

# Quantitative Exploratory Evaluation of the Frequency, Causes and Consequences of Rehabilitation Wheelchair Breakdowns Delivered at a Paediatric Clinic in Mexico

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## ABSTRACT

**Purpose:** *The United Nations Convention on the Rights of Persons with Disabilities recognises assistive technology such as wheelchairs (WCs) as a tool for social inclusion for this population. In less resourced settings, organisations lack information about effective models of WC service provision. The goal of this study was to investigate the lifespan of WCs and whether they provided reliable mobility, at one clinic in Mexico.*

**Methods:** *Caregivers of children, who had requested replacements for their WCs from a clinic in Mexico, were interviewed in Spanish. Among others, the questions pertained to repairs/modifications, adverse events and WC usage characteristics. The owners exchanged their WCs for new ones at the clinic, and the maintenance status of each returned WC was evaluated using the WC Assessment Checklist (WAC).*

**Results:** *Twenty-three donated WCs, used by children aged 3 to 14 years for an average of 19 months, were evaluated. Brakes (n=18), seat and back-sling upholstery (n=11 and 7 respectively), and armrests (n=14) were the components that failed most frequently. A total of 26 adverse events due to WC failure were reported. Adverse events were significantly associated with poor WAC scores (rs=-0.544, p=0.007).*

**Conclusions:** *Poor WC reliability, associated with adverse events which could undermine social engagement, indicates the need for a stronger WC and for regular maintenance. For instance, brake failures which were most often*

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*associated with adjustment issues, could have been resolved with maintenance, while seat and back-sling upholstery and armrest failures suggest that the WC may not be appropriate for the environment. Future work should investigate the robustness of these WCs using standardised methods (ISO 7176), as well as the impact of maintenance interventions on WC reliability.*

**Keywords:** *People with disabilities, mobility, less resourced settings, donated wheelchairs, wheelchair maintenance*

## INTRODUCTION

The World Health Organisation defines assistive technology as any device designed to improve functioning and to increase participation of people with disabilities (WHO, 2002). Studies in developed countries have demonstrated that access to this technology increases access to education (Beijen et al, 2007), employment (Langton and Ramseur, 2001), and maintains health (Johnson et al, 2007); therefore, it can contribute to enhanced capabilities and may reduce poverty among people with disabilities and their families (Saleeby, 2006; Borg et al, 2008; Borg et al, 2009). Furthermore, it has been demonstrated that capability deprivation and unrealised functioning are less likely to occur if appropriate assistive technologies are available (Borg et al, 2011b). For instance, an appropriate, well-designed and well-fitted wheelchair (WC) can be the first step towards inclusion, participation, and better opportunities in society for individuals with disabilities who need one as the primary means of mobility (May-Teerink, 1999; Borg et al, 2008; Shore, 2008). It can also reduce secondary medical complications such as upper limb pain and pressure sores (Boninger and Stripling, 2007; Borg et al, 2008). In contrast, users have reported that poorly-fitted WCs have resulted in injury and abandonment of the WC (Batavia et al, 2001; Mukherjee and Samanta, 2005). In spite of this evidence and the efforts of the stakeholders at the international and local levels, there is limited access to appropriate assistive technology devices (e.g. wheelchairs) and services in developing countries (Tan and Ang, 2008; WHO and USAID, 2011). In fact, the WHO has estimated that only 5% -15% of the world's population with disabilities have access to the assistive technologies they require (Kim and Mulholland, 1999; Borg et al, 2008; WHO, 2010). This is especially true for women and children (Francois et al, 1998). Since the wheelchair is one of the most commonly used assistive devices – needed by about 1% of the world's population -- it is possibly the most important technology to promote and support public health for people with disabilities around the world (Borg et al, 2008).

The Convention on the Rights of Persons with Disabilities (CRPD) specifically mentions the importance of assistive technologies in eight of its Articles (4, 9, 20, 21, 24, 26, 29, and 32) (UN, 2006). Under the Convention, people with disabilities have the right to demand appropriate and affordable assistive technology in order to have full participation in society and equal enjoyment of human rights (Borg et al, 2009). This technology should meet users' needs and be appropriate to the environment, safe, durable, and able to be maintained locally (Borg et al, 2008). States who ratified the CRPD have the obligation "to take effective measures to ensure personal mobility with the greatest possible independence for persons with disabilities" (UN, 2006). Guidelines for the delivery of assistive technology in the best possible way exist (Borg et al, 2008; Arledge et al, 2011); the current challenge is to make these assistive devices and services available to the people with disabilities in developing countries, in an accessible and affordable manner (Borg et al, 2009; Tomlinson et al, 2009; Borg et al, 2011a). The CRPD explicitly mentions the need for international technical and economical collaboration between developing and developed countries, to improve the availability of assistive technology devices and services in developing countries (Borg et al, 2009). In addition, there is a call to the scientific community to provide evidence that can guide governments and organisations in the development and implementation of effective policies and programmes to provide appropriate assistive technology (Kim and Mulholland, 1999; Borg et al, 2009; Borg et al, 2011a). Despite the emphasis on appropriate assistive technologies in the CRPD and the World Report on Disability, there is a paucity of objective evidence of how best to provide a WC.

Different mechanisms have been used in less resourced settings to cater to the need for WCs; the most often described are small-scale workshops and distribution of donated WCs (charitable model) (Pearlman et al, 2006). In the first method, individuals are trained and small workshops are set up in the country in need (Pearlman et al., 2006). In the charitable model, international organisations or foundations collect funds around the world to buy WCs that are then widely distributed in less resourced settings (Pearlman et al, 2006). Usually, the WCs are distributed with little professional, clinical or technical inputs and the majority of the products are "one size fits all" (Kim and Mulholland, 1999; WHO, 2011). Other mechanisms such as the manufacturing, globalisation and multi-modal models have been proposed but have not yet been studied in depth (Pearlman et al, 2006).

Regardless of the delivery mechanism that is employed, daily use and exposure to weather conditions and rough terrain often results in WC failures (Kim and Mulholland, 1999; Cooper et al, 2004; Fitzgerald et al, 2005). When the WC is in disrepair or requires frequent repairs, the individual's function can be reduced; without any form of mobility the individual may be injured or left out (Gaal et al, 1997; Borg et al, 2008; McClure et al, 2009). Additionally, when the WC performs poorly, user satisfaction is significantly reduced and it is more likely to be abandoned (Phillips and Zhao, 1993). This is especially true in developing countries where access to WCs is generally limited to imported ones, replacement parts are almost impossible or too costly to find, and users often do not have a back-up WC, thereby reducing their mobility and community participation for an undetermined period of time (Hotchkiss, 1987). In developed countries several studies have investigated, in both manual (light or ultra light-weight) and power WCs, the prevalence of WC failures, repairs and related adverse events such as injuries and participation reduction (Gaal et al, 1997; Fitzgerald et al, 2005; McClure et al, 2009; Chen et al, 2011; Worobey et al, 2012). Self-reported WC repairs over a 6-month period ranged from 26% to 53% of the participants in several studies (Fitzgerald et al, 2005; McClure et al, 2009; Worobey et al, 2012). Component failure was reported as a cause of adverse events (i.e. injury) by 33% (n=109) of participants in one study (Gaal et al, 1997). Adverse consequences due to WC breakdown, such as being stranded at home, were reported by 20% -31% of participants who reported at least one repair (McClure et al, 2009; Worobey et al, 2012). Neither of these studies found correlation between WC age and the number of repairs (Fitzgerald et al, 2005; McClure et al, 2009). It is difficult to generalise these results to developing countries because there are limited reports on outcomes of assistive technology in these settings (Borg et al, 2011b) and the availability and quality of WCs are limited, and environmental conditions are different (Kim and Mulholland, 1999; Pearlman et al, 2006).

## **Aims**

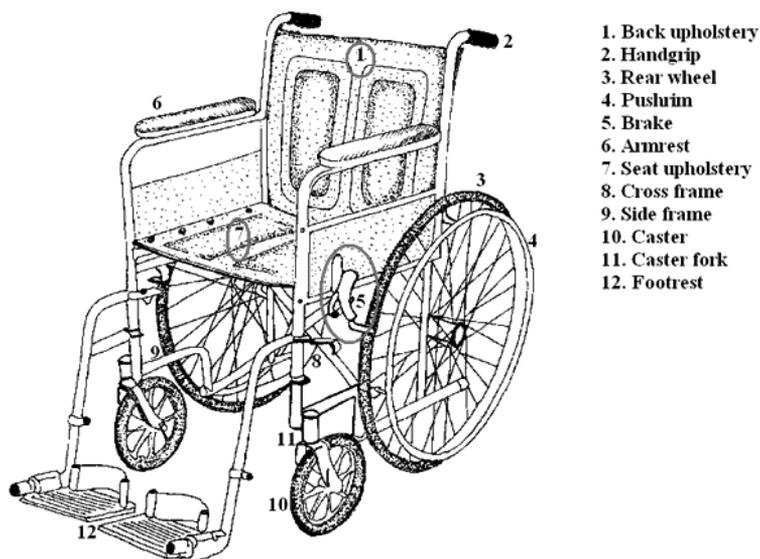
This study investigated the performance of WC delivery via the charitable model, by evaluating whether these devices served their purpose among those who received them from the rehabilitation facility in Mexico. The goal was to provide insights into the factors which contributed to the breakdowns and the adverse events which may have resulted, and to provide guidance on how to reduce breakdowns.

## METHODS

A convenience sample of WC users was recruited at a paediatric rehabilitation facility in central Mexico. The caregivers had reported to the social workers that there were problems with the WCs – either breakdowns or the user had outgrown the WC. New WCs were offered in exchange for the old ones, as part of the standard care at the clinic. At the time of the exchange, caregivers were asked if they would like to participate in a face-to-face interview regarding their experiences with the old WC. Verbal informed consent was obtained from all the participants. The study was approved by two university institutional review boards in the US (University of Pittsburgh and Carnegie Mellon University) and by an ethics panel on-site in Mexico.

Thereafter, participants were asked questions pertaining to: the number of months the old WC was used; average daily hours of usage; description of repairs or modifications (if any); and number of repairs made over the past six months (none, one to two, three to five, more than five, unsure). They were asked to mark the current WC components in disrepair on a WC line drawing that was provided to the caregiver. The variable **number of self-reported failures** was created by adding for each WC the number of components self-reported in disrepair. Figure 1 presents a sample illustration of one of the WCs evaluated,

**Figure 1: Example of WC line drawing with damaged back and seat upholstery and brake circled by a participant**



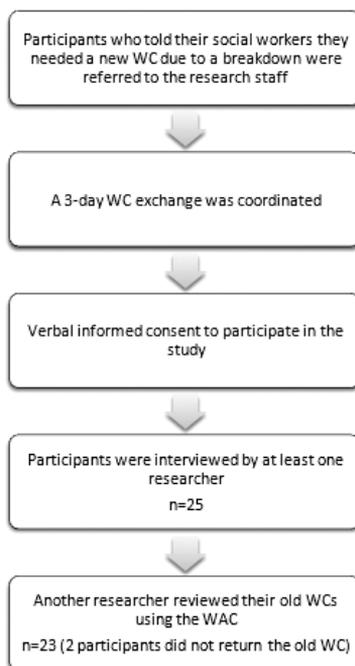
with the components in disrepair marked on the basis of the caregiver's response. In addition, questions were asked about the frequency of WC use over dirt roads or paths, and over rough or bumpy terrain (never, rarely, often, always, unsure) and how many times on an average the child in the WC went over a steep kerb. With an adapted version of the questionnaire used by McClure et al (2009), participants were asked about adverse events as a consequence of WC failure. They were given 5 choices of possible consequences: (1) no consequences, (2) been stranded (either at home or away from home), (3) been injured, (4) missed school, or (5) missed a medical appointment. Participants were instructed to select all the choices that applied. The variable **number of adverse events** was created by adding the number of reported consequences for each participant. All questionnaires and materials were translated into Spanish, and all in-person interviews were conducted in the same language.

