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RESEARCH PAPER

## 'The moment I leave my home – there will be massive challenges': experiences of living with a spinal cord injury in Botswana

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### ABSTRACT

**Background:** When suffering a spinal cord injury (SCI), the patient and family face numerous challenges regardless of socio-economic level. The stigmatisation of persons with disabilities has been reported, however, reports from Southern Africa are largely lacking. **Purpose:** To explore the experiences of living with a traumatic SCI in Botswana concerning perceived attitudes, obstacles and challenges. **Method:** A qualitative approach with semi-structured interviews was conducted. Thirteen community-dwelling persons who have lived with an SCI for at least two years participated. **Results:** A theoretical model was formed that illustrate the associations between the core category, Self, and the categories Relationships and Society. The model illustrates that personal resources, including a strong identity and a positive attitude, are crucial to the experience of inclusion in the community. A supportive family, a source of income, and faith were strong facilitators, while inaccessibility and devaluing attitudes were barriers. Having a disability led to increased risk of poverty and social exclusion. **Conclusion:** This study emphasised the importance of personal resources, family support, and improved accessibility to facilitate inclusion in the society. Informants requested legislation to advocate for the rights of persons with disabilities to be respected, with the aim of moving towards an equal accessible society.

### ARTICLE HISTORY

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### ► IMPLICATIONS FOR REHABILITATION

- Reclaiming or restructuring one's identity after a SCI is crucial for the person's ability to move on and develop beneficial coping strategies. Support from family and friends, staff and peer support are crucial parts in that process.
- Spirituality, values, needs and coping strategies vary profoundly among persons sustaining disabling injuries. In striving to optimise care, rehabilitation staff needs to be attentive to the personal resources and preferences to be able to individualise care, encounter, and facilitate transition back to the community.
- Family members play a crucial part in rehabilitation. It is essential for the patients' well-being and care that they get explicit descriptions of the patient's abilities.
- Living in a well-adapted home will facilitate well-being, independence, and return to work. Rehabilitation staff needs to focus their efforts on making this successful prior to discharge from hospital.

## Introduction

When a person suffers a spinal cord injury (SCI), the patient and family face numerous changes and challenges regardless of socio-economic level. However, the physical and social circumstances that individuals live in differ substantially around the world.

Studies from high-income countries describe challenges in accessing communities, financial strain which limits access and integration in society, and the stigmatisation of people with disabilities.[1–3] Informants described the biographical disruption with loss of

control and independence, and the impact on the identity.[4] Re-taking control of their lives, re-evaluating what is important and the development of inner strength and autonomy was essential for the establishment of meaning post SCI.[5,6] The process was facilitated by expert peers.[7]

Communities in low- and middle-income countries are often extremely inaccessible with harsh and difficult terrain. The source of income in these countries mainly derives from physical work, which for a person with traumatic spinal cord injury (tSCI) decreases the

possibility of returning to work duty.[8] Consequently, these circumstances are likely to increase the risk of poverty for the whole family.[8]

The exhibition of devaluing attitudes towards persons with disabilities [8–11] can further limit participation in society and become barriers for reintegration into the community. From the perspective of the family, a person with a disability can be seen as another mouth to feed, unable to contribute and therefore, become totally reliant on the family.[8] Access to health care, government support, strong religious beliefs, and having family harmony have been described as crucial factors for coping and for improving quality of life in the few studies from low- and middle-income countries from a patient perspective. [11,12]

Of recent, Botswana is described as Africa's success story that changed swiftly from being one of the poorest – to a middle-income country. Despite the transition, poverty is still faced by 18% of the population.[13] After independence, diamonds were found and the development of infrastructure, education, and health care were prioritised. Today health care is subsidised by the government, and for persons with disabilities it is free of charge. There are primary hospitals in the villages, district hospitals in small towns, and tertiary level referral hospitals in the two major cities.[14] There was no specialised SCI rehabilitation prior to 2010, but persons that were considered as having a good rehabilitation-potential could be transferred to South Africa for rehabilitation; however, this was rarely the case for persons with tetraplegia. A limited long-term disability allowance was approved in 2015, but at the time of the interviews only monthly food baskets could be provided. Spirituality is a big part of life in Botswana, with Christianity being the most widely practiced religion and is often mixed with practices of traditional, religious worshipping and the honouring of ancestors.[15]

Little is known about the barriers, perceived attitudes, and family and societal support systems for persons with SCI in low- and middle-income countries. Through increasing this knowledge, rehabilitation professionals, policy makers, and other stakeholders can be better informed in order to address such issues and help facilitate the transition of survivors of SCI back to the community.

