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Not just the right to a wheelchair but the right wheelchair – improving Brazilian wheelchair service delivery

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Abstract. This paper discusses the barriers encountered before and after the implementation of good practice in the delivery of wheelchair provision services in Belo Horizonte city, Brazil. The results demystify some participants' initial idea that using an assessment form might take significantly more time. Major barriers to implementation had regard to the assessment of pressure sores and a lack of wheelchair suppliers.

Keywords. wheelchair service delivery system, Wheelchair Service Training Package, Serviço Único de Saúde, Brazil

1. Introduction

It is estimated that approximately 10% of the world has a disability and that 10% of this section of the population requires a wheelchair (WHO, 2008). In 2003, it was estimated that 20 million of those requiring a wheelchair did not have one (Sheldon and Jacobs, 2006). It is a well-established fact that a service delivery system (SDS) is necessary to ensure the provision of an appropriate wheelchair (WHO, 2008; Andrich et al., 2013). An appropriate wheelchair meets the user's needs and their environmental conditions, provides proper fit, postural support and is safe and durable (WHO, 2008; WHO, 2012; WHO, 2013). SDSs help to ensure that an appropriate wheelchair is available in the country and it can be obtained and maintained at an affordable cost. Furthermore, this service gives the opportunity for user training and follow-up (WHO, 2008; Andrich et al., 2013).

States adopting the Convention on the Rights of Persons with Disabilities (CRPD) have the obligation "to take effective measures to ensure personal mobility with the greatest possible independence for persons with disabilities" (UN, 2006). This means ensuring access to appropriate wheelchairs, hence, an SDS is an ideal means of achieving this commitment.

In 2009, the CRPD was ratified in Brazil and soon made into law (SDH, 2010). In 2011, the government created the national plan for the rights of disabled people, Viver Sem Limites (VSL), with an investment estimated around US\$3.52bn for the first four years of the program (SNPDPD, 2013). VSL articulates policies regarding social inclusion, access to education, accessibility and health care. Various resources were made available to promote assistive technology (AT) acquisition and to the SDSs used to provide them, mainly through Brazilian national health service (Serviço Único de Saúde-SUS). As a consequence, the provision of wheelchairs has boomed in Brazil. For

example, 36,722 wheelchairs were delivered in 2011 compared to 19,890 delivered in 2008 (CNITSUS, 2013).

It should be noted, however, that all these improvements are recent and there is a lack of research and data available, apart from government publications, regarding the functioning of these services. Also, there is a lack of research and publications investigating whether user requirements and best practice within the wheelchair service delivery system (WSDS) are being considered and implemented in order to ensure the provision of an appropriate wheelchair.

This study accesses the WSDS in Belo Horizonte city, Brazil, and reviews it in light of the World Health Organization's WSDS best practice. More specifically, the study aimed to evaluate the applicability of the forms and checklists suggested in the wheelchair service training packages (WSTP) (WHO, 2012; WHO, 2013) and the guidelines on the provision of manual wheelchairs in less resourced countries (WHO, 2008). The study identifies current barriers and opportunities to its implementation in the Brazilian public health service, providing recommendations and interventions for the service. The study comprises three main stages: an exploratory stage to understand the Belo Horizonte AT SDS and identify a research focus, a preparatory stage to set the parameters for an intervention, and an evaluative stage to test and improve the interventions. This paper focuses on the barriers encountered before and after the study interventions.

2. Methodology

In the preparatory stage, a set of interventions based on WSTP forms and checklists were developed using a mix of methods including observations of the wheelchair service procedures (n=153) during a period of three months, semi-structured interviews (n=12) and application of a follow-up survey (n=11) with service stakeholders. The interventions were designed as a result of a triangulation process between:

- Evaluating the staff feedback on the WSTP Basic Level forms and checklist;
- Evaluating the staff feedback on the current barriers and opportunities;
- Considering the major gaps in the application of good practice in the service;

The intervention consisted of:

- A referral form;
- An entry level form to collect information about the user environment;
- A measurement tape to be given to the user with which to collect raw data;
- An assessment form;
- A wheelchair fitting checklist;
- A leaflet for the user about pressure sore prevention and care.

