Methodological description of the mapping of Brazilian long-term care facilities for older adults

Descrição metodológica do mapeamento das instituições de longa permanência para idosos no Brasil

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ABSTRACT

OBJECTIVE: To describe the methodological approach adopted to build a database of long-term care facilities (LCTFs) in Brazil.
METHODS: This exploratory research was conducted for 12 months, between August 2020 and July 2021, based on primarily publicly accessible data. First, the Unified Social Assistance System (Sistema Único de Assistência Social [SUAS]) database from 2019 was adopted as the primary source of information. In addition, public agencies and managers were consulted and invited to share their databases, while researchers and private entities collaborated by making their spreadsheets available. Data were organized in spreadsheets for each Brazilian state. LTCFs not catering to older adults (aged 60 years and over) were excluded. Duplicate data were excluded when overlaps were identified. **RESULTS:** This brief communication describes the methodology adopted for mapping 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 years or over, this number decreased to 2381 LTCFs. The consolidation and filtering of information from multiple data sources led to the identification of 7029 LTCFs throughout the country. **CONCLUSION:** Building a solid database was paramount to devising a national policy on long-term care. By including multiple sources, the scope of this survey was wider than all previous efforts and constituted an unprecedented collaborative experience in the country, including the potential to become the first national dataset for the Brazilian LTC sector.
KEY WORDS: aged; homes for the aged; nursing homes; residential facilities; Brazil.

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Received on: 09/28/2021. Accepted on: 10/17/2021

RESUMO

OBJETIVO: Descrever a abordagem metodológica adotada para a construção de um banco de dados brasileiro de instituições de longa permanência (ILPIs) no país. **METODOLOGIA:** Esta pesquisa exploratória foi realizada durante 12 meses, entre agosto de 2020 – 2021, com base principalmente em dados acessíveis ao público. Em primeiro lugar, o banco de dados do Sistema Único de Assistência Social para 2019 foi adotado como principal fonte de informação. Além disso, órgãos públicos e gestores foram consultados e convidados a compartilhar seus bancos de dados. