables the situation in Mongolia to be set in the light of internationally established recommendations.

Our study confirms the findings from previous studies in that *the physical environment* was identified as a major barrier affecting independence.<sup>5–7,38–40</sup> Legal frameworks, which address, for example, problems of accessibility, are increasingly being developed in low-resource countries.<sup>41</sup> In Mongolia, Construction and Urban Development Laws give basic standards on disability accessibility,<sup>42</sup> but effective enforcement is missing.<sup>26</sup> The IPSCI report recommends to consult persons with SCI in the design of buildings to ensure accessibility. Tax incentives for construction companies could also help to improve compliance.<sup>2</sup>

Mongolian Laws on Transportation and Social Protection of Persons with Disabilities guarantee *the access to transportation*, for example, by funding free services and subsidizing accessible bus services.<sup>43</sup>

However, these laws have not been implemented due to inadequate monitoring and enforcement,<sup>26</sup> which is common in many developing countries.<sup>44</sup> Because of the difficult access to public transportation, private vehicles represent an alternative though expensive solution,<sup>45</sup> as our findings also indicated. According to the IPSCI report, responsible agencies involving representatives of persons with disabilities should monitor access to public transportation services, and countries should offer subsidies or tax deductions to promote the purchase of adapted vehicles.<sup>2</sup>

Similar to our findings, Emma *et al.*<sup>46</sup> showed how *negative societal attitudes* were a cause of distress for wheelchair users. Several studies have explained that negative attitudes are often the result of cultural beliefs and lack of knowledge.<sup>47–49</sup> This is also the case in Mongolia,<sup>26</sup> where, for example, disabilities are believed to be a divine punishment for bad behaviors or mistakes in a previous life.<sup>50</sup> Here, the IPSCI report suggests the implementation of periodic awareness campaigns to improve both social and corporate awareness of the challenges of negative attitudes to disability through, for instance, the mass media and schools.<sup>2</sup>

Studies, especially in developing countries, have concluded that *healthcare and rehabilitation services* often do not meet the needs of persons with SCI.<sup>12,51</sup> Mongolia is not an exception. Our findings confirmed those of a previous study, which emphasized that healthcare professionals have limited awareness and knowledge of rehabilitation programs for disabilities and often confuse them with traditional medicine or physiotherapy.<sup>23</sup> To overcome this lack of knowledge, the IPSCI report<sup>2</sup> suggests including SCI topics in the training curricula of medical and allied health professionals.<sup>52</sup> In addition, the introduction of multidisciplinary rehabilitation teams<sup>53</sup> including occupational and vocational therapists is highly recommended for persons with SCI to prepare for daily activities and work.<sup>2</sup>

Health systems in many low-resource contexts face challenges in the supply of adequate *assistive technologies*.<sup>8,54</sup> The Mongolian government offers grants for various assistive devices and medical products through the social welfare system using private companies. However, the subsidies are insufficient for purchasing good quality items.<sup>26</sup> Thus, developing countries including Mongolia require the development of low-cost sustainable strategies to supply proper assistive devices.<sup>55</sup> Along with the IPSCI report,<sup>2</sup> the findings from several studies underlined the need to analyze the cost-effectiveness of assistive technologies in order to improve resource allocation<sup>56</sup> and to develop national

standards, taking into consideration the environment and the needs of users.<sup>57,58</sup> Mongolian producers of assistive technologies should be supported by international companies and involved in the development of these national standards.<sup>2</sup>

Life with an SCI is often characterized by frequent medical expenses, which present a *financial burden*.<sup>59,60</sup> The Mongolian government is able to cover several basic necessities through the social welfare system. However, this support is inadequate,<sup>61</sup> and thus persons with SCI have out-of-pocket expenses.<sup>26</sup> In line with the IPSCI report, countries should allocate sufficient funds for healthcare and rehabilitation services, including comprehensive and affordable health insurance to persons with SCI. Moreover, international partnerships providing technical and financial assistance should be developed to sustain services in the long term.<sup>2</sup>