Given this backdrop, the aim of this study was to explore the experiences of living with a tSCI in Botswana, including how people managed their daily lives with regard to attitudes from their family and community, support systems, obstacles they faced and environmental challenges.

## Materials and methods

### Design

A qualitative approach according to grounded theory [16] with an emergent design was used. Grounded theory was a suitable method since no previous knowledge in the field was available.

### Setting and participants

Recruitment of participants was conducted at a newly (2010) established SCI-rehabilitation centre. Persons living with a tSCI were asked at their first outpatient visit (May 2010 to February 2013) if they would consider participating in an epidemiological study ( $n = 57$ ) and asked to sign a written consent form. In this consent form the person was to indicate if he/she was willing to participate in the present interview study. Positive responses were given by 28 persons. Among those, 25 persons met the inclusion criteria who then constituted the sample from which our informants were selected:  $\geq 16$  years of age, tSCI for at least two years (excluded  $n = 2$ ), proficiency in the English language (the official language), and no secondary diagnose which affects the bodily functions, such as brain injury or stroke ( $n = 1$ ). Characteristics are presented in Table 1.

The informants were contacted by phone in order to schedule an interview approximately one year after the initial assessment at the rehabilitation centre. One person initially included in the study failed to attend the scheduled appointment and was consequently excluded from the study. Consent was verbally renewed over the phone and at the time of the interview.

The first author, I.L., was known to the majority of the participants, as she was the on-site coordinator for the project that established the SCI-rehabilitation centre. She spent three years in Botswana and is therefore increasingly familiar with the culture and environment.

### Data collection

Characteristics of the total 13 informants were collected from the patient files and are shown in Table 1, all were native to Botswana. The interview guide was developed during the study and emerging issues were incorporated (Table 2).

Initially, two test interviews were conducted and the questions regarding previous rehabilitation and secondary complications were thereafter removed since this information was available from the patients' files. These two test interviews were both included in the analysis

Table 1. Demographic and clinical characteristics of the persons who agreed to be interviewed and met the inclusion criteria, and of the included informants (*n*).

	Met inclusion criteria, <i>n</i> = 25	Included, <i>n</i> = 13
Gender		
Male	13	8
Female	12	5
Age		
16–30	4	2
31–45	15	9
46–60	6	2
Age at injury		
<16	1	0
16–30	16	9
31–45	8	4
Level of injury <sup>a</sup>		
Cervical 1–4 <sup>b</sup>	1	1
Cervical 5–8 <sup>b</sup>	7	5
Thoracic	15	5
Lumbar <sup>c</sup>	2	2
Marital status		
Married	9	5
Single	13	7
Relationship/cohabit	3	1
Living area		
City	9	4
Suburbs	3	3
Village	13	6
Education		
Primary school	1	1
Secondary school	11	6
Tertiary education	6	2
University	7	4

<sup>a</sup>All had motor complete injuries (AIS A or B).

<sup>b</sup>The cervical level of injury was divided in high and low tetraplegia because of the differences in function. Neurological level at cervical 1–4 involves complete loss of function in all four extremities; at level cervical 5–8 there are increasing degrees of function in the arms.

<sup>c</sup>Both were ambulating with bilateral crutches.

Table 2. Included themes for the interviews.

Introduction	Can you tell me about your life before the injury? In what ways has the injury affected your life? Consider both negative and positive aspects.
Initial themes	How do you manage your daily life? Can you describe the role of your family/extended family in your daily life? Could you describe obstacles and challenges that you face in your daily life after the injury? How to you experience attitudes from your family/society?
Ending questions	Do you have advice for those who are newly injured? Anything you would like to add?
Evolving issues	What does acceptance mean for you? What is your view on relationships? Partner? Do you think it is different for women with disabilities? Does attitude differ from men and women? What is the male role in the house/family? Fathers? Have you visit traditional healer or pastor? How was your experience?

due to richness of information. After that, two informants were selected due to their broad experiences and willingness to share. In the next step, theoretical sampling started in order to attain diversity regarding age, time since injury, level of injury, gender, level of

education and living area. In this step, three informants were interviewed. After further analysis, five additional informants were selected based on capturing different experiences and to further elaborate on the initial emerging themes of the study. Finally, one informant was interviewed to deepen the knowledge on the evolving areas. The informant who was identified as number three was addressed again in the end of the study to further elaborate on the last added themes, since I.L. knew that the informant had experience with these matters. Data collection was conducted during May 2013 and March 2014.

