Rapid Assessment of the Need, Demand, Supply, and User Satisfaction with AT among People Attending Rehabilitation Services in Sao Paulo, Brazil

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Abstract. Access to assistive technology (AT) in Brazil is intimately related to rehabilitation services. Studies have shown the complexity of access to AT in the country, with people seeking the care they need according to services availability, accessibility, and affordability. However, they used inconsistent approaches to measuring need for and use of AT and presented a lack of relevant information on demand, supply, and user satisfaction. This study aimed at identifying the prevalence of need, access, and use of assistive products (AP), as well as the barriers to access and users’ satisfaction with services and products provided to community dwelling people attending rehabilitation services provided by the public healthcare system in São Paulo, Brazil. Results show a large prevalence of need for and use of AP, although the unmet need is still high. Private and public sectors are the most relevant sources of products, with private funds being most frequently used to acquire them, despite a large financial barrier. It stressed the importance of the public healthcare system and many of its positive impacts on users, but also some of its limitations, such as service-related barriers. Users are mostly satisfied with the products and services they receive, although people with greater functioning difficulties report a moderately different situation. Hence, the study demonstrated that some user groups still face many barriers and obtain worst results of the system in place. Results are internationally comparable to other studies using similar methodology and demonstrate the impact generated by the local AT provision system.

Keywords: Need, Demand, Supply, User Satisfaction.
Introduction

Brazil is a vast, mostly urban country characterized by large metropolitan regions [1-3]. Located in the country’s southeastern region, the state of São Paulo concentrates almost a fourth of the Brazilian population (circa 46 million inhabitants), with the metropolitan region of the state capital accounting for approximately half of that. As such, the city of São Paulo alone was home to an estimated 12.3 million inhabitants in 2020, densely populated (7.3 thousand people/km²), with a HDI of 0.805 and a GDP/capita level of circa USD 10.3 thousand [4]. However, the city is marked by persistently high social and economic inequalities, with a Gini index of 0.539, only slightly lower than the national index (0.545) in 2019 [5].

As with other Latin American and Caribbean settings, local demographics are transitioning towards a rapidly ageing population [6], which also experiences an incomplete epidemiological transition [7]. As much as ageing and non-communicable diseases relate to functional decline and disability, data compiled from 39 national censuses, household surveys and targeted studies in the region show that 70 million people lived with some kind of disability between 2001 and 2013 [8], who could potentially benefit from assistive products AP and related services [9]. As in other parts of the world [10], disability in the region is more prevalent and more severe among women, the elderly, rural populations, indigenous peoples, black persons, and people living in poorer settings [11]. Recent data from the 2019 National Health Survey (NHS) in Brazil reiterate it, showing people with disability still have poorer educational outcomes, are excluded from the job market, and are overrepresented among the lowest income groups [12].

It also shows that 15.8% of those having at least some functioning difficulty had access to rehabilitation services during the 12 months period before the survey interview, and that 51.4% of them (totaling circa 4.3 million people) accessed it through the public healthcare system. These figures are slightly similar for the Brazilian southeastern region and the State of São Paulo specifically, where approximately 18.4% had access to rehabilitation services, 46.6% of which through the public healthcare system [12].

Access to assistive technology (AT) in Brazil is intimately related to rehabilitation services provision. According to the National Health Policy for Persons with Disability and the organizing principles of the Brazilian public healthcare system, AT service delivery is part of the scope of rehabilitation services provision and is considered an integral part of comprehensive rehabilitation treatment, which is targeted at meeting the needs of individuals with disabling health conditions, irrespective of disability status or certification [13]. Since the creation of this system, it has been responsible for covering most of the Brazilian population, who often relies on it as its sole health services provider. Although private health insurance plans exist in Brazil, they covered only 24.5% of the population in January 2021 [14].

In recent years, different studies explored the prevalence of need and use of AP, as well as their sources [12,15,16], but used inconsistent approaches to measuring them and lacked relevant information on demand for and supply of AP, as well as users’ satisfaction. They also show varying research designs and variable levels of studies coverage in terms of geography, population, and products.
This study aimed to identify the prevalence of need, access, and use of AP in the target population, as well as the barriers to access and users' satisfaction with services and products provided. Additionally, by selecting a target population of community dwelling people attending rehabilitation services provided by the local public healthcare system, the study aimed at gaining further insight on the strategies people use to meet their needs for AT and producing evidence on strengthens and weaknesses of the system in place.

