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Health Systems Indicators and Quality of Life in Persons with Spinal Cord Injury in South Africa

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Abstract

Background

Knowledge of health system indicators are essential to the living situation of persons with disabilities. Assessing and collating the performance of health systems is important in order to identify areas of improvement. The main aim of this study is to assess the relationship between health system indicators and self-reported quality of life (QoL) among persons with spinal cord injury who accessed either public or private health care services in South Africa.

Methods

A cross-sectional survey was implemented to analyse and compare health system indicators and self-reported QoL for 200 persons over the age of 18 with either a traumatic or non-traumatic spinal cord injury. The survey further compared the impact of public or private health care access on these indices. Health system indicators include: access to disability pension, vocational rehabilitation, health and nursing care, public space, medications, assistive devices and transportation. Self-reported quality of life indicators include: satisfaction with health; ability to perform activities of daily living; yourself; personal relationships; and living conditions. A total score of Quality of life was calculated using these 5 domains.

Results

The highest scores for health indicators were access to a disability pension (76%) and access to required health care (72%). Indicators that negatively affected respondents' lives were access to public spaces (70%), transport (56%), medications (56%) and nursing care (53%) which were reported to have made participants' lives significantly harder. Participants who accessed private health care reported a higher QoL score in comparison with those in the public health system who reported more problems. There was a negative correlation between QoL and access to a disability pension and a positive correlation between QoL and access to public spaces, medication, transport and nursing care.

Conclusion

Performance of health system indicators influence living situation, and different healthcare insurances play a significant role in health system performance and self-reported QoL among persons with SCI in South Africa. Additionally, persons with SCI who have the ability to overcome the challenges encountered due to poor performing health systems report better quality of life.

Introduction

Spinal cord injury (SCI) is a disabling condition associated with secondary health complications which result in a decline of physical, psychological, and social functioning that ultimately affects quality of life (QoL) [1–3]. Health care for persons with SCI plays a significant role in reducing and preventing an individual's risks associated with secondary or chronic conditions and is therefore positively linked with improving their QoL [4].

QoL refers to a person's experience of physical, psychological, social, spiritual and economic wellbeing [5, 6]. Health related quality of life (HRQoL) is a subset of QoL. When viewed from an insider perspective of "the body in dysfunction", it refers to the physical, role, social, and phycological functioning as well as general health of a person [7]. In public health, QoL is increasingly being recognised as a legitimate and fitting indicator of service need and usage by people with disabilities, including those with SCI. Thus, suggesting that QoL might greatly depend on health system performance, specifically when the chronicity and seriousness of secondary conditions associated with SCI are considered. However, there are numerous challenges associated with measuring the performance of health care systems, not least accommodating variables that reside outside the basic provision of medical services, such as facilities, financing mechanisms, accessibility and technologies [8].

Health care systems globally, whether in the public or private domain are essential for ensuring that the health care needs of a population are being met. Therefore, health care systems play a significant role in people's health, be it the physical, mental or social well-being of an individual. There is agreement that the global performance of a health system is linked to a country's development index [9]. Countries with higher economic wealth provide their citizens with a better health systems than those on the lower end of the economic scale. However, the health status of the population can also be influenced by other underlying determinants other than the performances of the health system such as genetics, societal and environmental characteristics [10].

Health care systems in South Africa are divided into two sectors, namely public or private. There are various differences between the two sectors and access to the private health sector is restricted to citizens who are able to afford health insurance costs. Public health care services are financed by the government, thus all South Africa citizens have access to free healthcare. In 2016 the Department of Health reported that the majority of South Africans (84%) depend on public healthcare facilities, with only 16% of the South African population with medical aid able to access health care in the private sector [11]. Although public health care services are available to all South African citizens, these facilities are overcrowded, under-resourced and understaffed, frequently characterised by long patient waiting times. Standards of health care in the public sector are often constrained in terms of human and financial resources as well as medication shortages. Because of such resource constraints, the public cannot fully benefit from a quality health care system [12].

