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ORIGINAL ARTICLE

Outcomes 2 years after traumatic spinal cord injury in Botswana: a follow-up study

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Study design: Prospective follow-up study.
Objectives: To identify indicators leading to compliance with yearly controls (YCs) and to describe the clinical and functional outcomes 2 years after traumatic spinal cord injury (SCI).
Setting: The national SCI rehabilitation centre in Botswana.
Methods: Included in the study were all people who were admitted with a traumatic SCI during a 2-year period and survived to be discharged ($n=38$). Data were collected at the YCs and included demographic characteristics and clinical and functional outcomes. Comparisons were made between those who did or did not attend YCs and between those who did or did not develop pressure ulcers (PUs).
Results: The follow-up rate was 71% (27/38) with higher attendance among those with complete injuries and those with secondary complications, especially pain. Age, gender, distance to the centre and education did not affect the follow-up rate. Self-catheterisation and suprapubic catheter were the preferred methods to manage neurogenic bladder dysfunction. Despite high rates of PUs (48%) and urinary tract infections (UTIs; 41%), no death had occurred during the follow-up period. Furthermore, one-third had resumed work.
Conclusion: Despite high rates of UTIs and PUs developed in the home environment, this study showed a high survival rate 2 years after traumatic SCI, which might be explained by the establishment of a specialised SCI unit and the high follow-up rate. In addition, the continuing contact with the SCI staff might have facilitated the relatively high return-to-work rate. Long-term follow-up seems possible even in resource-constrained settings with clearly stated objectives, transport, dedicated staff and well-educated patients and families.
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INTRODUCTION

Living with a spinal cord injury (SCI) implicates increased vulnerability for morbidity and premature death.[1] To maintain good health, regular medical follow-ups are essential to prevent, identify and treat secondary complications.[1] The availability of such services after SCI, however, varies depending on the economic situation of the country, the health-care system and the objectives of existing centres, from non-existing to lifelong follow-up by SCI specialists.

Structured medical follow-up visits constitute a challenge in many resource-constrained settings,[1–3] with lack of funding, dedicated people allocated for this task and means of communication as some reasons.[4–6] Patients are often discharged to remote villages with no transport available and the contact is likely to come to an end.[4–6] The few published follow-up studies from resource-constrained settings describe the challenges and the high frequency of people being lost to follow-up.[3,4,6]

Complications after SCI are commonly prevalent with pain being one of the most reported problems.[5,7,8] Pressure ulcers (PUs) and urinary tract infections (UTIs) are also reported in high rates, 30–54% and 17–46%, respectively,[2,5,7,9]and contribute to the high mortality rates in low- and middle-income countries, 24–85%.[4,5,7,10] In contrast, mortality after SCI in high-income countries is mainly caused by respiratory and cardiovascular diseases.[1]

Governmental support, for example, long-term disability allowance or paid caregivers, is lacking in many parts of the world, which renders the affected person to become a substantial burden and totally reliant on their families.[3,5] Inaccessibility in the homes and the communities and devaluing attitudes in society also severely restrict involvement in society and return-to-work opportunities.[1,5,11] These circumstances can further be aggravated by totally inaccessible public transport systems, if available at all, increasing the risk of isolation and exclusion from society.[1,11]

There is a scarcity of knowledge in low- and middle-income countries regarding the follow-up process and the relocation process back to the community after acute traumatic SCI (TSCI). Therefore, the aims of this study were to identify indicators leading to compliance with yearly controls (YCs) and to describe the clinical and functional outcomes 2 years after TSCI.

MATERIALS AND METHODS

Setting and population

Botswana, a land-bound country in the southern part of Africa, is rated as a middle-income country[12] and has a relatively well-developed health-care

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system. An SCI rehabilitation centre has been established at the national referral hospital in the capital and constitutes the setting for this study. The services provided at the centre include subacute rehabilitation, re-rehabilitation, outpatient clinics and life-long follow-up with YCs, that is, multi-professional assessments by SCI specialists: physicians, nurses, physiotherapists, and occupational therapists.