2 Methods

Answering a World Health Organization’s call on access to AT around the world [17], this survey used its rapid Assistive Technology Assessment (rATA) questionnaire and an adapted version of its protocol [18] to meet the needs of a subnational study targeting a specific population carried out remotely to accommodate for social distancing measures in place during the COVID-19 pandemic.

2.1 Study Design

A simple stratified probabilistic sample was drawn using 29 local rehabilitation facilities as its strata. Survey participants were identified and enumerated based on the registries of the facilities covered by the study.

Population subgroups defined by functioning domain (vision, hearing, mobility, cognition, self-care, and communication), age (0 to 18 years, 19 to 59 years, and 60 years or older), and gender were considered the main study domains for sampling purposes.

\[
n = \frac{p(1-p)}{(d/z)^2}
\]

The sample size was initially estimated by the formula presented above, where \(P\) is the proportion to be estimated, \(d\) is the maximum tolerated sample error, and \(z = 1.96\), for a corresponding parametrical curve with a 95% confidence interval. For purposes of this calculation, the proportion that estimates the widest sample size for a fixed sampling error [19], the study chose \(p = 0.50\). Also, it adopted \(d = 0.10\), the equivalent of a coefficient of variation estimated as 10.2%. With these figures, \(n = 96\) (rounded to 100). Considering that this sample size should be obtained for all domains and that the smallest of them represents 10% of the reference population, the final sample was estimated as 1000 participants (\(n/0.1 = 1000\)).

2.2 Participants

The reference population was all the community dwelling individuals aged six and older who have attended outpatient rehabilitation services provided by the public healthcare system, in the city of São Paulo, from July 2019 to December 2020. This period was selected to accommodate for variations in the flow of patients seeking care.
before and during the COVID-19 pandemic, according to feedback received from the São Paulo Municipal Health Secretariat.

A universe of 85,607 people were eligible to be included in the study, according to the records provided by the São Paulo Municipal Health Secretariat. Anticipating numerous losses due to non-response, the initial sample size was adjusted, and 3,000 individuals were drawn. Sampling was proportional to the number of people registered in each of the 29 rehabilitation facilities considered (which ranged from 738 to 8,354, according to the specific services provided in each facility). Out of the initial sample, 2,256 were enumerated. Enumeration happened progressively, to accommodate for the non-response rate observed.

2.3 Consent

To comply with Brazilian regulations on research involving human participants, the study was appraised and approved by Institutional Review Boards of both the University of São Paulo Medical School General Hospital and the São Paulo Municipal Health Secretariat. Study participants’ consent was obtained and registered verbally to accommodate for interviews being conducted remotely, over the phone or through teleconferencing. Whenever possible, study participants received an electronic copy of the consent form for their personal records. For participants under 18 or those unable to provide consent, the latter was obtained from their parents or other legally responsible adults.

2.4 Questionnaire

This study used the rATA questionnaire in Portuguese as originally published by WHO [17] after submitting it to a brief cognitive testing using a convenient, non-probabilistic sample (n=12) of AP users attending rehabilitation treatment at the Physical and Rehabilitation Medicine Institute of the University of São Paulo Medical School General Hospital (IMREA), who share the same health conditions and cultural background of this study population and were invited to provide their feedback on rATA’s questions and answer options in Portuguese, which were deemed satisfactory.

All interviewers had a background on psychology, occupational therapy, or social work, were trained to use the rATA questionnaire, and to conduct remote interviews using an electronic data collection tool. A sign-language interpreter was also available remotely, enabling video-based interviews with participants with hearing impairments who use Brazilian sign language, as needed.

2.5 Data Collection and Management

A protocol was established to complete and register each attempt to reach out and include potential study participants using purpose-specific running sheets. Interviewers attempted at least five times, in different dates and times of the day, to reach everyone enumerated according to the sampling strategy described before. The result of each attempt was recorded and informed the non-response rate of the study.
Interviewers made every effort to meaningfully include people with difficulties communicating or understanding the interview. Whenever needed, proxy interviews were used to include those who could not communicate or understand the questionnaire as used in this study. It was the same for children and adolescents to assent and participate actively in their interviews.

The study used the electronic tool developed by WHO to support rATA data collection (ArcGIS Survey123 Field App), accounting for the additional changes in the survey form required by the study in São Paulo. It used complementary strategies to improve data quality, which included flagging interviews for discussion with the field supervisor and the study coordinating team; checking data registries and audio records to follow up with any issues identified; and, using reinterviews to check for specific, sensitive aspects of the questionnaire.