The interviews were conducted in English, recorded, and transcribed verbatim, together with field notes taken by I.L. Interviews lasted between 45 min and 1 h 45 min, and were conducted at the informants' home (*n* = 6), workplace (*n* = 2), or in the private home of the interviewer (*n* = 5), depending on the preference of the informants. Only the informant and I.L. were present during interviews, except for a part of one interview that was attended by the informant's son, sister and mother and whose comments were included in the analysis.

### Data analysis

The open coding started after the second interview by using the computer programme Open Code 4.0.[17] Interviews were conducted in clusters of 2–5, while the analysis occurred concurrently. After the second interview an inductive process started, clustering codes together into sub-categories that led to the start of emerging properties. Constant comparison was used throughout the analysing process, comparing codes, properties, and sub-categories, which was facilitated by the construction of a matrix. After seven interviews, the sub-categories were clustered into categories. A list of properties and dimensions were composed, and this facilitated the construction of a preliminary theoretical model which illustrated the relationships between categories and the identification of the core category.

Then additional reviews of the transcripts coupled with listening to recordings and using personal memos were considered and analysed again, but now with the temporary model in mind. The categories were confirmed as being grounded in the existing data, focusing on the properties and dimensions (Table 3), and led to an adjustment of the model.

Finally, a comparison between all categories and codes was done in order to search for connections and to verify the interrelationships in the theoretical model. Three persons with different backgrounds and not previously engaged in the study read and made

Table 3. Examples of properties and dimensions in the categories.

Sub-categories	Properties	Dimensions
<i>Self</i>		
Identity	Self-attitude	Shame ↔ Victorious
	Participation	Exclusion ↔ Inclusion
	Coping strategies	Isolation ↔ Exposure
Spirituality	Go to church	Avoidance ↔ Challenge
	Church members	Irregular ↔ Active in church activities
	Faith	The same as others ↔ More understanding, encouraging
Income	Healing	→ Trust in support by God
	Social interaction	Chosen by God ↔ Belief God can restore
	Self-provision	Ridiculed by pastor ↔ Helped by pastor
Relationships	Maintain hope	Isolation ↔ Socialising
	Family situation	Anger/frustration ↔ Thankfulness
	Partner	Dependent ↔ Financial independent
Society	Community	Poverty ↔ Able to provide
	Home access	Hopelessness ↔ Hope
	Transport	Only extended family ↔ Close family
Attitudes	Community	Rejected ↔ Valued family member
	Stigma	Offered only shelter ↔ Supportive
	Cultural beliefs	Non married abandoned ↔ Spouse stay and support
Cultural beliefs	Stigma	None ↔ Employed paid caregiver
	Community	Rejected ↔ 'Normality'
	Stigma	Cannot cope ↔ Learn to know 'true friends'
Accessibility	Community	Environmental barriers ↔ Improved infrastructure
	Home access	Loads of sand ↔ Accessible new malls
	Transport	No adaptations ↔ Adapted inside
Attitudes	Community	Inaccessible public transport ↔ Own car
	Stigma	Rejection, outcast ↔ Great, welcoming
	Cultural beliefs	Devalued ↔ Valuable member of society
Cultural beliefs	Stigma	Not helpful or rude ↔ Extremely helpful
	Community	Feel looked down at ↔ Rarely encounter stigma
	Cultural beliefs	Cultural beliefs ↔ Governmental information campaigns
Cultural beliefs	Stigma	Traditional healer ↔ Searching for medical advances

comments of the manuscript; [18] one physiotherapist from South Africa, one person with native knowledge about Botswana, and one ethnologist from Sweden specialised in qualitative research.