The private health care sector in contrast to its public counterpart, is characterised by the provision of specialized care with units fully staffed with an entire adequate staffing levels, multidisciplinary medical team, necessary equipment, short waiting periods, better quality facilities and proper disease control and

prevention practices [12]. The current health care system in South Africa is therefore, a system burdened by various challenges including the unequal distribution of resources, poor management and leadership crisis, increased disease burden and slow progress in restructuring the healthcare system [13].

Having access to private health care insurance has been linked to the satisfaction with services and facilities among persons with disabilities in South Africa. For example, a 2015 country report showed that 91% of persons with disabilities who used private services were very satisfied with services and facilities. This compares with a 54% satisfaction rating for those using public services [14], suggesting that health systems have an impact on satisfaction with services. However, what remains unknown is how persons with SCI specifically experience services and facilities across these two health care sectors and the degree to which these experiences influence their levels of satisfaction. To address these unknown factors, the objectives of this study were: (1) To determine the extent to which health care indicators have been met as perceived by persons with SCI; (2) To determine self-reported QoL in the sample of persons with SCI; (3) To assess if differences in health care indicators and self-reported QoL exist between persons accessing public versus private health care; and (4) To assess the relationship between health system indicators and self-reported QoL.

Methods

Setting

Data were collected within communities in the metropolitan areas of Cape Town and Pretoria in the South African provinces of the Western Cape and Gauteng, respectively. The two provincial geographical settings differ in terms of health care system governance, availability and access to services. SCI participants utilizing public health care services in Cape Town and those accessing private health care in Pretoria were recruited.

Study design and sample

A descriptive cross-sectional survey was used to collect data. Non-probabilistic sampling was used to recruit participants aged 18 years and above with confirmed primary diagnosis of either traumatic or non-traumatic SCI. Participants were sampled from public and private registries in the respective health facilities. Individuals were excluded from the study if they had a severe cognitive impairment or if they were hospitalized at the time of the survey.

The Cape Town cohort (N=156) represented those using the public health care system and was part of an earlier epidemiological study. This study aimed to determine the incidence, cause, and injury characteristics of those with traumatic SCI during a one-year period (September 2013 to September 2014) [15]. Contact details of those in the incidence cohort were kept and all who were still alive at the time of the survey were eligible to participate. Upon the receipt of ethical clearance of the current study, all participants were re-invited to participate in the cross-sectional study focusing on functioning and health systems. Of the overall 145 participants, 87 were available and were followed up. Apart from this cohort,

an additional 69 participants were recruited from outpatients at the Western Cape Rehabilitation Centre and through peer supporters in the region. All participants completed formal inpatient rehabilitation and had returned for outpatient urologic clinic appointments or exercise therapy.

The private cohort (N=44) all attended Mediclinic Meulmed for their inpatient rehabilitation. All but two preferred to conduct the survey telephonically while the rest came to the rehabilitation facility to complete the survey, which was interview administered. The mean time duration since the injury was 9 years.

The survey was available in three languages, namely English, Afrikaans, and Isi-Xhosa and comprised 125 items, which took participants approximately 45-60 minutes to complete.

Data collection

Outcome Measure: Data were collected using the WHO-QoL-BREF and the International Spinal Cord Survey (InSCI) Questionnaire.

