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Methodological Description of Mapping Brazilian Long-Term Care Facilities for Older Adults

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Methodological Description of Mapping Brazilian Long-Term Care

Facilities for Older Adults

Descrição Metodológica do Mapeamento das Instituições de Longa-Permanência para Idosos no Brasil

Mapping Brazilian Long-Term Care Facilities

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ABSTRACT

Aim: describe the methodological approach adopted to build a Brazilian database of LCTFs in the country.

Methods: This exploratory research was conducted between August 2020 and 2021 based on primarily publicly accessible data. First, the database of the Sistema Único de Assistência Social for 2019 was adopted as the primary source of information. In addition, public agencies and managers were consulted and invited to share their databases. Likewise, researchers and private entities also collaborated by making their spreadsheets available. The information collected was placed in individual spreadsheets for each Brazilian state. LCTFs not catering to older adults (aged 60 and over) were excluded. Duplicate data were excluded when overlaps were identified for each new aggregated source.

Results & Discussion: This brief communication describes the methodology adopted for mapping the current status of Brazilian LCTFs. Despite its caveats, this study represents an important advance in the identification, characterization, and monitoring of these services nationwide. A total of 5769 facilities were found in the 2019 SUAS census. After excluding facilities not caring for residents aged 60 or over, this total decreased to 2381 LCTFs. Consolidating and filtering the information from multiple data sources led to the identification of 7029 LCTFs for the country as a whole.

Keywords: long-term care; older adults; care homes; aged; Brazil

INTRODUCTION

Long-term care facilities (LTCFs) for older adults can provide a range of services, including rehabilitation, healthcare, personal assistance, and end-of-life care.¹ For a contingent of vulnerable frail older adults, LTCF are not just a ‘home’, but their only option for emotional, physical, and social care.

The stage of maturity, preparedness, and organization of the long-term care (LTC) sector impacts not only the quality of care, but the availability of minimal datasets and information on the characteristics of the facilities,^{2,3} their residents, and staff, particularly in low and middle-income countries (LMIC).

Data from the latest Brazilian census carried out in the sector in 2009 suggest that LTCFs were present in only 29.9% of the country, totaling 3548 facilities.⁴ Akin to other LMICs, however, there were likely countless unregistered facilities that slipped under the radar of health units and social care policies.⁵

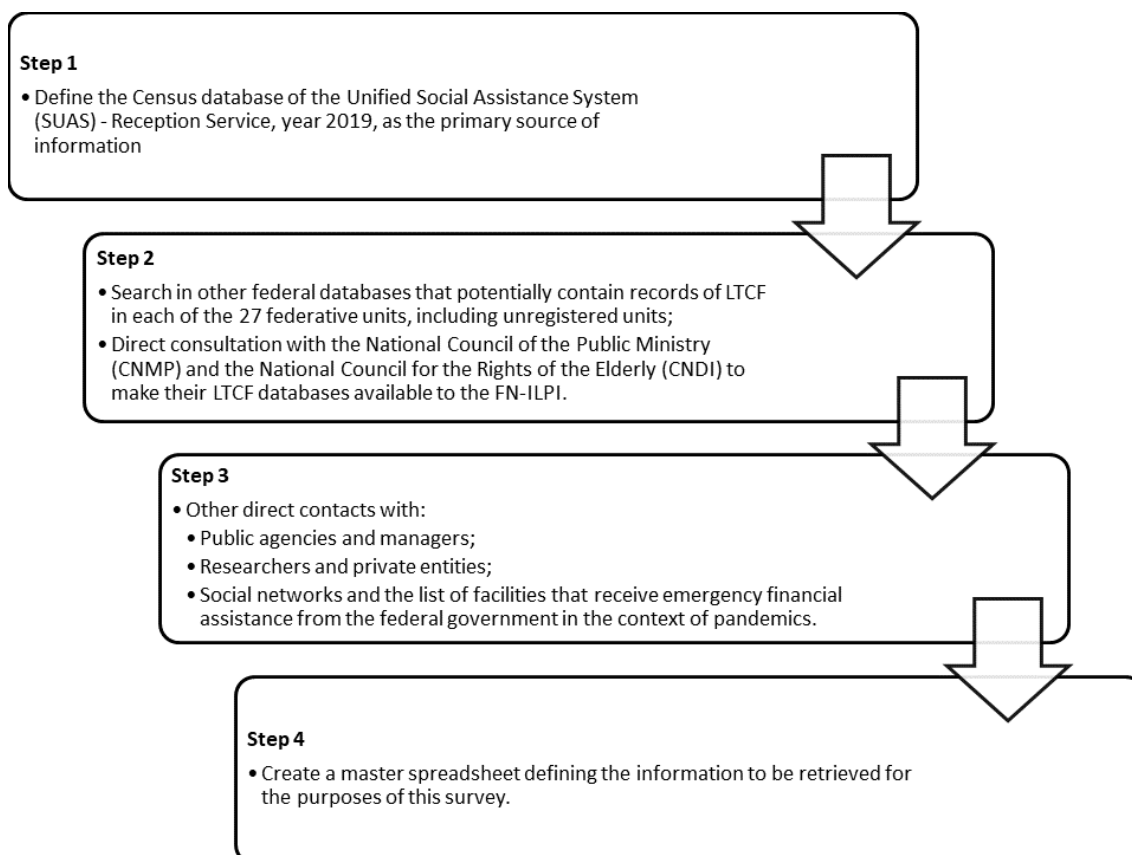
In the Brazilian scenario, the profile of the LTC sector is unclear. There are no official databases holding reliable information on the current number of facilities, their operating conditions, infrastructure, service provision, or the quantity and characteristics of their residents, seriously undermining organization of the sector. This basic information could serve to inform more effective public policies for dealing with, absorbing and mitigating emerging threats such as the COVID-19 pandemic.