Included in the study were all people who were admitted with an acute TSCI during a 2-year period (1 February 2011 to 31 January 2013) and survived to be discharged ($n=38$). Data regarding the admission phase have been described in a previously published study.[13]

Data collection and analysis

Data were collected at the second yearly assessments if conducted ($n=16$), otherwise data from the first YC were used ($n=11$) in the analysis. For comparison between the groups who did or did not attend YCs, data from the discharge assessments were used. The International SCI data sets[14] for lower urinary tract function, bowel function, pain, quality of life (QoL) and sexual function were used as outcome measures, complemented with the Functional Independence Measure (FIM)[15] and information regarding socio-demographics, return to work, complications and mortality. The neurological level and severity of lesion were determined according to the International standards of neurological classification of SCI[16] and classified as C1–8 American Spinal Injury Association (ASIA) Impairment Scale (AIS) grade A–C, T1–S5 AIS A–C and all AIS D.[17] One person with undefined severity of paraplegia was included in the paraplegia AIS A–C group as some function was preserved in the lower extremities and in the bladder and bowel functions, but the patient was non-ambulatory. Furthermore, telephone follow-ups were conducted with people who did not attend YCs.

Categorical variables are presented as absolute numbers and proportions and continuous variables as mean, s.d., median and interquartile range (IQR).[17] Non-parametric tests were used because of the small sample and non-normal distribution, Mann–Whitney *U*-test for analysis of differences between groups, Kruskal–Wallis test for analysis of variance between more than two groups and Wilcoxon signed-rank test for dependent variables. Categorical variables were analysed with Fisher's exact test. *P*-value for statistical significance was set to $P<0.05$. SPSS statistics version 22 (IBM, New York, NY, USA) was used for statistical analysis.

Ethics

The ethical committee at the Ministry of Health in Botswana (PPME: 13/18/1 Vol VIII (92) and HPDME-13/18/1 Vol IX (442)) and at the hospital (PMH 5/79 (27a) and PMH 5/79 (172)) approved the study.

RESULTS

Thirty-eight people had been discharged from the SCI rehabilitation centre after sustaining acute TSCI and were eligible for YCs: 19 with tetraplegia and 19 diagnosed with a complete injury (AIS A). Twenty-seven people (71%) attended YCs, of whom 14 attended both the first and second year. People complying with follow-up had a higher rate of complete injuries (AIS A versus B–D $P=0.029$), aetiology of road traffic crashes and secondary complications during in-patient care, especially pain. The level of injury, age, gender, distance to the SCI clinic or years of education did not impact the follow-up rate (Table 1). Assessments were carried out 24 months (median) after injury (min.–max. 6–38, IQR 12.5–27.5). Out of the 11 people who had not attended any YCs, we were able to contact six people (all males, tetraplegia AIS A–C = 2, paraplegia AIS A–C = 2, AIS D = 2). The reasons stated for not attending were that it did not seem meaningful ($n=1$), no transport ($n=1$) or not being scheduled ($n=4$).

Table 1 Demographic characteristics and clinical and functional outcomes of people who did or did not attend yearly controls