In the evaluative stage, the interventions were evaluated using observations of the wheelchair service procedures (n=95) during a period of two months and semi-structured interviews (n=28) with service stakeholders. First, the participants tested the interventions while being observed and timed (n=95), then they were interviewed

(n=19) to feedback on the interventions so as to identify the barriers to, and benefits from, applying the forms and checklist. Another round of semi-structured interviews (n=9) was conducted with service coordinators and managers in order to identify opportunities to mitigate those barriers encountered.

Service stakeholders involved in the study were occupational therapists, physiotherapists, wheelchair suppliers, service coordinators and managers. End users were only indirectly involved through the observations.

The observations conducted in the study took place at the three rehabilitation centres providing wheelchair service at Belo Horizonte SUS and had regard to the main wheelchair service procedures, made up from: user screening, user assessment and wheelchair delivery and fit. Observer as participant was the designated approach for the observations. This approach enabled the researcher to fully engage in the life and activities of the participant without taking part in them.

Data collected in the fieldwork were uploaded in the qualitative data analysis software NVivo (QSR International Pty Ltd), version 10.0. The audio data recorded from interviews were transcribed and coded using an inductive thematic analysis approach to identify key topics.

The evaluative character of this research stage had a small likelihood of psychological risk as participants could feel the quality of their work was being assessed. To reduce this risk all participants were invited to a presentation preceding their participation where the research purpose and methods were clarified. An opportunity was given to make questions about the research process and their participation. Ethical approval was gained from ethical committee departments of both Loughborough University, who supervised the work, and Belo Horizonte Municipal Health Office.

3. Results

3.1. Summary of the findings of the exploratory stage

Studies conducted at the exploratory stage had revealed that AT services in Belo Horizonte city fit the ‘medical model’ of SDS (Maximo and Clift, 2015). In this model, the prescription of an AT device is the responsibility of a qualified professional and AT eligible for public provision is usually regulated by a list of products or product specifications, with or without established prices or reimbursement thresholds (Andrich et al., 2013).

AT SDS in Belo Horizonte is conducted by means of three rehabilitation centres called CReabs (an abbreviation for *centro de reabilitação*). The service selects and provides from 95 AT items, adaptations, and substitutions described and priced in a list called OPM (an abbreviation for *órgãos, próteses e meio de locomoção auxiliar*).

It was noted that the wheelchair service varies according to the two main types of wheelchair offered: the standard and the adapted wheelchair. Standard wheelchairs are assessed, ordered and delivered by CReab staff. There are two main types of standard wheelchairs available in the OPM list. Adapted wheelchairs are assessed, fitted and delivered by CReab staff in conjunction with the wheelchair supplier staff. There are three main different types of adapted wheelchairs and eight different types of postural support device available in the OPM list. All wheelchairs are available in different sizes and have various features that can be selected as according to user needs.

3.2. Exploring service barriers and opportunities before implementation

Overall, the methods proposed to the preparatory stage were performed without major difficulties. Both participants and the wheelchair service' end users reacted well to the presence of an observer. Participants helped to introduce the observer to the user and getting their consent before each service procedure.

The first round of observations and interviews had revealed various gaps regarding the application of existing good practice, which are highlighted in this section.

There was no consensus between service staff on how to conduct the activities involved in the various service stages, such as the user screening, assessment and the wheelchair delivery. Only one CReab used an assessment protocol. However, this protocol was based only on staff experience, not in evidence-base practice or validated protocols. Additionally, no protocols are used to ensure the necessary assessments are covered when fitting the user in the wheelchair. As a consequence, the user positioning is not thoroughly checked through the service stages as recommended.

WHO recommends that same practitioner should accompany the user through the service delivery stages. At CReabs, this was not guaranteed, and it was notable that it was not encouraged.

There was no agreement about what kind of information should be passed on and who had responsibility to ensure this occurred. Many users ended up not being informed on various topics, which can lead to ignorance and bad practice.