In addition, a translated version of the WC Assessment Checklist (WAC) was utilised, to systematically evaluate each received WC in a consistent and objective manner. The WAC is a screening procedure that consists of a checklist and scoring system for categorising WCs, based on their physical and working conditions; it helps to identify and classify problems related to component failure (Kamarkar, 2009). The checklist is divided into six domains that correspond to the WC frame or component: WC frame and attachments, wheels and castors, postural seating and support, propulsion interface, wheel locks, and user WC interface. Each component is scored from 1 to 3 (3 - poor condition, 2- fair condition, 1- perfect condition, or not applicable) and then a total score was calculated as described in Kamarkar (2009). The WAC was expanded to make it more appropriate for use on the rehabilitation facility WC. For instance, an item was added to evaluate the condition of the guide that is located on the seat and attaches to the backrest post. This component is not commonly found in the WC delivered in the US. Figure 2 gives a flow chart of the processes of the study.

## Data Analysis

The statistical software package SPSS was used to analyse the data (SPSS Inc. Chicago, IL, USA). First, Spearman-rho correlation was run to evaluate if there was a significant correlation between number of self-reported failures and the frequency of WC use on rough or bumpy terrain and dirt roads or paths. Next, a Spearman-rho test was used to evaluate if there was a significant correlation between the number of self-reported failures and the number of steep kerbs the

**Figure 2: Study process flow chart including recruitment, consent, interviews and WC evaluation**



WC travelled over daily; the number of hours the WC was used per day; and the length of time (in months) the WC was used. Spearman-rho was also used to evaluate if there was a significant relationship between the WAC score and the number of adverse events and number of repairs reported in the previous six months. Descriptive statistics were calculated to assess the number of repairs needed over that six month period, and to identify the consequences of WC breakdowns.

## RESULTS

The children who used the WCs were on an average  $8.5 \pm 3.9$  years old, ranging from 3 to 14 years. Twenty-three hospital-style WCs were received during the WC donation/exchange event. The WCs were used for  $19.8 \pm 15.7$  months, ranging from 8 to 72 months. The average usage was  $4.1 \pm 4.9$  hours per day, ranging from 1 to 15 hours. While the majority ( $n=15$ ) of caregivers reported that they made modifications or repairs to the WC during the time it was used, the remaining 8 did not report any modification or repair. Of the total exchanged WCs, 6 had

modifications and repairs, 4 had only repairs, and 5 had only modifications. The majority of the modifications made by users (n=10) were focused on positioning, which included adding a cushion and a seat-belt. Another modification was the addition of a tray to allow the child to eat and study while seated on the WC. Previous repairs made to WCs were identified. Table 1 contains the information of self-reported number of repairs performed over the past six months. The majority of the repairs were on the brakes (n=5), seat and back upholstery (n=2), followed by front castors, armrest, footrest, and replacing missing screws (n=1). Figure 3 shows a foot- rest swing-away mechanism that was broken and then welded

**Table 1: Self-reported number of WC repairs performed in the previous 6 months**

# of WC repairs	# of caregivers	%
1-2 times	5	22%
3-5 times	2	9%
More than 5	1	4%
Not sure	1	4%
None	14	61%
Any number of times	8	35%

**Figure 3: Example of a footrest swing away mechanism repaired by welding the footrest to the WC frame**



to the frame during repair. Although welding may keep the footrest in place, it could be an obstacle when transferring the child out of the WC and during storage or transportation. The repaired portion was also unpainted and sharp, and could thus be dangerous to the child. Another example shown in Figure 4 is a dangerous protruding weld on the push rim. Nearly one half of all breakdowns - 48% (11/23) - led to an adverse event. Table 2 contains the frequency counts of the type of adverse events that resulted due to a WC breakdown.