Created last April (2020) amid emergency issues related to coping with COVID-19 in Brazilian LTCFs, the National Front to Strengthen LTCF for Older Adults (Frente Nacional de Fortalecimento à ILPI, FN-ILPI) comprises volunteers drawn from all regions of Brazil and different areas of knowledge, including specialists, scholars, managers and researchers in the areas of aging and public policy for older adults. One of the FN-ILPI working groups is dedicated to researching and diagnosing the situation of the LTC sector in Brazil. The main aim of the research conducted by the group is to map the spatial location of LTCFs by Brazilian region, characterizing them according to their legal status, capacity, and type of occupation. The purpose of this brief communication is to describe the methodological approach adopted to build a Brazilian database of LTCFs in the country.

METHODS

This exploratory research was conducted between August 2020 and 2021 based on primarily publicly accessible data; ethical approval was waived as no facilities were directly contacted. Figure 1 depicts the research project flowchart.

Figure 1 – Research Project Flowchart



Source: the study authors

First, the database of the Unified Social Assistance System (Sistema Único de Assistência Social - SUAS) census - Reception Services, for 2019 (available from <https://aplicacoes.mds.gov.br/snas/vigilancia/index2.php>) was consulted and adopted as the primary source of information. The SUAS Census, carried out annually by the Special Secretariat for Social Development of the Ministry of Citizenship, collects information on the standards of social assistance services, programs, and projects carried out within the scope of public social assistance units and organizations included in the social

assistance registry, as well as on the role of the Social Assistance Councils. Government agencies complete this survey at municipal and state levels, including LTCF for older adults, shelters, and temporary care services for children, adolescents, and adults.

Subsequently, the working group members were tasked with finding and reviewing other databases that could potentially contain records of LTCF in each of the 27 federal states, including unregistered facilities. In response to direct requests, the National Council of Public Prosecutors (Conselho Nacional do Ministério Público - CNMP) and the National Council for the Rights of the Elderly (Conselho Nacional dos Direitos da Pessoa Idosa - CNDI) made their LTCF databases available to the FN-ILPI.

In addition, public agencies and managers were consulted and invited to share their databases, particularly those connected with the State health and social assistance secretariats, health surveillance, older adults' councils, and State Public Prosecutors. Likewise, researchers and private entities also collaborated by making their spreadsheets available to the working group for consultation.

Complementary searches were then carried out on social networks and in the list of facilities eligible for emergency financial assistance provided by the federal government to mitigate the impact of the COVID-19 pandemic in the LTC sector.

The next step was to create and pre-test a master spreadsheet, defining the information to be collected for the purposes of the present study: institution name; trading name; National Legal Entity Registry Number (Cadastro Nacional de Pessoa Jurídica - CNPJ) and the National Classification of Economic Activities (Cadastro Nacional de Atividades Econômicas - CNAE); year of foundation; business address; and nature of the institution.

The information collected from each of these sources was placed in individual spreadsheets for each Brazilian state. LTCFs not catering for older adults (aged 60 and over) were excluded. Duplicate data were excluded when overlaps were identified for each new aggregated source. Missing information was filled in, when available, after checking social media, the CNPJ, and the National Register of Health Establishment websites. It was not possible to find direct conclusive evidence that all facilities were operating after the onset of the COVID-19 pandemic and, therefore, none of the LTCFs were excluded at this stage of the study.

