Wheelchair User's Voice: Evaluation of Appropriate Wheelchair Provision in El Salvador

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ABSTRACT

There is a significant global unmet need for appropriate wheelchairs worldwide. Studies suggest that only 17% and 37% of WC users have access to appropriate WCs and assistive technology devices. [1] For people who have a mobility impairment, access to a WC is an important step towards independence and participation. The purpose of this study was to investigate the impact of the World Health Organization's guidelines for manual provision in less-resourced settings (WHO 8-steps) [2], on the socioeconomic status, quality of life, health, wheelchair skills, and caregiver burden of wheelchair users in El Salvador. Wheelchair provision according to the WHO 8-steps has the potential to improve outcomes for wheelchair users including increased quality of life, decreased poverty likelihood, and increased health-related to wheelchair use. More research on the benefits of providing wheelchairs following the WHO 8-Steps approach is needed. This research-based evidence is necessary to drive policy and wheelchair provision programs in LMICs toward more effective interventions that maximize benefits for wheelchair users.

INTRODUCTION

There is a significant global unmet need for appropriate wheelchairs worldwide. Studies suggest that only 17% and 37% of WC users have access to appropriate WCs and assistive technology devices. [1] For people who have a mobility impairment, access to a WC is an important step towards independence and participation. The purpose of this study was to investigate the impact of the World Health Organization's guidelines for manual provision in less-resourced settings (WHO 8-steps) [2], on the socioeconomic status, quality of life, health, wheelchair skills, and caregiver burden of wheelchair users in El Salvador.

METHODS

Design

This study used a within-subject longitudinal design to compare outcomes before and after wheelchair provision following the WHO's 8-steps. Data was compared at various points in time: at baseline, wheelchair delivery, and 3- and 6-months after wheelchair delivery.

A consecutive sampling method was used for ethical considerations to select participants from the waiting lists of the partner wheelchair service provider organizations in El Salvador.

Outcome measures tools were administered through personal interviews. Additionally, wheelchair maintenance reminders were sent twice a week through text messages to a sub-cohort of randomly selected participants to assess the utility of information technology to promote care and proper functioning of the wheelchair.

Participants

The study recruited two types of participants:

1. Wheelchair users, defined as a person with a mobility limitation requiring a wheelchair as a primary means of personal mobility and waiting to receive one[1], 18-years or older, with the cognitive and verbal ability required to respond to the study questions or a proxy who could respond on his or her behalf, and desire to participate in the study. Only wheelchair users who did not require additional postural support to sit upright were included. All wheelchair users involved in the study provided informed consent.

2. Caregivers of wheelchair users, defined as those assisting the wheelchair users recruited for this study with activities of daily living. Caregivers involved in the study were required to be 18-years or older and the primary caregiver. All caregivers involved agreed to participate in the study and provided informed consent.

[1] The study included wheelchair users that previously owned a wheelchair and those that did not own a wheelchair at the study baseline.

Procedures

All wheelchair users were provided with a wheelchair and wheelchair services in line with WHO's 8-steps by a wheelchair provider previously trained in the basic and intermediate levels of the WHO's Wheelchair Service Training Package. Participation in the study was voluntary and wheelchairs were provisioned regardless of participation.

Wheelchair users or proxies were interviewed at the study baseline (2 months before wheelchair provision), at wheelchair delivery, and at 3- and 6-month follow-up visits. Data was collected using the following tools previously translated into Spanish: Poverty Probability Index (PPI), WHO-Quality of Life Short version (WHOQOL-BREF), the MIT-Health Status Questionnaire, Wheelchair Skills Test Questionnaire (WST-Q), and Breakdowns and Adverse Consequences Questionnaire (BAC-Q). Caregivers were interviewed using the Zarit Burden Interview (ZBI) tool to measure caregiver burden at the same time points.

Responses to study questions were entered into electronic devices using the KoboToolbox application, which did not require the availability of an internet connection at the time of the interviews.

The study was revised and approved by the National Ethics Committee for Health Research in El Salvador and the Institutional Review Board of the University of Pittsburgh.

Analysis

All data was analyzed using descriptive statistics and graphics. For continuous variables, mean and standard deviation (mean ± SD) is reported. For categorical variables, frequency and percentages are reported.

To detect significant changes within subjects over time, detailed graphical explorations were conducted for each result for the total sample and, after checking for test assumptions, paired t-tests or repeated-measures ANOVA were carried out. In cases where non-parametric data were analyzed, Wilcoxon signed-rank test and Friedman's ANOVA were used. The significance level was set at $p<.05$ with Bonferroni corrections for subsequent post-hoc comparisons.