Interviews were performed between March 24 and June 24, 2021.

2.6 Outcome Measures and Analyses

In addition to the minimum set of survey indicators identified by WHO (need, use, and unmet need for AT in the target population) [17,18] for each of the six functioning domains covered by the survey tool, these were disaggregated by age group and gender whenever the number of cases recorded for each additional domain offered reliable results (though not presented here). For this, data analyses used a specialized statistical software (IBM SPSS Statistics 27), with descriptive statistics being used to present the results in this article. Sampling weights were used to estimate study results for the entire target population, according to Table 1. For many results, actual counting values are presented unweighted for additional information.

<table>
<thead>
<tr>
<th>Age</th>
<th>Male</th>
<th>Female</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt; 17</td>
<td>0.72886</td>
<td>0.78067</td>
</tr>
<tr>
<td>18-39</td>
<td>1.16362</td>
<td>1.04255</td>
</tr>
<tr>
<td>40-54</td>
<td>0.90407</td>
<td>1.02532</td>
</tr>
<tr>
<td>55-64</td>
<td>0.95480</td>
<td>1.04946</td>
</tr>
<tr>
<td>65-74</td>
<td>0.98817</td>
<td>1.04469</td>
</tr>
<tr>
<td>75+</td>
<td>1.22983</td>
<td>1.36825</td>
</tr>
</tbody>
</table>

3 Results

Out of the 2,256 individuals enumerated, 926 consented to participate and answered the survey. Others either did not consent (n=386), were successfully identified but were unavailable (n=294), had inadequate contact information on local registries (e.g., wrong number) (n=538), were excluded for referring not meeting the survey criteria (e.g., not attending or having attended rehabilitation services) (n=45), were dead by the time of the interview (n=55), or were excluded for protocol deviations (n=2) or other reasons (e.g., failed contacts) (n=10).
Table 2 shows the main characteristics of the target population in terms of gender and age groups distributions, as well as functioning levels (maximum level of difficulty reported in any domain). The thresholds adopted reflect the reliability of study estimates considering the number of responses obtained for each group.

Table 2. Gender, age groups and functioning levels of the target population

<table>
<thead>
<tr>
<th>Variable</th>
<th>Group</th>
<th>Est.</th>
<th>Lower C.I.</th>
<th>Upper C.I.</th>
<th>Coefficient of variation</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td>Male</td>
<td>42.4%</td>
<td>39.3%</td>
<td>45.6%</td>
<td>0.038</td>
<td>417</td>
</tr>
<tr>
<td></td>
<td>Female</td>
<td>57.6%</td>
<td>54.4%</td>
<td>60.7%</td>
<td>0.028</td>
<td>509</td>
</tr>
<tr>
<td>Age group</td>
<td>6 to 17 y.o.</td>
<td>15.6%</td>
<td>13.6%</td>
<td>17.8%</td>
<td>0.068</td>
<td>193</td>
</tr>
<tr>
<td></td>
<td>18 to 64 y.o.</td>
<td>51.9%</td>
<td>48.7%</td>
<td>55.0%</td>
<td>0.031</td>
<td>470</td>
</tr>
<tr>
<td></td>
<td>&gt; 65 y.o.</td>
<td>32.6%</td>
<td>29.6%</td>
<td>35.7%</td>
<td>0.048</td>
<td>263</td>
</tr>
<tr>
<td>Functioning level</td>
<td>Some or no difficulty</td>
<td>43.4%</td>
<td>40.2%</td>
<td>46.6%</td>
<td>0.038</td>
<td>410</td>
</tr>
<tr>
<td></td>
<td>A lot of difficulty or cannot do at all</td>
<td>56.6%</td>
<td>53.4%</td>
<td>59.8%</td>
<td>0.029</td>
<td>516</td>
</tr>
</tbody>
</table>

Note: Est. = Estimate; C.I. = 95% Confidence Interval

3.1 Core Indicators

Table 3 shows the core indicators for the entire target population. Disaggregated data shows that core indicators are similar across genders, are high for all functioning domains and higher in the eldest group. Despite AT need and the prevalence of AP use being quite high across groups, the latter is slightly lower among people with difficulties communicating, remembering, and caring for themselves. Moreover, the met need is also lower among people with difficulties hearing, communicating, remembering, and caring for themselves.