**Figure 4: Example of a protruding welded point in a push rim**



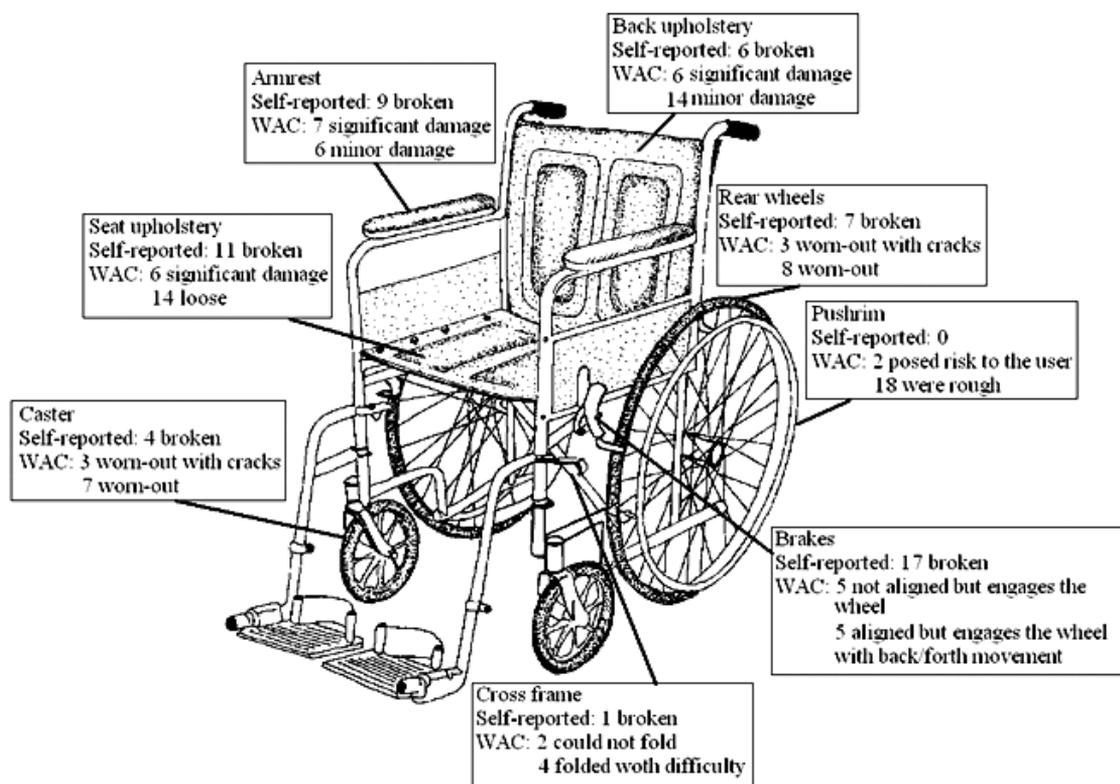
**Table 2: Number and type of adverse events due to a WC breakdown, self-reported by caregivers**

Adverse event	# of self-reported events
Stranded (at home or away)	6
Injured	8
Missed school	4
Missed medical appointments	3
Other (total)	5
A broken brake made the child afraid to use her WC	1
The child fell when trying to unfold the chair.	1
The WC got wet from the rain and took long to dry, and the child stood without a chair.	1
Had difficulty moving	1
The child slipped out of the chair due to lack of a belt to hold the legs and hips.	1

Of the 23 WCs evaluated, nearly all of them, 87% (n=20), were damaged. The components that were self-reported by the caregivers as being broken, in contrast to the ones identified by the researchers through the WAC, are shown in Figure 5. For instance, through the WAC analysis it was possible to identify 18 WCs with rough push rims that were unlikely to cause acute injury to the users, and 2 WCs with rough push rims that posed the risk of injury such as cuts to the hand (Figure 4). In contrast, caregivers did not report issues with push rims.