RESULTS

Table 1. Demographics

	All participants (N=247)
Age, in years (mean ± standard deviation)	54.9 ± 19.7
Live with a spouse or significant other (%, n)	
No	55%, n=137
Yes	45%, n=110
Education level (%, n)	
None	18%, n=45
Primary school (first to third grade)	15%, n=36
Primary school (fourth to sixth grade)	14%, n=35
Primary school (seventh to ninth grade)	18%, n=45
High school (incomplete)	2%, n=5
High school (complete)	18%, n=44
Technical education (incomplete)	0%, n=1
Technical education (complete)	3%, n=7
College (incomplete)	4%, n=10
College (complete)	7%, n=17
Postgraduate education	1%, n=2
Employment status (%, n)	
Unemployed	57%, n=140
Student	3%, n=7
Homemaker/full-time parent	14%, n=34
Self-employed part-time	7%, n=18
Self-employed full-time	6%, n=16
Employed part-time	1%, n=3
Employed full-time	12%, n=29
Medical condition (%, n)	
Spinal cord injury	31%, n=76
Amputation	26%, n=64

Aging / Weakness	7%, n=17
Rheumatoid arthritis	5%, n=13
Stroke	5%, n=12
Spina Bifida	5%, n=12
Injury	5%, n=12
Consequences of Polio	4%, n=11
Brain injury	4%, n=9
Cerebral Palsy	4%, n=9
Other conditions	12%, n=12

Demographics

A total of 247 wheelchair users were included in the study; 38% (n=93) were female and 62% (n=154) were male. The average age was 54.9 ± 19.7 years for all wheelchair user participants, 62.7 ± 19.7 years for female wheelchair user participants, and 50.1 ± 18.1 years for male wheelchair user participants. 67% (n=175) of participants previously owned a wheelchair at study baseline. A summary of other demographic details can be found in Table 1.

Socioeconomic and health indicators

On average, the likelihood of the wheelchair user households of living below the National and the USAID "Extreme" poverty lines was significantly reduced from baseline to 6-months after receiving a wheelchair, $t(161)=2.90$, $p=.004$ and $t(161)=2.55$, $p=.012$.

Overall rates of quality of life and satisfaction with health significantly increased from baseline to 6-months, $z=-4.41$, $p=.000$ and $z=-3.43$, $p=.001$. The physical health and environment domains of the WHO Quality of Life assessment at 6-month follow up had significant increases over baseline measurements, $t(163)=-4.66$, $p=.000$ and $t(163)=-4.51$, $p=.000$.

Health-related to wheelchair use as defined by the presence of pressure sores, falls during wheelchair transfer and riding, injuries in upper extremities and hands, and back pain significantly changed over time; $X^2(3)=9.74$, $p=.021$; $X^2(3)=42.02$, $p=.000$; $X^2(3)=28.58$, $p=.000$; $X^2(3)=9.14$, $p=.027$; $X^2(3)=14.81$, $p=.002$; and $X^2(3)=46.01$, $p=.000$; respectively. Pressure ulcers were significantly reduced from baseline to delivery, $z=-3.53$, $p=.000$. Falls during wheelchair transfers were significantly lower at delivery, and 3- and 6-months in comparison with baseline; $z=-4.42$, $p=.000$; $z=-5.73$, $p=.000$; and $z=-4.96$, $p=.000$; respectively. Falls during wheelchair riding were significantly lower at delivery, and 3- and 6-months in comparison with baseline; $z=-4.13$, $p=.000$; $z=-4.13$, $p=.000$; and $z=-3.65$, $p=.000$; respectively. Injuries and pain in the upper extremities were significantly lower at 3- and 6-months in comparison with baseline, $z=-2.90$, $p=.004$ and $z=-2.89$, $p=.004$. Injuries and pain in the hands were significantly lower at 6-months in comparison with baseline, $z=-4.02$, p=.000. Back pain was significantly lower at delivery, and 3- and 6-months in comparison with baseline; $z=-4.06$, $p=.000$; $z=-6.48$, $p=.000$; and $z=-5.68$, $p=.000$; respectively; and significantly lower at 3- and 6-months in comparison with delivery, $z=-4.62$, $p=.000$ and $z=-4.22$, $p=.000$. See Table 2 for more details on socioeconomic and health indicators.

Table 2. Socioeconomic and health indicators

	Baseline	Delivery	3-Months follow-up	6-Months follow-up
Poverty Probability Index (PPI)[1]				
National poverty line (mean ± SD)*	25.6 ± 19.6	-	-	21.8 ± 18.4
USAID "Extreme" poverty line (mean ± SD)*	9.0 ± 10.3	-	-	7.1 ± 10.5
Quality of Life (WHOQOL-BREF)[1]				
Overall quality of life (mean ± SD)*	2.7 ± 1.2	-	-	3.3 ±1.3
Satisfaction with health (mean ± SD)*	2.7 ± 1.2	-	-	3.2 ± 1.0
Physical Domain (mean ± SD)*	11.9 ± 3.2	-	-	13.3 ± 3.2
Psychological Domain (mean ± SD)	13.1 ± 3.7	-	-	13.3 ± 4.5
Social Relationships Domain (mean ± SD)	15.0 ± 3.7	-	-	14.4 ± 4.8
Environment Domain (mean ± SD)*	11.9 ± 2.5	-	-	13.0 ± 2.6
Health status (MIT-Health Questionnaire)				
Pressure sores [1,2,*]	12%, n=30	5%, n=8	6%, n=13	5%, n=8
Falls during wheelchair transfer[2, 3, *]	32%, n=56	15%, n=24	6%, n=11	7%, n=12
Falls during wheelchair riding[2, 3, *]	21%, n=36	7%, n=11	7%, n=14	6%, n=10
Upper extremity injury or pain[2, 3, *]	24%, n=42	15%, n=24	12%, n=24	10%, n=16
Hand injury or pain[2, 3, *]	23%, n=40	12%, n=19	11%, n=22	5%, n=8
Back pain[2, 3, *]	58%, n=101	38%, n=63	19%, n=38	19%, n=32