Variables	*Yearly control* (n = *27*)	*No yearly control* (n = *11*)	P-*value*
Demographics			
Age at injury (years)			0.358[a]
Mean (s.d.)	33 (13)	29 (13)	
Median (IQR)	31 (24–39)	27 (18–40)	
Gender, *n* (%)			0.452[b]
Male	18 (67)	9 (82)	
Female	9 (33)	2 (18)	
Cause of injury, *n* (%)			**0.012**[b]
Traffic-related injury	20 (74)	3 (27)	
Other	7 (26)	8 (73)	
Socio-demographic variables			
Marital status, *n* (%)			0.452[b]
Single	18 (67)	9 (82)	
Married–cohabit	9 (33)	2 (18)	
Education (years)			
Mean (s.d.)	10 (5)	10 (5)	0.884[a]
Median (IQR)	10 (9–12)	10 (6–14)	
Distance from clinic (km)			0.569[a]
Mean (s.d.)	248 (248)	213 (312)	
Median (IQR)	220 (10–400)	20 (10–400)	
Clinical outcomes			
Severity of injury, *n* (%)			0.238[b]
AIS A–C	21 (78)	6 (54)	
AIS D	6 (22)	5 (46)	
Level of lesion, *n* (%)			0.476[b]
Tetraplegia	12 (44)	7 (64)	
Paraplegia	15 (56)	4 (36)	
Complications, *n* (%)	27 (100)	6 (54)	**0.001**[b]
No complications	0 (0)	5 (46)	
Pain	24 (89)	3 (27)	**0.007**[b]
No Pain	3 (11)	5 (46)	
Missing	0 (0)	3 (27)	
Pressure ulcers	13 (48)	2 (18)	0.145[b]
No pressure ulcer	14 (52)	9 (82)	
Urinary tract infections	8 (29)	3 (27)	1.0[b]
No urinary tract infection	15 (56)	6 (55)	
Missing	4 (15)	2 (18)	
Functional outcomes			
Mode of mobility, *n* (%)			0.116[b]
Wheelchair	22 (81)	6 (54)	
Active manual	14	1	
Electric	1	1	
Active indoors/electric outside	4	1	
Partly ambulatory and wheelchair users	3	3	
Ambulatory	5 (19)	5 (46)	
Without assistive device	3	4	
With crutches	2	1	

Abbreviations: AIS, American Spinal Injury Association (ASIA) Impairment Scale; IQR, interquartile range; s.d., standard deviation.
Significant difference is marked in bold.
Data are derived from the discharge assessments.
[a]Mann–Whitney *U*-test.
[b]Fisher's exact test.

Demographic characteristics

Demographic characteristics are presented in Table 1. Out of the 27 people attending YC, 9 were living with their spouse or cohabitant, 18 people were single of whom 13 lived with their families, 2 with relatives, 1 with the children and caregiver and 1 lived alone (missing data = 1). Housing standards included electricity and water for 19 people, 2 lived in mud houses and, for the remaining people, the standard was in between those two (missing data = 2). Toilet and bathroom were situated inside the house of 11 people. Insurance coverage, limited or full Motor Vehicle Accident Fund, was approved for 21 people, whereas the rest were uninsured.

Outcomes

Neurological recovery of at least one grade improvement on the AIS scale was seen in two individuals since discharge. The total motor FIM scores for the whole and the paraplegic group were significantly increased compared with discharge scores (Table 2). Divided in single items, the one area of improvement for the total group was toilet transfers ($P=0.010$). Manual or electrical wheelchairs were used full time by 70% (Table 3). Of the six people who were reached by telephone, two were ambulatory, one partly ambulatory and three full-time wheelchair users.

Clean intermittent catheterisation, that is, self-catheterisation, or suprapubic catheter (SPC) was the preferred method to manage neurogenic bladder dysfunction (Table 3). Of the five people who at discharge had an indwelling catheter, one remained with indwelling catheter, one had changed to SPC and one performed self-catheterisation (not attending YC = 2). People using SPC at discharge remained with SPC (not attending YC = 2). Of the 10 people who previously self-catherised one had gone back to indwelling catheter, whereas the rest remained self-catherising (missing data = 1, not attending YC = 1). For managing neurogenic bowel dysfunctions, digital ano-rectal stimulation was the primary method, performed on bed by four people, whereas the rest used toilet or commode chair (missing data = 4).