Coding and analysis were mainly done by I.L., with continuing reviews and discussions with M.L. C.N. participated in the overall analysis, having read the four most representative interviews. L.N.W. read and made comments of the manuscript.

### Ethics

This study was approved and yearly renewed by the ethical committee at the Ministry of Health in Botswana (PPME: 13/18/1 Vol. VIII (92)) and at Princess Marina Hospital (PMH 5/79 (27a)).

### Results

The analysis resulted in one core category, labelled as Self, and the two interrelated categories, Relationships and Society. Personal resources within the Self were central for the informants to achieve a satisfactory life situation.

The Self was strongly affected by attitudes and support from families, friends and the society, which either facilitated or hindered the experience of inclusion in the community. The families stood for emotional and practical support for the informants, which facilitated the maintenance of a positive attitude in life and the development of beneficial coping strategies. The society's impact was mainly externalised as inaccessibility and devaluing attitudes. A theoretical model was developed, based on the results of the data analysis, to illustrate the impact and the interaction of the factors influencing the informants' current life situation (Figure 1).

### Self

The informants expressed that being strong, having a positive attitude, and believing in oneself were crucial factors in helping to restore their identity after the SCI. Faith was a strong facilitator, while having a steady income strongly affected the informants' view of themselves as being able to contribute to society.

To reclaim *identity*, to accept oneself as a person with a disability, and to have the ability to adjust to the situation,

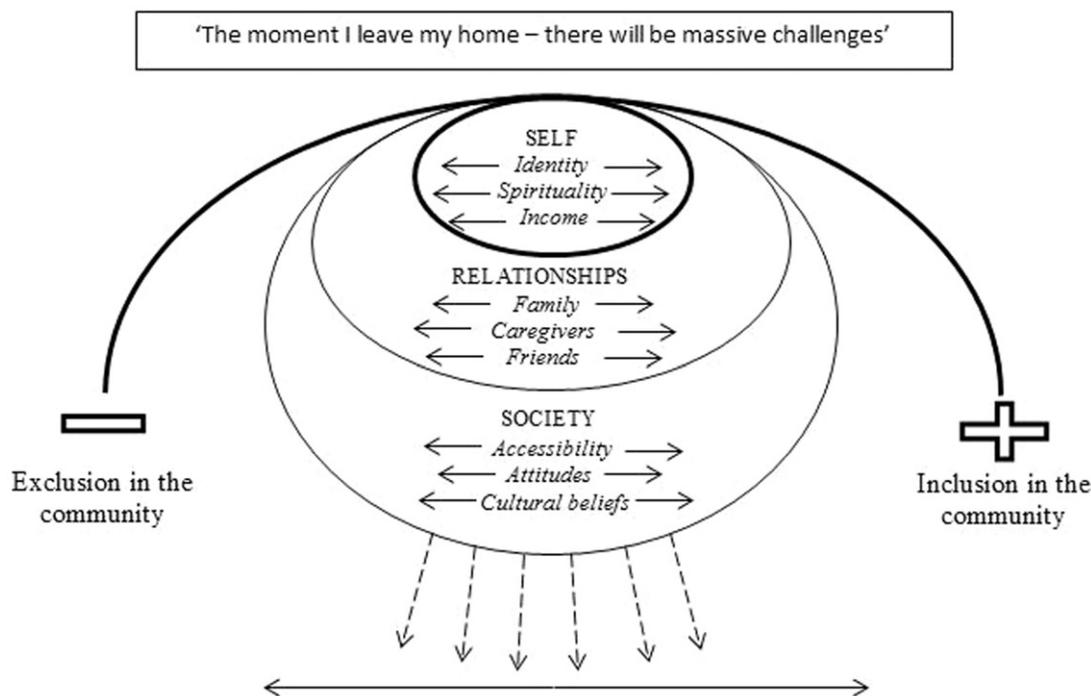


Figure 1. This theoretical model illustrates the relationships between the core category, Self, and the categories Relationships and Society, which can represent factors affecting whether to experience inclusion or exclusion in the community, based on data from informants living with a spinal cord injury in Botswana.

were all considered important factors among informants to reach 'normality', and to experience inclusion in society. The informants acknowledged that their own attitude towards themselves affected how they were perceived or approached by society. Having positive role models could facilitate acceptance and motivation, while being an inspiration and counselling people with a recent injury were described as strengthening their self-esteem. One informant described his approach:

There is always challenges in life, every day, but what matters most is about how you tackle the challenges. . . I don't look back on to the negatives. . . I have a better mind to think and focusing onto what I need for the day. (#2 Male, Tetraplegia)

On the other hand, stressful emotions, such as shame and humiliation were also expressed, feeling awkward due to rejection, viewed as being helpless or being pitied. Fear was expressed in different contexts: feeling vulnerable and fearing for one's own safety, fear of death when living with a high SCI, and fear of embarrassment in public.

The strategies for coping with the injury and with the devaluing attitudes in society as described by the informants varied and covered wide dimensions. Strategies ranged from thankfulness to anger and from challenging oneself to avoiding situations. Examples of these strategies included socialising in order to increase people's exposure so they would get used to persons

with disabilities, or isolation to avoid negative stares or attracting attention (such as at weddings or funerals). Holding on to dreams from before the injury and appreciating people's uniqueness were examples of positive attitudes that facilitated coping strategies.

*Spirituality* and a deep trust in God was a positive force associated with coping and feeling supported and encouraged. Thoughts of being chosen by God because of one's own capability to cope were described as in the following example:

I believe God made me to be this way because he wanted me to be stronger for my kids. And it really hit me more than once that my injury was in a way a blessing in disguise to my family. (#1 Male, Tetraplegia)

Informants visiting pastors hoping for a miracle of being cured often described sadness or humiliation as a result, while informants in search of encouragement and strength could experience a positive and non-judgmental approach. An informant experienced the following:

In church . . . I was ridiculed to public spectacle. They would lift me and try to make me walk and even step on my feet as they pray for the miracles to manifest. This will really make me scared and even emotionally helpless. . . It was both positive and negative. Partially positive because the word of God on its own is fulfilling and gracious, but mostly negative because of the humiliation you go through during revival. (#3 Female, Tetraplegia)

Keeping updated on scientifically proven facts went hand in hand with maintaining hope for a miracle to happen, thus hope for a cure did not put life on hold, as stated by one informant.

Miracles do happen. . . Like if the doctors say that you will never walk, then we look at okay, God has created, God can still restore, but it doesn't say that you don't follow the doctors instruction . . . you do exercise, take medication while hoping that a miracle will come. (#13 Female, Tetraplegia)

The importance of returning to work was unanimous, even though reasons varied. Besides having a source of *income*, feeling useful, being able to provide, and contributing to society was also paramount. Support from employers varied from totally lacking and even dismissal, to a supportive atmosphere leading to re-employment. Unemployment caused stress and anxiety and feelings of being disqualified or rejected by employers and colleagues, which was expressed in the following quote:

People still have the mind-set that 'what can come out from a quadriplegic?', so they will be a bit hesitant in terms of the jobs that they will give you. (#10 Male, Tetraplegia)

Having an income affected self-identity but also independence, availability of caregivers, transport, and socialisation. Not having a steady income was seen as the biggest challenge, and informants felt that having funding would solve most of their problems. Informants, who were working, still expressed financial concerns due to the increased living expenses when living with a disability. Some also expressed empathy for those who did not work. A lack of financial security could lead to isolation, health risks, dependency, and feelings of frustration from becoming a financial burden to others. The mother of one informant described the situation as:

This one is not working, that one is not working, so we are poor, poor, poor people. We just eat porridge, porridge without anything, tea without milk, tea without bread, children can't get fit. (Mom to #6 Female, low Paraplegia)

One informant described the double burden of having been the breadwinner of the family:

I was the only person who could rescue my family, so that means now that financial problem is another issue now, because I cannot support them and they cannot support me financially. This means now it is also coming to issues of poverty. (#4 Male, Tetraplegia)

## Relationships

Family support and attitudes differed substantially; it was mainly dependent on whether close family

members were present or in instances where the informant had to rely on extended family members (the informants defined close family as the biological family, primarily mother, spouse, children, and siblings, while the extended family were relatives such as cousins, aunts, and uncles). Family support was essential to the informants emotionally, for living circumstances, and for caregiving.