Table 3. Core indicators: Use, need and met need

<table>
<thead>
<tr>
<th>Indicator</th>
<th>Estimate</th>
<th>Lower C.I.</th>
<th>Upper C.I.</th>
<th>Coefficient of variation</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Use</td>
<td>72.9%</td>
<td>69.9%</td>
<td>75.6%</td>
<td>0.02</td>
<td>657</td>
</tr>
<tr>
<td>Need</td>
<td>82.4%</td>
<td>79.9%</td>
<td>84.7%</td>
<td>0.015</td>
<td>749</td>
</tr>
<tr>
<td>Met need</td>
<td>48.5%</td>
<td>46.0%</td>
<td>51.0%</td>
<td>-</td>
<td>-</td>
</tr>
</tbody>
</table>

3.2 Most Used and Demanded Products

It is evident that many of the most used AP are also among the most demanded, showing that some, such as spectacles (used by 42.9% [CI 40.0-45.9]; demanded by 41.6% [CI 37.2-46.1]); hearing aids (used by 12.9% [CI 11.1-14.9]; demanded by 21.8% [CI 18.3-25.7]); shower and toilet chairs (used by 7.5% [CI 5.9-9.1]; demanded by 5.9% [CI 4.1-8.4]); and, manual wheelchairs for active users (used by 5.4% [CI 4.2-6.8]; demanded by 5.8% [CI 4.0-8.2]), are among the most relevant products in this setting.
3.3 AP Sources and Payers

Irrespective of the level of importance attributed by users to each product or any other aspect, data shows that, across domains, the most frequent source for AP is the private sector (54.8% [CI 51.9-57.8]), followed by the public sector (31.2% [CI 28.6-34.0]), friends and family members (9.2% [CI 7.6-11.0]), and NGO (3.7% [CI 2.7-5.0]).

The relevance of the private sector is significant for not only being the most frequent, but also because the study target population is of people serviced by the public healthcare system. Major exceptions to this general picture are people with difficulties communicating and caring for themselves, for whom the public sector is a more frequent source than the private sector, and NGO are more relevant.

This study also indicates that users themselves pay out-of-pocket for most of all AP (40.1% [CI 37.2-43.1]). Additionally, users’ friends and family members obtain many of the AP privately sourced (25.1% [22.6-27.8]), with insurance companies (0.1% [0.0-0.5]) and other stakeholders being very rare.

The disaggregation of survey responses show that the public sector, NGO, and friends and family members are more frequent sources and payers of AP used by those who have greater functioning difficulties across domains.

Data on the distance travelled by AP users demonstrate most people in the target population get their AP close to home (52.7% [CI 49.5-55.9] in less than 5km).

3.4 Satisfaction with AP and Related Services

AP users are mostly satisfied with the products, training and follow up and maintenance services they received. For all three different fields, more than 75% of AP users are at least a little satisfied with the products and services received. Nevertheless, according to disaggregated data, satisfaction levels are slightly lower, and dissatisfaction levels higher, among those with greater functioning difficulties, especially with reference to training and follow up services.

Users’ reports on the suitability and usability of their AP are largely positive across functioning domains and for people with different levels of functioning difficulties, showing people can use their AP to meet their needs, although those with greater functioning difficulties report a moderately different situation with respect to usability and environmental barriers. The latter still prevent users from making the most of their AP in some cases, which is especially true for people with difficulties moving around, communicating, and caring for themselves, as well as among people with greater functioning difficulties across domains.

3.5 Barriers to Access

Table 4 clearly shows that the major barrier to AP access among the study target population is being able to pay for them. A qualitative analysis of the large number of “other” answers shows that service-related barriers (such as getting an appointment or prescription, as well as service disruptions due to the COVID-19 pandemic) follow
financial barriers closely behind and are largely associated with services provided by the public healthcare system.