The current definition and categorization of disability in Mongolia are based on the medical model, which focuses on the impairments<sup>26</sup> and assigns a very high disability score to individuals with SCI. This is often perceived as an inability to work. The medical model of disability, common in other developing countries,<sup>62</sup> is incompatible with the modern concept of disability promoted in the CRPD.<sup>63</sup> In line with the CRPD, the IPSCI report suggests to revise the categorization of disabilities by adopting the biopsychosocial model, which views disability as the result of complex interactions between persons with health conditions and their environment.<sup>2</sup> A categorization of disability based on such international standards might optimize the allocation of resources<sup>64</sup> and provide a better legal framework to protect the rights of persons with SCI.<sup>65</sup>

### Methodological considerations

A major strength of this study is the adoption from the perspective of individuals with SCI,<sup>36</sup> which is considered to be a central factor in SCI rehabilitation.<sup>37,66</sup> Moreover, this study contributes to the existing literature about environmental factors in low-resource countries.

Several limitations of this study should be considered. Firstly, our study included only persons with traumatic SCI. The findings can therefore not be generalizable to the entire population living with SCI in Mongolia. Secondly, we sampled participants by taking into account their living environment (rural vs urban), but did not sample them by level of injuries and sex. Finally, as the sample was restricted to persons aged 18–45 we have not captured the perspective of those ageing with SCI.

### Conclusion

This study contributes to the identification of targets for interventions aimed at improving the lived experience of persons with SCI in Mongolia. The described environmental barriers are claimed to have an impact on the development of secondary health conditions, limiting activities and restricting participation in almost all areas of life. The study points out a high demand for specialized SCI care and rehabilitation services in Mongolia. Our findings reveal that while the Mongolian government already has laws and policies in place to improve access to the physical environment, transportation, assistive devices and employment, much more must be done to enforce them. Future research may focus on the prioritization of targets for intervention.

### Acknowledgements

We thank the teams of the two organizations for their great work in recruitment and all the participants contributing to our study. We would also like to acknowledge the reviewers of this manuscript for their insightful and detailed comments, that have much contributed to its improvement. This study was performed as part of the first author's PhD work, which was supported by the Swiss Government Excellence Scholarships for Foreign Scholars and Artists.

### Disclaimer statements

**Contributors** None.

**Funding** None.

**Conflicts of interest** The authors declare that they have no conflict of interest.

### References

- 1 World Health Organization (WHO). World Report on Disability. Geneva: WHO Press; 2011.
- 2 World Health Organization (WHO). International Perspectives on Spinal Cord Injury. Geneva: WHO Press; 2013.
- 3 Brinkhof MW, Al-Khodairy A, Eriks-Hoogland I, Fekete C, Hinrichs T, Hund-Georgiadis M, *et al*. Health conditions in people with spinal cord injury: contemporary evidence from a population-based community survey in Switzerland. *J Rehabil Med* 2016;48(2):197–209.
- 4 Cao Y, Walker EA, Krause JS. Environmental barriers and subjective health among people with chronic spinal cord injury: a cohort study. *J Spinal Cord Med* 2015;38(4):526–31.
- 5 Reinhardt JD, Ballert C, Brinkhof MW, Post MW. Perceived impact of environmental barriers on participation among people living with spinal cord injury in Switzerland. *J Rehabil Med* 2016;48(2):210–8.
- 6 Chang FH, Liu CH, Hung HP. An in-depth understanding of the impact of the environment on participation among people with spinal cord injury. *Disabil Rehabil* 2018;40(18):2192–9.
- 7 Tsai IH, Graves DE, Chan W, Darkoh C, Lee MS, Pompeii LA. Environmental barriers and social participation in individuals with spinal cord injury. *Rehabil Psychol* 2017;62(1):36–44.

- 8 Pacheco D, Gross-Hemmi MH. The cross-cultural societal response to SCI. *Am J Phys Med Rehabil* 2017;96(2 Suppl 1): S41–54.
- 9 World Health Organization (WHO). *International Classification of Functioning, Disability and Health*. Geneva: WHO Press; 2001.
- 10 Reinhardt JD, Mansmann U, Fellinghauer BA, Strobl R, Grill E, von Elm E, et al. Functioning and disability in people living with spinal cord injury in high- and low-resourced countries: a comparative analysis of 14 countries. *Int J Public Health* 2011;56(3): 341–52.
- 11 Parnes P, Cameron D, Christie N, Cockburn L, Hashemi G, Yoshida K. Disability in low-income countries: issues and implications. *Disabil Rehabil* 2009;31(14):1170–80.
- 12 Burns AS, O’Connell C. The challenge of spinal cord injury care in the developing world. *J Spinal Cord Med* 2012;35(4):195–7.
- 13 Renaud R, Locke HN, Hariharan R, Chamberlain MA, O’Connor RJ. Developing a spinal cord injury rehabilitation service in Madagascar. *J Rehabil Med* 2018;50(5):402–5.
- 14 Tangcharoensathien V, Witthayapipopsakul W, Viriyathorn S, Patcharanarumol W. Improving access to assistive technologies: challenges and solutions in low- and middle-income countries. *WHO South East Asia J Public Health* 2018;7(2):84–9.
- 15 Zakrasek EC, Creasey G, Crew JD. Pressure ulcers in people with spinal cord injury in developing nations. *Spinal Cord* 2015;53(1): 7–13.
- 16 Ahmed N, Quadir MM, Rahman MA, Alamgir H. Community integration and life satisfaction among individuals with spinal cord injury living in the community after receiving institutional care in Bangladesh. *Disabil Rehabil* 2018;40(9):1033–40.
- 17 Singh R, Yadav S, Meena V. Community reintegration postspinal cord injury: Indian scenario. *J Orthop Allied Sci* 2017;5:15–20.
- 18 Lee BB, Cripps RA, Fitzharris M, Wing PC. The global map for traumatic spinal cord injury epidemiology: update 2011, global incidence rate. *Spinal Cord* 2014;52(2):110–6.
- 19 Moshi H, Sundelin G, Sahlen K-G, Sörlin A. Traumatic spinal cord injury in the north-east Tanzania – describing incidence, etiology and clinical outcomes retrospectively. *Glob Health Action* 2017;10(1):1–8.
- 20 Ronca E, Scheel-Sailer A, Koch HG, Essig S, Brach M, Münzel N, et al. Satisfaction with access and quality of healthcare services for people with spinal cord injury living in the community. *J Spinal Cord Med* 2018;2:1–11. Epub 2018 July 3.
- 21 Swiss Paraplegic Research. ICF-based case studies. Case study 12: SCI and environmental accessibility [Internet]. 2018 [cited 2018 August 13]. Available from <http://www.icf-casestudies.org>.
- 22 Fantom NJ, Serajuddin U. The World Bank’s classification of countries by income. World Bank Group [Internet]. 2016 [cited 2017 October 4]. p. 46. Available from <http://documents.worldbank.org/curated/en/408581467988942234/The-World-Banks-classification-of-countries-by-income>
- 23 Khan F, Amatya B, Avirmed B, Yi YK, Shirmen B, Abbott G, et al. World health organization global disability action plan: the Mongolian perspective. *J Rehabil Med* 2018;50(4):358–66.
- 24 Morante D. Occupational therapy emerging in Mongolia: a case study. *World Fed Occup Ther Bull* 2017;73(2):88–93.
- 25 Como E, Batdulam T. The role of community health workers in the Mongolian CBR programme. *Asia Pac Disabil Rehabil J* 2012;23(1):14–33.
- 26 Implementation of the UN convention on the rights of persons with disabilities in Mongolia. Submission to the CRPD committee of the response to the list of issues on Mongolia by disabled people’s organizations of Mongolia [Internet]. 2015 [cited 2016 March 14]. p. 6–40. Available from [http://tbinternet.ohchr.org/Treaties/CRPD/Shared%20Documents/MNG/INT\\_CRPD\\_CSS\\_MNG\\_19556\\_E.doc](http://tbinternet.ohchr.org/Treaties/CRPD/Shared%20Documents/MNG/INT_CRPD_CSS_MNG_19556_E.doc)
- 27 National Statistical Office of Mongolia. National report: population and housing by-census of Mongolia [Internet]. 2015 [cited 2018 August 13]. p. 19–29. Available from [https://1212.mn/BookLibraryDownload.ashx?url=hun\\_am\\_oron\\_suutsnii\\_2015\\_toollogo\\_eng.pdf&ln=Mn](https://1212.mn/BookLibraryDownload.ashx?url=hun_am_oron_suutsnii_2015_toollogo_eng.pdf&ln=Mn)
- 28 Gassmann F, Francois D, Trindade LZ. Improving labor market outcomes for poor and vulnerable groups in Mongolia. World Bank [Internet]. 2015 [cited 2016 Dec 22]. p. 4. Available from <http://hdl.handle.net/10986/23671>
- 29 Gantsetseg KH, Davaajargal S, Narantuya KH, Boldbaatar B, Norolkhoosuren B, Dorjmyagmar D, et al. Non-communicable diseases. In: Narantuya B, (ed.) *Health Indicators-2016* [Internet]. Ulaanbaatar: Center for Health Development; 2016 [cited 2017 October 4]. p. 72–82. Available from <http://www.chd.mohs.mn/2017/smta/2016%20Health%20indicator.pdf>
- 30 Neumann N, Warburton D. A review of the modern Mongolian healthcare system. *Cent Asian J Med Sci* 2015;1(1):16–21.
- 31 Tsilaajav TS, Ser-Od E, Baasai B, Byambaa G, Shagdarsuren O. Provision of services. In: Kwon S, Richardson E, (eds.) *Mongolia Health System Review*. Geneva: WHO Press; 2013. p. 101–27.
- 32 Mahdi S, Viljoen M, Massuti R, Selb M, Almodayfer O, Karande S, et al. An international qualitative study of ability and disability in ADHD using the WHO-ICF framework. *Eur Child Adolesc Psychiatry* 2017;26(10):1219–31.
- 33 Alford VM, Ewen S, Webb GR, McGinley J, Brookes A, Remedios LJ. The use of the international classification of functioning, disability and health to understand the health and functioning experiences of people with chronic conditions from the person perspective: a systematic review. *Disabil Rehabil* 2015;37(8):655–66.
- 34 Gale NK, Heath G, Cameron E, Rashid S, Redwood S. Using the framework method for the analysis of qualitative data in multi-disciplinary health research. *BMC Med Res Methodol* 2013;13: 117–25.
- 35 Braun V, Clarke V. *Successful Qualitative Research: A Practical Guide for Beginners*. London: SAGE; 2013.
- 36 Jesus TS, Bright F, Kayes N, Cott CA. Person-centred rehabilitation: what exactly does it mean? Protocol for a scoping review with thematic analysis towards framing the concept and practice of person-centred rehabilitation. *BMJ Open* 2016;6(7):1–8.
- 37 VanderKaay S, Moll SE, Gewurtz RE, Jindal P, Loyola-Sanchez A, Packham TL, et al. Qualitative research in rehabilitation science: opportunities, challenges, and future directions. *Disabil Rehabil* 2018;40(6):705–13.
- 38 Welage N, Liu KP. Wheelchair accessibility of public buildings: a review of the literature. *Disabil Rehabil Assist Technol* 2011;6(1): 1–9.
- 39 Yarfi C, Ashigbi EYK, Nakua EK. Wheelchair accessibility to public buildings in the Kumasi metropolis, Ghana. *Afr J Disabil* 2017;6:1–8.
- 40 Botticello AL, Tulsy D, Heinemann A, Charlifue S, Kalpakjian C, Slavin M, et al. Contextualizing disability: a cross-sectional analysis of the association between the built environment and functioning among people living with spinal cord injury in the United States. *Spinal Cord* 2018;1–10. Epub 2018 Aug 14.
- 41 Venter C, Savill T, Rickert T, Bogopane H, Venkatesh A, Camba J, et al. Enhanced accessibility for people with disabilities living in urban areas. Department for International Development Engineering Knowledge and Research [Internet]. 2015 [cited 2017 December 5]. p. 16–20. Available from [https://www.researchgate.net/publication/37150904\\_Enhanced\\_Accessibility\\_for\\_People\\_with\\_Disabilities\\_Living\\_in\\_Urban\\_Areas](https://www.researchgate.net/publication/37150904_Enhanced_Accessibility_for_People_with_Disabilities_Living_in_Urban_Areas)
- 42 Legalinfo.mn [Internet]. Ulaanbaatar: Integrated system of legal information; c2015 [cited 2018 January 4]. Article 21: urban development laws implementation; [about 2 screens]. Available from <http://www.legalinfo.mn/law/details/530>
- 43 Legalinfo.mn [Internet]. Ulaanbaatar: Integrated system of legal information; c2015 [cited 2018 January 4]. Article 10: rights and obligations of carriers; [about 3 screens]. Available from: <http://www.legalinfo.mn/law/details/29?lawid=29>
- 44 Kunieda M, Roberts P. Inclusive access and mobility in developing countries. World Bank [Internet]. 2006 [cited 2018 January 5]. Available from <http://siteresources.worldbank.org/INTTSR/Resources/07-0297.pdf>
- 45 The American Association of People with Disabilities. Equity in transportation for people with disabilities [Internet]. 2018 [cited 2018 August 13]. p. 3–5. Available from <http://www.civilrightsdocs.info/pdf/transportation/final-transportation-equity-disability.pdf>
- 46 Williams E, Hurwitz E, Obaga I, Onguti B, Rivera A, Sy TRL, et al. Perspectives of basic wheelchair users on improving their access to wheelchair services in Kenya and Philippines: a qualitative study. *BMC Int Health Hum Rights* 2017;17(1):22.