Support and perceived attitudes from *family* members varied, in both the close and extended families. Attitudes ranged from the informants experiencing full support to that the disability 'was not welcome' in the family. Lack of supportive attitudes could lead to family break-ups, such as being abandoned by siblings. Feeling supported by the family was crucial with regard to acceptance, maintaining a positive attitude, and for practical support such as caregiving. Informants living with a close family member expressed feelings of contentment with their family support. However support could also be considered 'too much', which discouraged independence, as one informant explained:

I was staying with my sister, she was doing everything for me, cooking for me, washing for me, clothes, everything. Then I changed my mind, because my problem was going to be worse. I just wanted to be independent. . . The problem with the family now, that attitudes, they don't want you to do anything. And the other thing about the family is just, is because they want to hide you. Like if you are using a wheelchair or if you can't do anything . . . they just want you to stay home. (#8 Male, low Paraplegia)

In the absence of close family, the informants had to rely on the extended family, which often lead to challenging situations and feeling disregarded or rejected. Even though informants expressed frustration over the lack of support from extended family members, occasionally they expressed an understanding towards the fact that their relatives' close family had first priority. One informant living with an extended family member expressed his frustration:

It [the injury] took my life, because now I can't do anything for myself. . . First of all I don't have parents . . . so I just struggle for myself. . . The people I'm living with are not treating me well. . . They're working but they can't even give me 10 pula (US\$1.5) . . . can't buy food so I struggle for myself to find what I can eat. (#11 Male, Paraplegia)

Informants that were not dependent on relatives often experienced a good relationship with them. Informants that were in 'non-married' relationships at the time of the injury were left by their partner post-injury, while none of the informants that were married got divorced.

The wives of husbands that had an SCI became the natural *caregiver*, while married women who sustained an SCI had a maid as a caregiver, if possible. Married female informants referred to their husbands as supportive and that they assisted them with issues such as transport, but usually not with daily intimate activities. Some informants had employed personal assistants when financially possible, whereas others were assisted by their family members. Traditionally caregivers are female, as one informant described:

If ... it's culture or nature or so ... we have believed that ladies are the caretaker, so that is what I experience in this house. The relatives, I don't see much of their assistance or their support... The brothers, they can come, you know we'll talk, but to do something. (#4 Male, Tetraplegia)

*Friends* that maintained contact gave a sense of 'normality' to the informants when they were treated the same as before the injury. Informants also stated that 'you get to know who your true friends are'. Some friends assisted with transport and money, while others disappeared due to not being able to cope, or they 'got tired of assisting'. One informant stated that they often felt better understood by people who had similar experiences:

Some of my friends ... have the SCI... We can talk about this freely... After that, almost for 2 month you feel free, you feel like a normal person. (#8 Male, low Paraplegia)

## Society

Inaccessibility in society, the community, and in the home was one of the major barriers for the informants with regard to living a desirable life, feeling included, and being independent. Devaluing attitudes towards persons with disabilities was imminent and it was thought to be partly due to old traditional belief systems held mainly within the older generations.

One of the main barriers in the community was limitations in *accessibility*, such as a lack of ramps, inaccessible public transport, and sandy environments. These limitations restricted many aspects of the informants' lives such as participating in social activities, access offices and medical facilities, and the use of public transportation, which ultimately limited their independence. Access in the home villages was partly possible with an electrical wheelchair, during the dry season only, or with a car. The informants described various living circumstances with houses that ranged from simple constructions with a pit-latrine and water accessible from the outside, to brick houses with water, bath, and toilet inside. Informants who had the economical means

to remodel their house installed ramps and created more space in the bathroom and bedroom in order to move around independently. Informants living with extended family members were often offered only shelter in non-adapted houses. The emotional consequences of inaccessibility were shared by the informants, such as isolation and humiliation, illustrated in this quote:

The only time that I feel good about doing something ... is when I'm at my home, but the moment I leave my home ... there will be massive challenges. First of all, just being out there ... there is loads of sand... When I take myself to the clinic, they have to take my vitals from outside, you know from under the tree, which is not good, I mean it's humiliating and embarrassing. (#3 Female, Tetraplegia)

Even though improvements in accessibility have occurred during the past years, especially in new buildings such as the city shopping malls, the village stores, clinics, and the majority of the public buildings were still inaccessible, and the feeling of being less valued was expressed, as in the following example:

To attend a meeting and there is not accessibility in that building, you find that the person I am meeting has to come down and we have the meeting out on the street or on the parking lot. (#10 Male, Tetraplegia)

The informants' perception of *attitudes* in society varied from feeling respected by most people, to feeling disregarded and rejected. Nevertheless, they all had experiences of being treated badly at some point since their injury, which was described by the informants as 'being looked down on' or 'not seen as a human person'. One example of how negative characteristics are attributed to a physical disability was described:

When you are disabled, people think that you are not normal. You don't think straight ... you can't even say something that is reasonable or good. (#12 Female, Paraplegia)

Church members were generally described as more understanding and encouraging than other people. They came to the house to pray with the informants for encouragement and strength, which was viewed as a positive gesture. Devaluing attitudes was seen to be worse when coming from governmental employees or health professionals. However, thanks to the increased public exposure of persons with disabilities, the government's work to sensitise society and the generational change of attitude, the informants experienced overall improved societal attitudes. On the other hand, unchanged attitudes were also described.

*Cultural beliefs* and traditions affected the informants to different degrees. Even though their own experiences were rare, they described that it was a common practice in Africa to hide your disabled family member due to

shame. The informants stated that injuries are seen as a curse or a punishment for a sin, especially by the older generations, and are therefore shameful. This view was thought to reinforce the negative attitudes.

It was common to visit traditional healers post-injury, which informants turn to mainly due to pressure by their family or friends, or to show respect to their parents. No improvements were noted, but humiliation was described:

The one who did the healing, than because it didn't work then it was like 'your witch is very tough'. (#9 Male, Paraplegia)

I don't go to traditional healers myself . . . they will tell you 'your aunty bewitched you that's why you are in a wheelchair'. There is always conflicts coming from them . . . families will be breaking up because they tell you this and that. (#13 Female, Tetraplegia)

## Discussion

The main findings of this study were the importance of the informants' personal resources in developing coping strategies that facilitated experiences of societal inclusion. Having a source of income and family support were crucial facilitators, while inaccessibility and devaluing attitudes were barriers to inclusion in the society. The findings led to the construction of a theoretical model (Figure 1) which illustrates the facilitators and barriers identified by the informants as impacting on their experiences of inclusion or exclusion in society.

The findings that self-attitude, self-confidence, psychological strength, hope, and spirituality are of considerable importance after a devastating event, such as an SCI, have been shown previously.[12,19–22] In an earlier study,[23] informants living with chronic pain emphasised the importance of emotional and practical support from families, peers, and the workplace when they strived to return to work. In our study, we found that these were all important factors for developing a strong self, which in turn affected identity, contentment with one's situation, the experiences of 'normality', and inclusion in society.

The importance of faith after sustaining a severe disability has previously been reported,[12,19,24,25] including beliefs of being 'chosen by God' due to having the strength to deal with difficult situations such as an SCI.[19] McColl et al. [25] studied spirituality in persons with acute tSCI and traumatic brain injuries and identified three different relationships: with the self, with others, and of a more transcendental nature. Our study emphasised the positive impact faith and spirituality had on the informants' well-being. Hope for a cure and a better future were mainly put in the hands of God,

especially if other facilitators were lacking, i.e. family support and having an income. Negative aspects of spirituality were only raised in conjunction with visiting healing ceremonies. The impact of faith might be different in a more secular society, which, among others, Augutis et al. (2012) showed in their study of coping strategies post-SCI among teenagers in Sweden. In this study only a few of the informants mentioned religion or spirituality as a strategy for coping.[26]

Family support for persons with SCI has been reported as being decisive for resilience,[19] adaptation to living with an SCI,[27] quality of life,[11,28] and as caregivers.[29] In our study, the importance of family support included all of the above, and a lack thereof caused a substantial decline of possibilities of developing a strong self and to experience inclusion in society, especially if financial means were lacking.