[1] Includes all wheelchair users in the study. [2] In the 3 months previous to the interview. [3] Includes participants who had a wheelchair at baseline.* Significant differences found. SD= standard deviation

Wheelchair skills, wheelchair breakdowns, and adverse consequences

Wheelchair users who had a wheelchair at baseline had a significant change in their capacity to use their wheelchair, $X^2(2)=28.98$, $p=.000$. There was a significant increase in the total capacity score from baseline (44.01

± 27.01) to 3-months (51.19 ± 26.15, z=-5.08, p=.000), and 6-months (48.70 ± 26.47, z=-2.65, p=.008), but a reduction in capacity from 3-months to 6-months (z=-3.38, p=.001).

The number of wheelchair breakdowns that required repairs was significantly different over time $X^2(3)$=51.99, p=.000. At 3- and 6-months the number of breakdowns was significantly lower in comparison to baseline and delivery; z=-6.87, p=.000 and z=-4.15, p=.000; and z=-6.30, p=.000 and z=-3.46, p=.001; respectively. Receiving wheelchair maintenance reminders did not significantly influence the number of wheelchair breakdowns at 3- and 6-months, U=4566.50, z=-.041, p=.967 and U=3075.00, z=-1.35, p=.176.

Caregiver burden

Caregivers of users who received wheelchairs in line with WHO's 8-steps did not have a significant reduction in caregiver burden at 3-months (25.36 ± 15.66) and 6-months (25.54 ±14.63) compared to baseline measurements (29.63 ±13.91), $F(2,54)$=2.32, p=.108.

DISCUSSION

All wheelchair users participating in the study, including those without a wheelchair at baseline, were included in the assessment of poverty probability, quality of life, and satisfaction with health at baseline and 6-months. Due to the study design, which lacked a control group, improved outcomes may not be attributed directly to the WHO 8-steps provision process itself but may be related to the effects of increased personal mobility through access to a mobility device. Indicator analysis by wheelchair ownership at baseline found no significant difference in poverty likelihood at baseline and 6-months. However, higher baseline ratings of quality of life and satisfaction with health were seen in those who did have a wheelchair at baseline. Satisfaction with health ratings, remained significantly higher at 6-months for those previously owning a wheelchair, whereas the quality of life ratings showed no significant difference between these two groups at this time point.

The overall effects of wheelchair services may be observed from the start. Improvements in health factors related to wheelchair use were observed from baseline to delivery. This was likely because service providers began giving advice preventing health complications (such as pressure relieving, and transfer techniques, and proper posture) at assessment when first identifying a user at risk, thereby reducing their risk of developing health complications. Other phenomena may have influenced health-related results, such as knowing they were being followed up regarding the health complications or over-reporting them in the first interview to emphasize the need for a wheelchair. Subsequent analysis will be performed to assess factors that may have influenced these results.

Improvement in the wheelchair skills capacity score from baseline to 3- and 6-month follow-up were as expected as users received basic training on how to use their wheelchair as part of the services received. However, the improvements did not have a long-term effect as a significant reduction in capacity was found from 3 to 6-months presumably due to insufficient dose of training to ensure skill transfer, lack of practice, among other reasons that will be discussed further in another publication.

Reduction in the number of wheelchair breakdowns that required repair was also as expected as the wheelchairs provided during the study were new and more reliable. All wheelchairs provided in the study were ISO 7176-8 certified, which ensures the wheelchairs are high quality and more durable for less-resourced settings where the conditions of the environment tend to be rougher.

Even though a reduction in caregiver burden was observed, it was not significant, suggesting that providing a wheelchair may help with the mobility of the person being cared for but not necessarily reduce the level of assistance needed in all aspects of care.

The findings of this study indicate that people with mobility limitations in low- and middle-income countries (LMICs) are likely to benefit from the provision of a wheelchair and the associated wheelchair services. However, the benefits of appropriate wheelchair provision in line with the WHO's 8-steps are yet to be proven. More randomized controlled studies and systematic reviews evaluating the impact of wheelchair provision interventions, and more specifically the WHO 8-steps approach, are needed to make the case for wheelchairs to be provided following standardized processes [3].

It is recommended that governments, private-entities, and not-for-profits develop and operationalize standards related to manual wheelchair provision, to control for quality of wheelchair provision and rehabilitation interventions.

CONCLUSIONS

Wheelchair provision according to the WHO 8-steps has the potential to improve outcomes for wheelchair users including increased quality of life, decreased poverty likelihood, and increased health-related to wheelchair use. More research on the benefits of providing wheelchairs following the WHO 8-Steps approach is needed. This research-based evidence is necessary to drive policy and wheelchair provision programs in LMICs toward more effective interventions that maximize benefits for wheelchair users.

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