There is no culture to evaluate the presence, risk or history of pressure sores in the wheelchair user. Physical evaluation of pressure sores by CReab staff was observed only in one case and, during the user assessment, verbal enquiry relating to pressure sores was only seen in four cases.

The wheelchair seems to be the item with the longest waiting list from AT services provided at CReabs. Suppliers have 60 days to deliver a standard wheelchair and 90 days to deliver an adapted wheelchair after the assessment, when the device is specified. However, these deadlines are often not met. Participants mentioned the whole process can take a year or more considering there are other stages before assessment. This was a frequent complaint during the user observations and some users reported they were waiting for two or three years for the wheelchair to be provided.

The main barrier to implementing validated protocols and evidence based practice was reported to be a lack of access to these resources and a lack of time to follow best practice, due the service overload. The main opportunity identified is that most CReab staff and service managers welcomed the use of protocols if external support is provided to implement them.

3.3. Exploring service barriers and opportunities after implementation

Similar to the preparatory stage, there were no major difficulties to perform the methods proposed to the evaluative stage and both participants and the wheelchair service end users reacted well to the presence of an observer.

Overall, there was a high level of acceptance from the CReab staff in evaluating the proposed interventions. Some participants working on user screening demonstrated resistance, saying they lacked time and training to use the protocols. It was observed that resistance tended to be greater from participants that, for reasons such as unavailability or data collection limitations, did not take part in the previous stages of

the research. Those involved prior to the evaluation stage reported less resistance and felt engaged in the process. One participant quote illustrates this issue well: “*When you sit and talk with us, question us and give us the opportunity to contribute you are dealing with the resistance we have, so this process facilitates and helps a lot*” (Interview with a staff member at CREAB 1, author’s translation).

Despite there being a minor increase in the average time spent on assessment when using the assessment form (See Figure 1), this increase did not reach statistical significance (at $P>0.5$) when compared to the time spent without using the form.

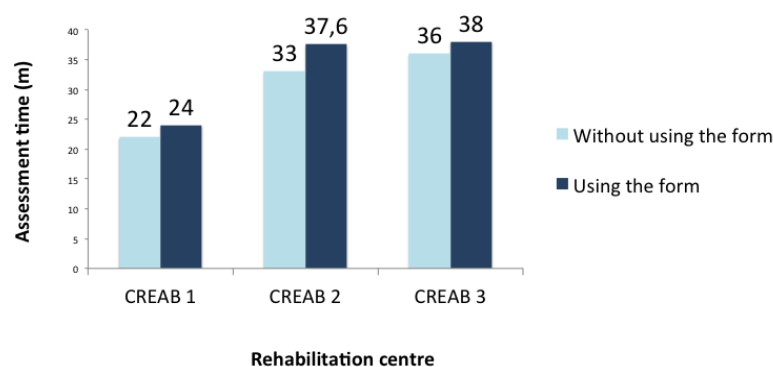


Figure 1. Average care time at assessment stage.

It was patent that participants did not assess users for the presence, risk, or history of pressure sores as recommended in the assessment form. They also did not perform the task of manually checking the level of pressure under the user’s ischial tuberosities (‘sit bones’) as suggested at the delivery stage of the fitting checklist. When participants were asked about the reasons for not performing those tasks, the main reasons given were due uncertain hygiene conditions of the users and the fact that they did not know what to do with this information if they did acquire it. Adding to this problem, the participants was either not trained or unaware of any existing criteria for the provision of cushions to relieve pressure, such cushions being one of the newest items included in the OPM list. Accordingly, no prescription of cushions to relieve pressure was observed during the study.

Despite the fact that participants did not perform the suggested task of checking the pressure under the user’s ischial tuberosities, there was no observed resistance to evaluating the proposed wheelchair fitting checklist. With regards to the ‘check posture’ section of the checklist, it was clear during observations that some participants ticked the boxes without checking the posture and others performed only a quick or vague examination.

Finding suppliers that are willing to participate the wheelchair public tender was another reported concern. During the observations, supplier’s staff often complained how difficult it was to sustain their business with SUS for reasons such as the low price paid per wheelchair and because of delays in payments.

