

“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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Conclusions

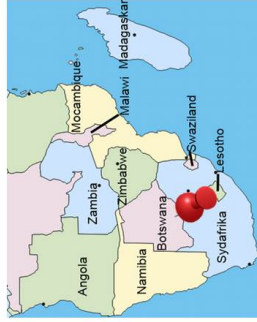
This study emphasizes the need for specialized rehabilitation and for legislation to advocate for rights to be respected of persons with disabilities, with the aim of moving towards an equal accessible society with increased accessibility.

Having a disability involves increased risk of poverty and social exclusion. Living in a society where a disability is seen as a curse or a punishment for a sin, might aggravate that situation.

Background

Studies regarding experiences of living with a spinal cord injury (SCI) are mainly from high-income countries. Inaccessibility, financial strain, and stigmatization are described to limit integration.

In low resource countries the situation is often aggravated due to extreme inaccessibility, devaluing attitudes, and lack of social welfare systems. The few studies published describe the importance of access to health care, faith, family support for coping, and improved life quality.



Traditional house and yard.
← Regular pit-latrine.
Commonly used wheelchairs, usually without a cushion. →



Study aim

To explore the experiences of living with a traumatic spinal cord injury in Botswana with reference to perceived attitudes, obstacles and challenges.

Method

Semi-structured interviews were conducted and analyzed according to Grounded Theory.

Participants

Thirteen English-speaking adult persons living with traumatic SCI for at least 2 years. Mean time since injury was 10 years (4–22).

Demographic and clinical characteristics of informants

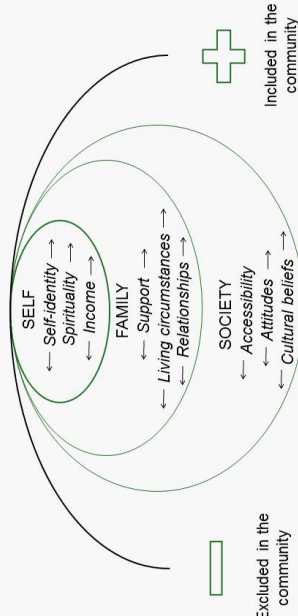
| Variable | Category | n |
|-----------------|---------------------|-----|
| Gender | Male/Female | 8/5 |
| Age | 16-30 | 2 |
| | 31-45 | 9 |
| | 46-60 | 2 |
| Age at injury | 16-30 | 9 |
| | 31-45 | 4 |
| Level of injury | Cervical | 6 |
| | Thoracic | 5 |
| | Lumbar (ambulating) | 2 |
| Living area | City | 4 |
| | Suburbs | 3 |
| | Village | 6 |
| Education | Primary school | 1 |
| | Secondary school | 6 |
| | Tertiary education | 2 |
| | University | 4 |

[at the village clinic] they have to take my vitals outside, from under the tree, which is not good, it's humiliating and embarrassing'

'Miracles do happen, like if the doctor say you'll never walk, then we look at okay, God has created - God can still restore but ...you do exercise, take medication while hoping that a miracle will come'

Results

The core category 'SELF' and the interrelated categories FAMILY and SOCIETY, illustrate the facilitators and barriers described which affected the experience of being included or excluded in the community.



An assured self-identity was crucial to experience inclusion. Close family support and/or a source of income were strong facilitators or barriers, when lacking.

Wide dimensions were described for all sub-categories, except for spirituality, that was a facilitator only, and inaccessibility, that was mainly a barrier.

Having an income affected all levels of life, including self-identity in being able to contribute to society.

'I was the only person who could rescue my family ... coming to an issue of poverty'

Inka Löfvenmark is a physiotherapist at Spinalis SCI-unit in Sweden and the project coordinator for the Spinalis Botswana SCI-rehabilitation project (a partnership between the Ministry of Health in Botswana and the Spinalis Foundation in Sweden, partly funded by Sida). The authors thank Sida, Neuro Sweden (Neuroförbundet) and The Spinalis Foundation for financial support for this study.



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