- 47 Bunning K, Gona JK, Newton CR, Hartley S. The perception of disability by community groups: stories of local understanding, beliefs and challenges in a rural part of Kenya. *PLoS One* 2017;12(8):1–20.
- 48 Etieyibo E, Omiegbe O. Religion, culture, and discrimination against persons with disabilities in Nigeria. *Afr J Disabil* 2016;5(1):1–6.
- 49 McLean KA, Hardie S, Paul A, Paul G, Savage I, Shields P, *et al*. Knowledge and attitudes towards disability in Moldova: a qualitative study of young people's views. *Disabil Health J* 2017;10(4):632–5.
- 50 Lofvenmark I, Norrbrink C, Nilsson Wikmar L, Lofgren M. 'The moment I leave my home - there will be massive challenges': experiences of living with a spinal cord injury in Botswana. *Disabil Rehabil* 2016;38(15):1489–90.
- 51 Kamenov K, Mills JA, Chatterji S, Cieza A. Needs and unmet needs for rehabilitation services: a scoping review. *Disabil Rehabil* 2018:1–11. Epub 2018 Jan 6.
- 52 Gutenbrunner C, Bickenbach J, Melvin J, Lains J, Nugraha B. Strengthening health-related rehabilitation services at national levels. *J Rehabil Med* 2018;50(4):323–4.
- 53 Stucki G, Bickenbach J, Gutenbrunner C, Melvin J. Rehabilitation: the health strategy of the 21st century. *J Rehabil Med* 2018;50(4):309–16.
- 54 Matter R, Harniss M, Oderud T, Borg J, Eide AH. Assistive technology in resource-limited environments: a scoping review. *Disabil Rehabil Assist Technol* 2017;12(2):105–14.
- 55 Pearlman J, Cooper RA, Zipfel E, Cooper R, McCartney M. Towards the development of an effective technology transfer model of wheelchairs to developing countries. *Disabil Rehabil Assist Technol* 2006;1(1–2):103–10.
- 56 Schraner I, De Jonge D, Layton N, Bringolf J, Molenda A. Using the ICF in economic analyses of assistive technology systems: methodological implications of a user standpoint. *Disabil Rehabil* 2008;30(12–13):916–26.
- 57 Borg J, Ostergren PO. Users' perspectives on the provision of assistive technologies in Bangladesh: awareness, providers, costs and barriers. *Disabil Rehabil Assist Technol* 2015;10(4):301–8.
- 58 Mhatre A, Martin D, McCambridge M, Reese N, Sullivan M, Schoendorfer D, *et al*. Developing product quality standards for wheelchairs used in less-resourced environments. *Afr J Disabil* 2017;6:1–15.
- 59 Fyffe DC, Botticello AL, Myaskovsky L. Vulnerable groups living with spinal cord injury. *Top Spinal Cord Inj Rehabil* 2011;17(2):1–9.
- 60 White BAB, Dea N, Street JT, Cheng CL, Rivers CS, Attabib N, *et al*. The economic burden of urinary tract infection and pressure ulceration in acute traumatic spinal cord injury admissions: evidence for comparative economics and decision analytics from a matched case-control study. *J Neurotrauma* 2017;34(20):2892–900.
- 61 Asian Development Bank. Economic analysis. Ensuring inclusiveness and service delivery for persons with disabilities [Internet]. 2017 [cited 2018 January 8]. p. 1–5. Available from <https://www.adb.org/sites/default/files/linked-documents/48076-002-ea.pdf>
- 62 McPherson A, Durham J, Richards N, Gouda H, Rampatige R, Whittaker M. Strengthening health information systems for disability-related rehabilitation in LMICs. *Health Policy Plan* 2017;32(3):384–94.
- 63 United Nations (UN). Convention on the Rights of Persons with Disabilities (CRPD). Geneva: UN; 2006.
- 64 Stucki G, Bickenbach J. Functioning information in the learning health system. *Eur J Phys Rehabil Med* 2017;53(1):139–43.
- 65 Madden R, Glozier N, Mpofu E, Llewellyn G. Eligibility, the ICF and the UN convention: Australian perspectives. *BMC Public Health* 2011;11(Suppl 4):S6–11.
- 66 Heinemann AW, LaVela SL, Etingen B, Miskovic A, Locatelli SM, Neumann HD, *et al*. Perceptions of person-centered care following spinal cord injury. *Arch Phys Med Rehabil* 2016;97(8):1338–44.