4. Discussion

During the study, it was observed that resistance to evaluating the proposed interventions varied according to the level of the participant's engagement in the whole study. Various studies using experience-based design, or similar participatory design approaches, acknowledge the influences that participant's levels and type of user engagement at different stages have on the type of transformations proposed to the organisational setting (Bowen et al., 2013; Sanders and Stappers, 2008; Tan and Szebeko, 2009).

It is a well-established fact that long-term users of wheelchairs are likely to develop pressure sores (WHO, 2008; WHO, 2012; WHO, 2013). WHO recommends that every user should be assessed for the presence, risk or history of pressure sores (WHO, 2008; WHO, 2012; WHO, 2013). One of the recommended ways of preventing a pressure sore is by using a pressure relief cushion. These were only included in the OPM list seven months prior to the evaluation stage of the research (Brasil, 2014) and new cushions were only available to order by the end of the study. The result shows that participants still did not assess users for pressure sores and did not know what to do with information gained for this process. This shows that there is an urgent need to train staff with regards to pressure sore identification and prevention strategies. Also, there is a need to define associated criteria for the provision of pressure relief cushions.

Another major barrier encountered is the waiting time until user receives the wheelchair. Despite CReabs not making available data that would enable direct waiting time comparison, user complaints were frequent during the observations and some users mentioned they were waiting over two years to receive a wheelchair. Different studies show similar difficulties in other regions of Brazil (Galvão, 2008; Galvão, Barroso and Grutt, 2013; Caro et al., 2014). One study undertaken in a public rehabilitation centre at Rio Grande do Norte Estate (Galvão, 2008) reported between 0 to 36 months for the user to receive their wheelchair, with an average time between 13 and 18 months. A more recent study undertaken at the same rehabilitation centre (Galvão, Barroso and Grutt, 2013) reported that 43% of the wheelchairs were delivered in less than 90 days, 29% in less than 30 days, 16% delivered between 6 to 9 months and 9% between 9 to 12 months. A study by Caro et al. (2014) revealed an average waiting time of 30 months for a user to access a piece of AT at one rehabilitation centre in São Paulo Estate.

A further barrier encountered that directly affects the waiting list and the time to receive a wheelchair regards the lack of suppliers willing to participate in the public tender. As a consequence, the 2016 public tender for wheelchair provision in Belo Horizonte SUS had to be cancelled due lack of supplier participation. Suppliers often complained during the studies that the price stated on the OPM list was only updated once in seven years while inflation in Brazil had grown drastically in recent years. The consumer price index used to measure the inflation rate showed increases of 6,3% in 2014 and 10,6% in 2015 (Global Rates, 2015).

The results generated in this study demystified some participant's initial idea that completing the assessment form might take significantly more time. On the contrary, using the forms allowed objective information to be collected including information that goes beyond the medical perspective and that also considers users lifestyle, activities and environmental information. This information supports user-centered and evidence-based decision-making throughout the service stages, improving the service

effectiveness, the match between user and technology and consequently reducing wasted resources.

5. Conclusions

This paper provides insight into the evaluation of a set of interventions based on the WHO wheelchair service training packages at three rehabilitation centres in Belo Horizonte city, Brazil.

Overall, the interventions were well accepted but it was noted that resistance to their evaluation came primarily from participants that did not have the opportunity to engage in previous research stages. This confirms the influences that participant's level and type of engagement has on the transformations proposed to the organisational setting.

The results of the study have dispelled some participant's initial concerns idea that using an assessment form might take significantly more time. On the contrary, using the forms allowed the collection of objective information that goes beyond the medical perspective but that also considers the user's lifestyle, activities and environmental information.

A significant concern identified in the study was that the majority of participants did not assess users for pressure sores either before or after the interventions. This shows that there is an urgent need to raise the awareness and to train staff with regards to pressure sore identification and prevention strategies. It is also clear that there is a need to define criteria for the provision of pressure relief cushions as a pressure sore intervention strategy.

The knowledge generated in this study will help to comprehend and improve various other services provided in a similar context as well as improving the efficiency and effectiveness of wheelchair service provision.

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