Seventeen people had rated sexual function (male = 13, female = 4), see Table 4. One person refrained from answering, one was a child and data were missing for eight. QoL was rated by 20 people (male = 14, female = 6, missing data = 7) with ratings between 0 and 10 (completely dissatisfied–completely satisfied). Questions were stated as 'how satisfied are you' with the following: 'life as a whole', which was rated at a median (IQR) value of 7 (5–9.5); 'physical health' rated 7(5–9); and 'psychological health, emotions and mood', rated 10 (8–10). Women rated 'physical health' significantly lower compared with men ($P=0.034$).

Return to work

Eight people had returned to work and four were students (missing data = 2). Of the 13 people not working, two were not working previously (housewives) and one person had received early retirement. No association between return to work and years of education was found. Of the six people followed-up by phone, four were full- or part-time employed or in school.

Complications and mortality

Sixteen people reported pain, all of whom had pain during in-patient care and 11 people had been treated for UTI (Table 5). Thirteen people had developed PUs in the home environment, all of them with a complete injury (AIS A) ($P=0.000$), and all, but two, had been treated for PUs during in-patient care. Of the 14 people who did not develop PUs in their home environment, 2 had been treated for PUs during in-patient care and 4 had a complete injury (Table 6). Furthermore, one person had been diagnosed with AIDS and had initiated highly active antiretroviral therapy and one had been diagnosed with diabetes. Of the six people who were reached by telephone, none reported PUs, three complained of pain, two reported UTI and one bladder and kidney problems.

Mortality was zero during the study period (missing data = 1).

DISCUSSION

The main findings of this study were the high follow-up rate after discharge from TSCI rehabilitation compared with what have been shown in studies from the neighbouring countries and that as many as one-third of the people involved had returned to work. In addition, PUs were prevalent in half of the former patients; however, no death occurred during the 2-year follow-up period.

Comparisons between the situations for people with SCI before or after the establishment of the specialised rehabilitation centre are challenged by the lack of previous studies in the field. However, according to physicians with long experience of TSCI management in Botswana, mortality 1 year after discharge was estimated to be around

Table 2 Motor FIM[a] score at the time of discharge and yearly control

Type of injury	*Discharge* (n = *38*)	*Yearly control* (n = *27*)	n[b]	P-*value*[c]
C1–8 AIS A–C				
n (missing)	7 (2)	7 (0)		
Median (IQR)	55 (22–69)	62 (34–78)	6	NA
T1–S5 AIS A–C				
n (missing)	16 (2)	12 (0)		
Median (IQR)	82 (68–84)	82 (69.5–83)	11	0.021
All AIS D				
n (missing)	8 (3)	5 (3)		
Median (IQR)	91 (87–91)	91 (86–91)	5	NA
Total				
n (missing)	31 (7)	24 (3)		
Median (IQR)	82 (63–86)	81.5 (66–83)	22	0.020

Abbreviations: AIS, American Spinal Injury Association (ASIA) Impairment Scale; C, cervical; FIM, functional independence measure; IQR, interquartile range; NA, not applicable; S, sacral; T, thoracic.
[a]FIM motor score (nos. 1–13), minimum–maximum score 13–91.
[b]Number of people with valid FIM assessments carried out at both discharge and yearly control.
[c]Wilcoxon signed-rank test was used to analyse changes in motor-FIM scores from discharge (with classification according to the AIS at the yearly controls).

Table 3 Functional outcomes among people attending yearly controls (*n* = 27)

Variables	n *(%)*
Mode of mobility	
Wheelchair	21 (78)
Active manual	11
Electric	2
Active indoors and electric outside	6
Partly ambulatory and wheelchair users	2
Ambulatory	6 (22)
Without assistive device	5
With crutches	1
Bladder management method	
Normal function	8 (30)
Indwelling catheter	2 (7)
Suprapubic catheter	6 (22)
Intermittent catheterisation[a]	8 (30)
Missing data	3 (11)
Bowel management method	
Normal function	9 (33)
Digital stimulation	13 (48)
Other[b]	2 (8)
Missing data	3 (11)

[a]Carried out by assistant for one.
[b]Enema and straining were other methods for bowel management.