Table 3 contains the results from the correlation analysis between the number of self-reported failures and terrain and frequency of WC use. For the WAC, Spearman-rho tests found a significant negative relationship between the WAC score and the number of adverse events ( $r_s = -0.544$ ,  $p = 0.007$ ). The results also showed a negative trend between the WAC score and the frequency of WC repairs over the previous 6 months ( $r_s = -0.389$ ,  $p = 0.074$ ).

**Figure 5: WC components failure reported by the caregiver and identified through the WAC**



**Table 3: Spearman correlation results between self-reported failure and usage variables**

Correlation	# of self-reported failure
Use bumpy or rough terrain	rs=0.052, p=0.409
Dirt roads	rs =0.292, p=0.176
Steep kerb	rs =0.079, p=0.0721
Use per day (hours)	rs =0.296, p=0.170
WC use months	rs =0.085, p=0.700

## DISCUSSION

Most of the WCs evaluated in this trial were the hospital-type, which are most commonly distributed in developing countries through the charitable model of delivery (Pearlman et al, 2006; Pearlman et al, 2008). This type of WC is designed for temporary indoor use only (Kim and Mulholland, 1999), is not adjustable (Howitt, 2006), and not designed to provide postural support (Borg et al, 2008). Usually the components of hospital-style WCs are not designed to be replaced; therefore, they are difficult to repair (Howitt, 2006). It is very likely that the spare or replacement parts are not available or are too costly to obtain (Kim and Mulholland, 1999; Howitt, 2006). As seen from the results of this study, the WCs fail quickly (between 8 -72 months), whereas current WC provision guidelines indicate that their average life expectancy should be 5 years (Sheldon and Jacobs, 2006). High rates of brake and seat sling and/or back support failures were found. These failures are of particular concern because they represent a threat to the users' safety and well-being. The sling seat and back in this type of WC are designed for short-term use because they are made of stretchable material that encourages pathologic postures. For instance, over a period of time upholstery problems can lead to deterioration in posture which will give rise to back and neck pain, as well as spinal and pelvic deformities (Cooper, 1998; Ham et al, 1998). Even worse, users get used to these pathologic body positions and their bodies could permanently become deformed. The need for WCs with good postural support systems is also a concern (Borg et al, 2008). Appropriate postural support for those who need it represents the difference between independence and dependence, as well as the risk of serious injury that can even lead to death (Howitt, 2006; Borg et al, 2008).

Some of the repairs that were identified, such as the welded push rim and the welded footrest, suggest the possibility that bicycle repair shops, or other places

that do not specialise in WC repairs, make repairs without understanding the human-WC interaction. This could pose unintended safety threats to WC users. This finding suggests that WCs should be sturdy and easily repaired (Howitt, 2006) and also that there is a need for local repair centres that have the capacity to understand the user needs and the device. The repair centre should be able to make adequate repairs and have spare or replacement parts available (Sheldon and Jacobs, 2006). However, these repair centres might not benefit all of the users. Results revealed that 15 out of 23 caregivers reported having made repairs or modifications to the WCs on their own.