## Appendix 1: Topic guide

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- Opening questions:
    - Can you tell me about your daily life?
    - On a typical day what do you do, how does your day look like?
  - ICF domains:
    - General questions
    - ICF categories:
      - Probing questions
- Activities and Participation*
- Chapter 4. Mobility:
    - Can you tell me how you move around inside and outside of your home?
    - Walking and moving (d460 Moving around in different locations, d465 Moving around using equipment); Changing and maintaining body position (d410 Changing basic body position, d420 Transferring oneself); Moving around using transportation (d470 Using transportation, d475 Driving):
      - How do you move around within your home? (e.g. within a room, between rooms, and around the whole living area)
      - What about transfers? (e.g. moving from a wheelchair to a bed when you are ready to sleep)
      - Can you tell me how you go out?
      - How do you use public and private transportation in Mongolia?
      - What kind of support do you need to move around inside and outside of your home?
      - What is helpful or difficult for you in moving around?
  - Chapter 5. Self-care:
    - Can you tell me how you manage caring for yourself in daily life?
    - (d510 Washing oneself, d520 Caring for body parts, d530 Toileting, d540 Dressing, d550 Eating, d560 Drinking, d570 Looking after one's health):
      - How do you manage your personal hygiene? (e.g. toileting, washing and showering)
      - What about eating and drinking?
      - What do you do in your everyday life to take care of your personal health? (e.g. getting regular health exams, taking medications, prevention of pressure ulcers, bladder management, doing exercise and following special diets)
      - What kind of support do you need to care for yourself in daily life?
      - What is helpful or difficult for you in caring for yourself in daily life?
  - Chapter 6. Domestic life:
    - Can you tell me how you manage your household work?
    - Acquisition of necessities (d610 Acquiring a place to live, d620 Acquisition of goods and services); Household tasks (d630 Preparing meals, d640 Doing housework):
      - Do you do all the household work by yourself? (e.g. cleaning, cooking, going to supermarket to buy food, and getting water if he/she lives in a yurt)
      - Do you need help from someone for the household work?
      - What is helpful or difficult for you in doing your household work?
  - Chapter 7. Interpersonal interactions and relationships:
    - How is your relationship with your family members, friends or colleagues?
    - Particular interpersonal relationships (d740 Formal relationships, d750 Informal social relationships, d760 Family relationships, d770 Intimate relationships):
      - Has your relationship with your family members, friends or colleagues changed since the injury? If yes, how has this changed?
  - Chapter 8. Major life areas:
    - Can you tell me more about your work or education life (if he/she is a student)?
    - Education (d820 School education, d825 Vocational training, d830 Higher education); Work and employment (d840 Apprenticeship, d845 Acquiring, keeping and terminating a job, d850 Remunerative employment):
      - Has your work or education life changed since the injury? If yes, how has this changed?
      - What has been most helpful or difficult to participate in work or education?
  - Chapter 9. Community, social and civic life:
    - Can you tell me about your hobbies?
    - (d910 Community life, d920 Recreation and leisure, d930 Religion and spirituality):
      - How often do you do your hobbies?
      - Has this changed since your injury? If yes, how has this changed?
      - What has been most helpful or difficult to do your hobbies?
- Environmental Factors*
- Chapter 1. Products and technology:
    - Can you tell me what kind of assistive equipment or products you use in daily living?
    - (e115 Products and technology for personal use in daily living, e120 Products and technology for personal indoor and outdoor mobility and transportation, e150 and e155 Design, construction and building products and technology of buildings for public and private use):
      - Was or is it easy for you to get access to assistive equipment or products? (e.g. wheelchairs, crutches, transfer devices) If yes or no, why?
      - Was it easy or difficult for you to learn how to handle or use that assistive equipment or products? How is it in your current situation?
      - What has been most helpful or difficult to handle or use that assistive equipment or products?

- Chapter 2. Natural environment and human-made changes to environment:
    - Can you tell me what it is like to live in your town or village for a person with SCI?
  - Chapter 3. Support and relationships:
    - Can you describe to me what personal support or care is necessary in your daily life?
  - Chapter 4. Attitudes:
    - How do you think that the Mongolian society sees persons with SCI in general?
  - Chapter 5. Services, systems and policies:
    - Can you tell me what kind of services did or do you receive in relation to your injury?
  - Closing questions:
    - Where do you see a priority in investing or changing something for your personal benefit?
    - Is there anything else you would like to say about how what we have been discussing today?
- (e210 Physical geography, e225 Climate):
    - What is helpful or difficult for you to live in your town or village?
    - Does this vary throughout the seasons?
  - (e310 Immediate family, e320 Friends, e325 Acquaintances, peers, colleagues, neighbors, and community members, e330 People on positions of authority, e355 and e360 Health and other professionals):
    - What personal support or care has been helpful in your lived experience since the injury?
  - (e410 Individual attitudes of immediate family members, e420 Individual attitudes of friends, e445 Individual attitudes of strangers):
    - Do you have special experiences in this area?
    - Do you think the Mongolian society is in general supportive for persons living with SCI?
  - (e.g. e515 Architecture and construction services, systems and policies; e540 Transportation services, systems and policies; e575 General social support services, systems and policies; e580 Health services, systems and policies):
    - Do you think it was or is easy for you to access these services? If yes or no, why?
    - What were or are benefits of these services for you?
    - Any challenges?
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