Table 4 Sexual function assessed with the ISCoS data set for sexual function, rated by 17 people who attended yearly control (*n*)

	Normal	*Reduced/altered*	*Absent*	*Unknown*	*Missing data*
Psychogenic erection/arousal	5	4	5	3	0
Reflex erection/arousal	6	3	5	2	1
Ejaculation (only men)	2	4	2	4	1
Orgasmic function	4	3	3	6	1

Abbreviation: ISCoS, International Spinal Cord Society.

Table 5 Complications and consequences of TSCI since discharge

	n *(%)*
Pain	16 (59)
Shoulder pain	6 (37)
Urinary tract infection	11 (41)
Missing data	2 (7)
Pressure ulcer/s	13 (48)
Heterotopic ossification/myositis	2 (7)
Spasticity	15 (56)
Problematic spasticity	8 (53)
Missing data	2 (7)

Abbreviation: TSCI, traumatic spinal cord injury.

Table 6 Characteristics of people with or without pressure ulcers since discharge (*n* = 27)

Variables	*Pressure ulcers* (n = *13)*	*No pressure ulcers (n = 14)*	P-*value*
Age at injury (years)			0.437[a]
Mean (s.d.)	33 (8)	32 (16)	
Median (IQR)	34 (29.5–37.5)	27.5 (23–44)	
Education (years)			0.446[a]
Mean (s.d.)	11 (4)	9 (5)	
Median (IQR)	12 (9–12)	9.5 (5.5–14)	
Gender, n (%)			0.420[b]
Male	10 (77)	8 (57)	
Female	3 (23)	6 (43)	
Marital status, n (%)			1.0[b]
Single	9 (69)	9 (64)	
Married/cohabit	4 (31)	5 (36)	
Type of injury, n (%)			**0.002[b]**
AIS A–C	13 (100)	6 (43)	
C1–8	5	2	
T1–S5	8	4	
AIS D	0 (0)	8 (57)	
Level of injury, n (%)			0.704[b]
Tetraplegia	5 (38)	7 (50)	
Paraplegia	8 (62)	7 (50)	

Abbreviations: AIS, American Spinal Injury Association (ASIA) Impairment Scale; C, cervical; IQR, interquartile range; S, sacral; T, thoracic.
Significant difference is marked in bold.
[a]Mann–Whitney *U*-test.
[b]Fisher's exact test.

85% among wheelchair users prior to the establishment of the Spinalis SCI rehabilitation centre. PU and UTI were the major causes of death, escalated by high rates of depression. Patients were mainly discharged to remote home villages with, primarily, the mothers as designated caregivers and nearly all were lost to follow-up.[2]

Follow-up after TSCI has also proven to be a major challenge in the majority of resource-constrained settings. The most follow-ups conducted in low- and middle-income countries are reported to be conducted through home visits, questionnaires and/or phone calls.[4,5,7,10] In Nigeria, attempts of hospital follow-up visits revealed a follow-up rate of 1.5–3%.[6] The successful follow-up rate of almost three-quarters of the people in our study can be attributed to various reasons: the changed objectives of the rehabilitation centre, a dedicated nurse appointed for scheduling and well-established patient information regarding the importance of follow-up. Hospital/clinic transports to the centre were also available; however, they were often unreliable, which could lead to extended administrative scheduling arrangements, long waiting times and frequent cancellations. Complications during in-patient care and having a complete injury increased compliance with YC, which might have depended on the scheduling routines and the person's incentives to approach the health-care system. People with AIS D injuries had been scheduled to a lesser degree; they also seemed to have fewer incentives to seek follow-up. According to the staff member appointed for scheduling, the reasons for failing to schedule follow-up visits included the ward phone being blocked for calling cellphones, ambulatory people were scheduled at a lower rate and one patient had been to regular outpatient visits for wound dressings but scheduling for YC had been missed. People with traffic-related injuries also attended YCs at a higher rate probably explained by that the Motor Vehicle Accident Fund occasionally could assist with transport. Interestingly, the distance to the clinic did not affect the follow-up rate, even though travel distance could be up to 900 km. To accommodate the long distance travellers, the unit provided lodging at the ward. Even though documentation from YCs was lacking for 11 people, staff members had contact with the majority of the patients.