When a social welfare system fails to support their disabled citizens, the family becomes the only available support system. No disability allowance was available in Botswana, but some informants who lived in poverty received a small monthly ration of basic food supply. The financial, emotional and practical burden on caregivers can be substantial, especially in low-resource countries.[29] In our study, the support provided by close family members was dependent on the practical and economic circumstances of the family. Caregivers within the close family were mainly non-paid women, mothers, wives or sisters who often had the total caretaker responsibility, which was found to be common in similar contexts.[29] However, the informants often expressed contentment with the arrangement, even if resources were scarce, and preferred a caregiver that they knew well. Some informants had distant family members or non-related caregivers who were employed and paid either by the informant or by the Motor Vehicle Accident Fund (parastatal insurance for people involved in road traffic crashes). This situation created a sense of independence and autonomy.

Being treated the same way as they were before the injury by friends increased the feeling of 'normality'. This corresponds well with Goffman's [30] theory that experiences of stigma decreased when persons with disabilities are socialising with non-disabled persons. However the feeling of 'normality' also increased when spending time with peers who better understood the situation.

Stigmatisation and devaluing attitudes towards persons with disabilities have been described in several studies,[1,2,8,22,31,32] as well as how an already complex life situation could be aggravated by living in an unequal or economically low-resourced country.[12] This was also the finding in our study with inaccessibility as one of the major barriers, which reinforced

stigmatisation. Informants voiced the need for increased efforts by the government to improve access and implement legislation which could improve their situation.

It has been described that the power of public stereotypes creates or reinforces barriers for persons with disabilities. However, some people tend to demonstrate more resistance and can develop positive self-identities and beneficial coping strategies [33] despite or even because of their injuries. There was a similar finding in our study where the informants' experiences of public stigma differed. Some experienced more barriers while others, with sufficient support, managed to develop a strong sense of self and could fight against the culture of shame.

Traditional beliefs, such as a disability being a curse or due to sinning, are likely to increase the barriers to participation in society,[8] including chances of employment. Social beliefs and expectations that persons with disabilities should be cared for [8] can lead to families obstructing independence by not motivating or encouraging training. This was also the case for some of our informants whom initially experienced too much support, partly due to their families wanting to be nice and caring, and partly to keep the patient inside due to shame or embarrassment. The rapid change in Botswana society which includes a well-educated, young population who have a modern lifestyle combined with their parents' generation which hold a more traditional belief system and devaluing attitudes, causes big challenges for persons with disabilities. Nevertheless the informants stated that attitudes and accessibility are improving, and are believed to continue to improve, contributed to the government works, an increased exposure of persons with disabilities, and the generation change.

Parts of the results of this study could most likely be transferred to other contexts, such as challenges with inaccessibility, stigma, and the importance of personal resources and a supportive family. However, the determining role of family support for caregiving and living circumstances or having a steady income would most likely be of greater importance in low-resource countries. Challenges for persons with disabilities are present in all contexts and as mentioned by some informants from Sweden,[6] sport involvement and buying a car were profound facilitators for independence and reintegration, but in many resource-poor countries, basic needs such as getting a decent wheelchair might be a challenge.

### **Methodological considerations**

One of the strengths of this study is the previous contextual knowledge that the first author (I.L.) had

concerning the setting and environment. Familiarity with the participants could be viewed as a limitation if individuals felt obliged to participate considering prior and future assistance. To minimise this risk, the guarantee of anonymity and promise that participation would not affect any future care was provided to all participants.

Another limitation might be selection bias. We excluded non-English-speaking persons, and therefore probably the poorest persons. During sampling we deliberately enforced a variation in background variables among the informants, including an even distribution between living areas, and both urban and rural areas were included, covering a distance of 300 km. The level of education among our informants was relatively high, which possibly increased internet use, return to work, and the ability to fight the shame-culture. Even though we captured a wide range of experiences transferability might be limited. However some findings, such as the importance of identity, family and society, are similar to findings from high-income countries which can facilitate transferability. Meanwhile the role of spirituality might differ from more secular societies. It is for the reader to conclude if transferability to other contexts is feasible.

To ensure trustworthiness [18] the following steps have been taken. With prolonged engagement the environment was well known to I.L., peer debriefing for external comments was used as well as analyst triangulation.

### **Conclusion**

This study emphasised the importance of strong personal resources, a supportive family, and improved accessibility to facilitate participation in the society. Spirituality was a strong facilitator and inaccessibility a barrier for inclusion in the society. Informants requested legislation to advocate for the rights of persons with disabilities to be respected, with the aim of moving towards an equal accessible society with increased accessibility and more equitable employment opportunities.

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