Table 4. Barriers to AP access identified by the target population

<table>
<thead>
<tr>
<th>Barrier</th>
<th>Estimate</th>
<th>Lower C.I.</th>
<th>Upper C.I.</th>
<th>Coefficient of variation</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cannot pay</td>
<td>42.2%</td>
<td>37.7%</td>
<td>46.8%</td>
<td>0.055</td>
<td>197</td>
</tr>
<tr>
<td>Other</td>
<td>31.0%</td>
<td>26.9%</td>
<td>35.5%</td>
<td>0.07</td>
<td>143</td>
</tr>
<tr>
<td>Lack of support</td>
<td>8.9%</td>
<td>6.6%</td>
<td>11.9%</td>
<td>0.15</td>
<td>43</td>
</tr>
<tr>
<td>Unavailability</td>
<td>7.3%</td>
<td>5.2%</td>
<td>10.1%</td>
<td>0.167</td>
<td>34</td>
</tr>
<tr>
<td>Inadequacy</td>
<td>4.6%</td>
<td>3.0%</td>
<td>7.0%</td>
<td>0.211</td>
<td>22</td>
</tr>
<tr>
<td>Lack of time</td>
<td>4.2%</td>
<td>2.7%</td>
<td>6.4%</td>
<td>0.218</td>
<td>20</td>
</tr>
<tr>
<td>Lack of transportation</td>
<td>1.2%</td>
<td>0.5%</td>
<td>2.8%</td>
<td>0.452</td>
<td>5</td>
</tr>
<tr>
<td>Stigma / Shyness</td>
<td>0.7%</td>
<td>0.2%</td>
<td>2.1%</td>
<td>0.572</td>
<td>3</td>
</tr>
<tr>
<td>Total</td>
<td>100.0%</td>
<td>100.0%</td>
<td>100.0%</td>
<td>-</td>
<td>467</td>
</tr>
</tbody>
</table>

4 Discussion

In 2019, 52.7 million, or 28.5% of the Brazilian population referred having at least some difficulty to see, hear, use their upper and lower limbs, or cope with intellectual and mental impairments when performing activities of daily living [12]. It is understandable that this study identified a higher need for AT, once these are people attending or having recently attended rehabilitation services, hence possibly benefiting from AP temporarily or permanently.

As with other studies, this found that AP use is associated with older age and greater functioning difficulties [20]. Our results on AP use also corroborate previous findings showing that a third to a fourth of people living with some functioning difficulties in the city of São Paulo did not use AP [16]. Interestingly, whilst the prevalence of both AT need and AP use is higher among people with greater functioning difficulties, their met need is lower, showing this group still have needs that haven’t been met by the system, services, and products available.

The 2019 Brazilian NHS also showed that while many people used AP (e.g. 40.4% used vision aids, 1.7% used mobility aids, and 0.8% used hearing aids in the general population), only 5.7% of those were sourced from the public healthcare system. Nevertheless, it is largely due to the high prevalence of spectacles use (and other visual aids), which are often (95.5%) privately acquired. On the other hand, the public healthcare system provided for 16.6% of the users with impaired lower limbs functions; 25.3% of those with impaired upper limbs functions; and 44.7% of those with impaired hearing functions [12].

Like others [21,22], our own study showed that the limited use of and demand for AP outside the domains of mobility, hearing and vision might imply the lack of users’ awareness of the AP that might benefit people with communication and cognition difficulties.

Furthermore, the short distances travelled by AP users might be answerable by individuals being referred to rehabilitation facilities that are closer to their homes, a general
operating principle of the local healthcare system. The availability of private providers could also be accountable to the city of São Paulo being a well-resourced setting, where suppliers and professionals are concentrated [23]. On the other hand, disaggregated information demonstrates that people living with greater functioning difficulties travel longer distances than others, probably showing a limited number of providers capable of meeting the needs of users with complex health conditions or functioning status.

AT affordability and availability are barriers in other settings [22], but this study’s specific design identified many service-related barriers, which could be a target of interventions designed to improve AP access through the local public healthcare system and be incorporated into rATA answer options to clearly identify them in other settings.

5 Conclusion

Using the rATA tool and survey methodology proved itself a successful strategy to identify the prevalence of need, access, and use of AP in the target population, as well as the barriers to access and users’ satisfaction with products and services provided. With the upcoming results of similar studies, comparing rATA results will open avenues to better and sounder comparative analyses of assistive technology systems worldwide, and inform monitoring and evaluation at all levels.

With respect to its specific setting, this study shed light on the relevance of the private sector in providing AP, despite the significant financial barrier many AP users still face, what often results in users depending on the support of family members and friends when they cannot afford to pay for them directly. It stressed the importance of the public healthcare system and many of its positive impacts on users, but also some of its limitations, such as service-related barriers. Other actors, such as NGO and insurance companies, have only a marginal participation in the AT sector in this setting.

Importantly, the study showed the positive results obtained by the services and products currently available, which meet many of the needs and satisfaction criteria of users themselves. Nevertheless, it also demonstrated that many AP user groups still face a number of barriers and obtain worst results of the system in place, such as people with greater functioning difficulties across domains and those with difficulties communicating and caring for themselves.

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References