The practice of self-catheterisation is the recommended method to manage a neurogenic bladder.[18] In the home environment, self-catheterisation continued to be the preferred method for bladder management, a positive change from the previous use of indwelling catheters. Because of an improved availability of catheters, the SCI centre had changed their recommendations from multiple to single use of non-coated catheters in the home environment.

Return to work is challenged by many factors for people with disabilities, especially in resource-constrained settings with inaccessible public transportations and low expectations and devaluing attitudes from employers and society.[1] In addition, manual labour is common and workplace adaptations rare, even when possible. Among the participants in our study, 30% had returned to some kind of

employment and 15% to studies compared with the global employment rates of 37% after SCI.[1] These relatively high rates might be due to some changes in attitude towards people with disabilities during the past years, governmental assistance to re-employ people and provide assistance (for example, teacher aids in schools for teachers) and an altered view of the abilities of a person with SCI.

Risk factors for developing PU include, on top of the SCI, indicators frequently present in resource-constrained settings, such as low income, low education level, immobilisation, lack of appropriate technical aids and malnutrition.[19] Despite the improved rehabilitation services in Botswana with patient and family education and provision of technical aids, the incidence of PU in our study still correlates with other resource-constrained settings.[5,7,19] In contrast, no person died during the 2-year follow-up period, possibly explained by the continuing follow-up care, proper technical aids, an increased knowledge among the staff and that patient and family education had taken place. For one person with an AIS D injury, the contact had ended and the status is unknown; however, with walking abilities the risk of complications and death is considerably lower. The above facts indicate a substantial improvement in survival rates compared with the prior situation and compared with studies from other sub-Saharan Africa countries where mortality among the community dwelling people with SCI remains high.[4,5,20]

The main strength of this study is the national catchment area for people with TSCI, with patients being discharged to all areas of the country that the study represents. The protocols used were derived from the International Spinal Cord Society (ISCoS), with the exception of FIM, which has been under debate regarding its use with the SCI population and has been considered too indiscrete to catch progress. Nonetheless, FIM was the functional outcome measure in use and changing protocol was not feasible at the time, which possibly could have caused occasional lack of documented progress. Other limitations that need to be addressed include that QoL and sexual function were only rated by 60–75% of the people attending YCs. Reasons for this include unclear routine surrounding when the protocols should be used, unclear designation of people/professionals to address these issues and that some staff-members felt uncomfortable with the subjects. QoL ratings seem to be high, which can depend on a bias towards addressing QoL issues with people more satisfied with their situation. Finally, because of the small sample the statistical analysis should be cautiously interpreted. Despite these mentioned limitations, this study contributes with new information regarding the transition back to the community after a TSCI in sub-Saharan Africa.

CONCLUSION

Despite the relatively high rates of UTI and PU developed in the home environment, this study showed a high survival rate 2 years after TSCI. This might be explained by the high follow-up rate after discharge and the establishment of a specialised SCI unit. Complete injuries and the presence of secondary complications increased the compliance with attending YCs. In addition, return-to-work rate was relatively high, especially taken into account the challenging environment, which possibly has been facilitated by the continuing contact and support by the SCI staff. Long-term follow-up seems possible even in resource-constrained settings with clearly stated objectives, transport, dedicated staff and well-educated patients and families.

CONFLICT OF INTEREST

The authors declare no conflict of interest.

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