RESULTS AND DISCUSSION

This brief communication describes the methodology adopted by the FN-ILPI to carry out initial mapping of the current status of Brazilian LTCFs. Despite its caveats, this study represents an important advance in the identification, characterization, and monitoring of these services nationwide.

A total of 5769 facilities were found in the 2019 SUAS census. After excluding facilities not caring for residents aged 60 or over, this total decreased to 2381 LTCFs.

Consolidating and filtering the information from multiple data sources led to the identification of 7029 LTCFs for the country as a whole. Of this total, 4232 facilities were identified in the Southeast region, 1874 in the South, 493 in the Northeast, 351 in the Midwest, and 79 in the North region of the country.

The lack of reliable data on the status of LTCFs, residents, and staff constitutes an issue of global importance, particularly during the current COVID-19 pandemic. In Brazil, akin to many LMIC, there is an evident shortcoming regarding the availability of public databases for the sector.⁷ Although of vital importance, obtaining a single solid national dataset for the LTC sector poses a major challenge.

According to 2019 SUAS official data, after exclusion of facilities not caring for residents aged 60 or over, the number of LTCFs in the country totaled 2381, a figure not reflecting the actual number of LTCFs operating in Brazil. Although this database includes a large number of LTCFs for older adults, comprising public, nonprofit and for-profit entities, its coverage is insufficient, overlooking many small and unregistered facilities, as well as privately run facilities.

In 2010, researchers from the Institute of Applied Economic Research (IPEA) published the first census of Brazilian LTCF, revealing that about 1% of Brazilian older adults (around 90 000 people) were residing in a total of 3548 facilities. Most of these LTCFs (65%) were non-profit philanthropic entities.⁴

A national survey based on the 2014 SUAS database identified 1450 facilities, catering for approximately 51 000 older residents the majority of whom were considered

frail.⁸ Although national regulations define LTCFs as ‘social shelters’, this survey showed they were provided (or were supposed to provide) health care services, given their residents' physical and cognitive vulnerability. The survey also showed that the quality of this support was poor and found a lack of adequate infrastructure for care delivery. Comparison of data from the 2014 survey with those of the SUAS Census of 2019 showed an estimated increase of around 78 000 residents without, however, a concomitant or significant improvement in care conditions.

The absence or ineffectiveness of long-term care policies in the country has contributed to an even more critical scenario with the emergence of the COVID-19 pandemic. Insufficient and poor-quality national data acts as a barrier to adopting well-informed interventions. However, the actions undertaken by the FN-ILPI have prevented Brazilian facilities from experiencing the same degree of tragic events seen in the sector in other countries.⁶

Building a solid database was paramount to devising a National Policy on Long-Term Care and was achieved through the concerted efforts of professionals mobilized with a shared goal. Despite its gaps, the resulting database represents an important advance in identifying, characterizing and monitoring these services nationwide.

The number of LTCFs identified by the present survey was 105% higher than the number recorded in the 2010 census.⁴ This growth was found across all regions, but the extent of the increase varied by region. The highest increase was seen in the South region, with a 171% rise in LTCF over the period, followed by the Northeast (104%), Southeast (94.4%), Midwest (34.7%), and North region (40.2%). The largest increase according to legal status was found among private institutions. This increase helps support the need to expand the provision of LTC to a rapidly aging population. However, the fact that this burden has been addressed largely by the private sector reveals that demand has outstripped supply of services in the public sector.⁹

Some limitations of this work should be considered. Although multiple diverse sources have been consulted at federal, state, and municipal levels, including social media research, some small and clandestine LTCFs may not have been included, particularly in more remote areas. Smaller and unregistered facilities, whose social and financial support

tends to be weaker, have been more severely affected by the crisis imposed on society by the COVID-19 pandemic.

By including multiple sources, however, the scope of this survey is far greater than all previous efforts and constitutes an unprecedented collaborative experience in the country. Furthermore, this initiative has the potential to become the first national dataset for the Brazilian LTC sector.

If even legitimate LTCF go undocumented, what does this tell us about clandestine facilities? The inclusion of clandestine and unregistered facilities can serve to promote their regularization and the provision of adequate care for residents. Future research should draw on national datasets to update the data gathered by the original 2010 census. There is an urgent need to further this goal considering the limited data so far established. To this end, the FN-ILPI researchers are conducting a research project adopting an updated version of the instrument applied by the IPEA researchers. Likewise, future studies should adopt cross-sectoral collaboration, qualitative projects and snowball-type methodologies, allowing the identification and inclusion of a larger number of clandestine and unregistered facilities. These responses can help inform a more comprehensive permanent strategy for the sector. Devising these measures is essential to organize the sector and delivery care to this vulnerable contingent of society.

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