The World Health Organization QoL (WHO-QoL-BREF) measures self-reported QoL from 5 items. This includes satisfaction with health, satisfaction with the ability to perform daily activities, satisfaction with yourself, satisfaction with personal relationships, and satisfaction with living conditions. An overall QoL was calculated using the above-mentioned items. Each participant was asked to rate their QoL over the past 14 days on a 5-point Likert scale (1, very dissatisfied to 5, very satisfied). Health systems indicators selected from the International Spinal Cord Survey based on the recommendations of the International Perspectives of Spinal Cord Injury [16] were linked to the items of WHO-QoL-BREEF. The following items from the International Spinal Cord Injury Survey questionnaire [17] were selected for the health system indicators: (1) Do you currently receive disability pension or similar benefits?; (2) Did you receive vocational rehabilitation after SCI?; (3) In the past 12 months, have you needed health care but did not get it?; (4) Access to public space, e.g. inaccessible public buildings, parks; (5) Social attitudes, e.g. stigma, prejudice, and ignorance; (6) Access to assistive devices, (short distance) e.g. stair, lifts, walking aids, or wheelchair; (7) Access to transportation (long distance) e.g. lack of adapted car or hard to use public transportation; (8) Reception of nursing care, e.g. home health care or personal assistance; (9)Access to medication, aids, and supplies, e.g. catheters, splints, pillows.

Health indicators 1-3 required a yes/no response while indicators 4-9, asked participants to say what influence the indicators had on their lives.

Data analysis

The Statistical Package for Social Sciences (SPSS) Version 26 was used to analyse the data.

Descriptive statistics summarize demographic (age, sex, marital status, educational level, work status, household income) and injury characteristics (type of injury, level of the injury, severity of the injury, time living with the injury), and outputs were presented as frequencies and percentages. Health system indicators were dichotomized by coding 1 for a positive meaning (e.g. had no influence, had access,

received the services) and 0 for negative meaning (had influence, had no access, did not receive services). The responses on self-reported QoL from a 5-point scale (1, very dissatisfied to 5, very satisfied) were also dichotomized by coding 1 for positive meaning (Satisfied, very satisfied) and 0 for negative meaning (very dissatisfied, dissatisfied, neither satisfied nor dissatisfied). The overall QoL score was obtained by calculating the total score ranging from 0% to 100% of the 5 items using the WHO methodology [18], where higher values show a higher QoL. The frequencies and percentages of dichotomised data from health system indicators and self-reported QoL were calculated. The results of the 2 cohorts (private versus private) on health system indicators and self-reported QoL were then compared for differences. These were done by Cross-tabulation using a Chi-Square test- of independence. Correlation analyses were also done to assess for relationships between health system indicators and self-reported QoL of the study sample. A p-value at 0.05 was considered significant.

Results

Socio-demographic characteristics

The overall sample consisted of 200 traumatic and non-traumatic SCI participants from both public and private facilities. Table 1 presents the basic characteristics of the study sample. The majority of the participants were from the public cohort (78%), and were predominantly male (75%). The median age at the time of survey was 36 years, with the public cohort reporting a much older age. The median time for living with the injury was 6 years, with the private cohort reporting a much longer period. Traumatic aetiology was the primary cause of the injury (92.5%) across both cohorts. While public cohort participants reported physical assault as a leading cause (39.1%), road traffic accidents (36.4%) were more prevalent with the private cohort. Paraplegia and complete injury were the main diagnosis irrespective of the cohort. Only 9.5% of the total cohort had university education and 24.5% were employed, however highest proportion of employed participants (56.8%) were found in the private cohort with the highest number (56.8%) of paid work in the private cohort. The majority reported a monthly household income of between R1000-R3000. However, when disaggregated across the two cohort groups, a significant difference was observed. 34% of private cohort participants reported a household income of above R20 000 compared with only 4% in the public cohort.

Health System Indicators

Table 2 summarizes the results of health system indicators and highlights the differences between those accessing public or private health care (objectives 1 and 3). Access to disability pension was reported by 76% of the study sample. The difference between public and private cohorts who received a disability pension was statistically significant (p<001), with 82% of participants in the public cohort receiving disability pension compared to 54% of participants in the private cohort. With respect to health care needs, 72% of the study sample reported that their health care needs were met, and no significant differences were observed between the public and private cohorts (p=.396). About 57% of the participants reported that they have received vocational rehabilitation after their injury. There were also significant

differences in terms of vocational rehabilitation between the two cohorts, with the public cohort reporting that a higher percentage (60%) of participants who received vocational rehabilitation, compared to 43% in the private cohort, (p=.042). Access to public space was the most problematic health indicator, with 70% of all participants reporting that insufficient access to public space made their lives harder (p=.459). Additionally, factors that made participants' lives harder across both cohorts were the lack of or insufficient access to transport and medications (56%) and assistive devices (53%). There was a statistically significant difference between the two cohorts in terms of 1) access to transport, 2) medications and 3) assistive devices/technology, with the public cohort being more negatively affected in all above mentioned domains. For 58% of participants in both cohorts, negative societal attitudes had no influence on their lives (p=.227).

Self-reported quality of life

Figure1 and Table 3 present the results of self-reported QoL of the participants and highlight differences between persons with public and private healthcare insurances (objective 2 and 3). The overall satisfaction of the sample was 56% with the private cohort reporting significantly higher satisfaction rates (64%) than the public cohort (52%). Satisfaction with one-self (72%) closely followed by satisfaction with health (69%) were the two highest scored items, with higher scores reported for the private cohort comparative to the public cohort. Satisfaction with living conditions (59%) was the lowest scored domain, with the public cohort reporting the lowest score. In general, individuals in the private cohort significantly reported higher self-reported QoL scores than those in the public cohort. Significant differences were evident in (1) The overall satisfaction; (2) satisfaction with living conditions and (3) satisfaction with personal relationship scores; for the private cohort, personal relationships and living conditions recorded satisfaction scores of 84% compared to those in the public cohort where satisfaction scores were noted as follows: satisfaction with relationship, 61%) and satisfaction with living conditions, 52%.

Relationship Between Health System Indicators and Self-reported Quality of Life

The relationship between health system indicators and self-reported QoL was examined and the results are presented in table 4 (objective 4). Access to disability pension and health care negatively correlated with self-reported QoL.There was a positive correlation between self-reported QoL a and access to public space, medication, transport and nursing care. Participants who indicated that the forementioned factors had no or limited influence on their lives had higher self-reported QoL scores.

Discussion

This study provides the first comparative analysis of health system indicators and self- related QoL for persons affected by a SCI accessing either the public or private health care sectors in South Africa. Concerning our study sample, no significant differences exist, in terms of demographic and injury-related factors, when compared to previous reports from local [15] settings, indicating that the findings of this study may be generalisable to the source population.

Quality of life

The overall self-reported QoL of the study sample was 56%. The difference between the two cohorts in terms of self-reported QoL was statistically significant, with the private cohort reporting higher self-reported QoL compared to the public cohort. These results confirm a previous country report which showed that about 91% of the persons with disabilities using private health care services were very satisfied with services and facilities compared to only 54% using public services [14]. The differences identified between the public and private cohorts in terms of satisfaction may be justified by the financial status of the participants. About 34% of participants in the private cohort reported the a household income of between R20000 and R50000 per month compared to only 4% of participants in the public cohort that reported such an income. The higher household income reported by individuals with private cohort might have facilitated the affordability of private health care sector, which has been previously reported to offer satisfactory services compared to the public health care sector [12]. The results of this study are therefore, consistent with previous findings which show a significant association between higher household incomes and better QoL scores for persons with SCI [19,20].

Health systems indicators

In this study, 76% of participants indicated that they were receiving a disability pension. A statistical significance was noted in the differences between private and public cohorts, with a greater proportion of the public cohort receiving a disability pension. These differences can be attributed to the financial and/or employment status of the participants. It was noted that about 56% of participants in the private cohort were employed compared to only 15% in the public cohort, which may indicate that disability pension might have been the primary source of financial support to compensate the income losses, for many of the public cohort.