Additionally, a WC 'check-up' approach which has been used successfully by others to reduce adverse events (Hansen et al, 2004), may be helpful. The study results show that the WAC could be used as a tool to systematically assess and alert the clinical or technical staff when a WC requires major repairs, since WC users might be unable to determine when adjustments may be needed. Maintenance is an important step in protecting the usable life of WCs, and more importantly, reducing potential threats to user safety (Gaal et al, 1997). There is evidence to show that risk of accidents is greater for those who fail to do regular maintenance of their WCs (Chen et al, 2011). The high prevalence of brake and upholstery failures suggests that frequent preventive maintenance may increase the lifespan of this type of WC. For instance, proper and frequent maintenance of the front castors and rear wheels greatly improves performance; proper adjustment of brakes helps improve safety and performance; and replacement of worn items, such as the wheels, spokes and upholstery can help avoid adverse events. It is recommended that the staff at the rehabilitation facility review preventive maintenance techniques with each family, either through informal discussions, workshops or manuals. A provisional manual should include description of weekly, monthly, and yearly maintenance. For example, it could include tips on cleaning and oiling the castors' supports, which would improve the WC's manoeuvrability for both the user and caregiver. In addition, the proper functioning of the rear wheels (alignment), castors (freely rotation), and castors' fork (perpendicular to the floor) need to be checked. The WHO's Wheelchair Service Basic Training Package, which was launched in June 2012, may help provide this training.

In this study, self-reported WC failure was compared with the results of a detailed evaluation. More than one-third of the study sample (35%) reported at least one repair in the previous 6 months, which falls in the range of earlier studies

(Fitzgerald et al, 2005 ; McClure et al, 2009 ; Worobey et al, 2012). The results are similar to those of other studies wherein no significant relationship was found between the age of WCs and the number of repairs done (Fitzgerald et al, 2005). The adverse event rate (48%) in this study is substantially higher than the figure (30%) reported in other studies (Worobey et al, 2012), indicating a higher risk associated with breakdowns in this type of WC.

## CONCLUSION

The most common component failures reported were brakes, sling upholstery and armrest – the components crucial for safety and health. Comparison of the self-reported data of failed components and the data from the WAC revealed that many of the components simply needed maintenance and were not completely broken. Therefore, one way to extend the life of these devices may be to train the users/caregivers to maintain their own devices, or to set up a repair service at the clinic. However, since seating and postural support were cited as the main reason for performing modifications to the WCs, it suggests that either the WCs were not appropriate for the users or were not properly adapted. There is a need for adequate WCs and customised seating systems and associated delivery services to meet clients' needs, so that the ultimate goal of enhancing participation is accomplished.

## Implications and Limitations

The results of the study point to the need for research that addresses a systematic perspective of WC provision in less resourced settings, including devices and their associated delivery services, that strive for cost-effective provision which includes not only mobility but seating and positioning (Borg et al, 2011a). Efforts should focus on the selection or re-design of the WCs to ensure they match both the user and the environmental requirements which often include high kerbs, potholed streets, gravel and mud (Kim and Mulholland, 1999; Pearlman et al, 2006; Pearlman et al, 2008). These environmental conditions apply considerably more strain on the device which it is less likely to withstand (Kim & Mulholland, 1999). Therefore, there is a need for improved devices that have longer durability. Usually minimum quality standards are not in place nor enforced in developing countries; thus, end users are not protected against low-quality technology (Pearlman et al, 2008). As suggested by a previous study (Pearlman et al, 2006), future work should include objective outcome measures such the

ISO/ANSI/RESNA WC Standards to test WCs durability (Borg et al, 2008). Also, usability testing should be performed by users, where folding and lifting the chair, repositioning adjustable parts, and maintenance and repair are evaluated (Pearlman et al, 2006; Borg et al, 2008). In addition, personnel involved in the provision of WCs need to be trained in all the steps of the process including user evaluation, WC recommendation and fitting, and follow-up and maintenance. The WHO's Wheelchair Service Basic Training Package is a comprehensive programme that can meet this need.

The limitations of this study include the possible underestimation of the number of repairs because of recall bias (Gaal et al, 1997; Fitzgerald et al, 2005; McClure et al, 2009; Chen et al, 2011). The results showed differences between the self-reported method and the WAC. For instance, it was found that the self-reported method overestimates the degree of damage, if the WAC is used as a gold-standard. Another limitation of this study is that the WC sample is biased, because the devices were returned as they were in disrepair. Finally, the sampling was not random and the sample size was small which threatens the generalisability of the results.

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