Although disability pensions were received by the majority of participants, it negatively correlated with self-reported QoL, with those that were receiving disability pension value of 130 $ reporting lower self-related QoL. The possible explanation to this is evident in Table 2 and Table 3 in the results section. The results in Table 2 show that most of the participants receiving a disability pension were from the public cohort while Table 3 shows that participants in the public cohort were less satisfied compared to those in the private cohort. Therefore, this may explain that self-reported QoL of participants might be positively correlated with general household income rather than access to disability pension as participants that were from private cohort indicated having a higher household income, less access to disability pension but had a higher self-reported QoL compared to those in the public cohort. These results support findings of a previous study which also reported that household income was significantly associated with higher overall life satisfaction in individuals with disability [20].

Inaccessible public space, insufficient or missing transport, medication, assistive devices and nursing care were established as problematic health indicators that made the lives of the participants harder, with the public cohort being more affected compared to the private cohort. This is consistent to previously reported findings. A study that aimed to examine differences in experienced environmental barriers

between individuals with and without disabilities in South Africa, Sudan, Malawi and Namibia found that access to natural environment, transportation and access to health care services created the biggest barriers [21]. These barriers led to limited activity and reduced community participation for individuals with disabilities. Therefore, the results of this study confirms that the former findings hold true for persons with SCI.

Conclusion

Performance of health system indicators influence living situation, and different healthcare insurances play a significant role in health system performance and self-reported quality of life among persons with SCI in South Africa. Furthermore, people who are able to overcome challenges associated with insufficient or missing health care indicators report higher self-reported QoL.

There are socio-economic policy implications evident from the findings of this study. Firstly, there is a need to remove social economic inequalities that exist among persons with disabilities in South Africa. Secondly, barriers to functioning associated with inaccessible natural and built environmental, transportation, medications, assistive devices as well as nursing care, need to be addressed in order to facilitate and encourage full involvement in society among these vulnerable population. Finally, since the ability to overcome the challenges associated with insufficient or missing health system indicators were significantly associated with better self-reported QoL, individually tailored intervention programmes designed to facilitate the adaption to disability targeting persons with SCI accessing the public health care is recommended.

Study Limitation

Although this study demonstrates the existence of significant differences between public and private cohorts in terms of health system indicators and self-reported QoL, a considerable discrepancy in group sample sizes occurred. Thus, the capacity of the study to determine the relationship between health system indicators and quality of life while moderating for the effect of access to healthcare insurance was limited. The comparison of the results based on the private and public cohort should therefore be interpreted with discretion. Furthermore, the absence of a national population-based registry for SCI in South Africa directly challenges the generalisability of the study findings.

Abbreviations

SCI: spinal cord injury; **QoL**: Quality of life; **HRQoL**: Health related quality of life; **WHO**: World Health Organization; **SPSS**: The statistical package for social sciences.

Declarations

Ethics approval and consent to participate: The ethics committee of the University of the Western Cape approved this study (**BM/16/3/24**). The written consent to participate was obtained from the respondents who participated in the study.

Data Archiving: The dataset generated and analysed during the current study is available from the corresponding author on reasonable request.

Consent for publication: Not applicable

Competing interests: The authors declare no competing interests

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Authors' contribution:

EN: Involved in conceptualization of the study, processing and analysis of data, drafted the first version on the manuscript, submitted the paper and acted as a corresponding author.

AR: Involved in conceptualisation and revision of the paper.

JM: Involved in conceptualisation and design as well as revision of the paper.

FT: Involved in fund procurement, conceptualisation and design, as well as revision of the paper for submission

CJ: Procured funds for the study; conceptualised and designed the study; drafted sections of the manuscript and revised subsequent drafts. All authors reviewed the manuscript.

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Tables

Due to technical limitations, table 1,2,3,4 is only available as a download in the Supplemental Files section.

Figures

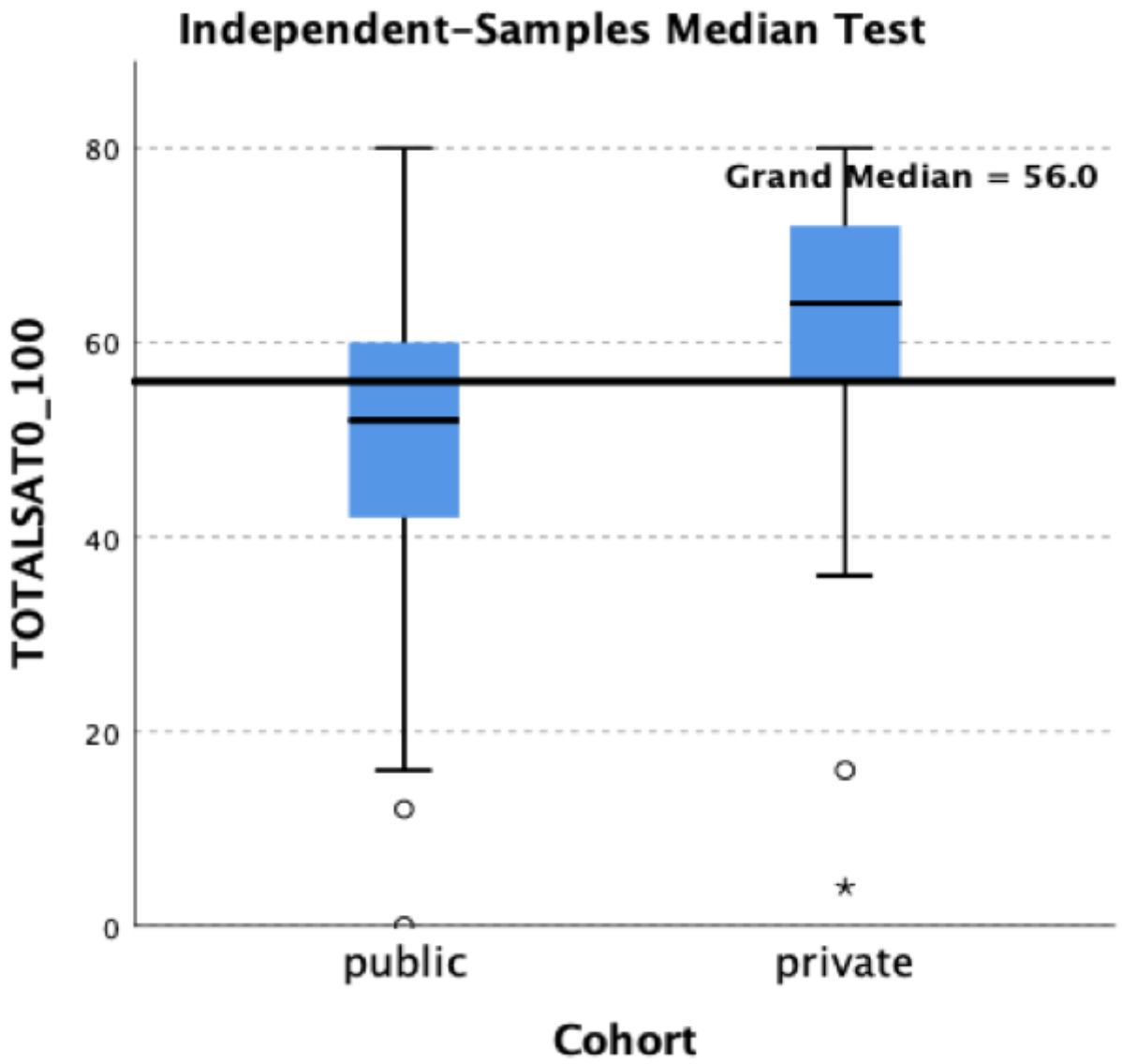

Figure 1

The overall satisfaction (0-100 scare)

Supplementary Files

This is a list of supplementary files associated with this preprint. Click to download.

- Table1.jpg
- Table2.jpg
- Table3.jpg
- Table4.jpg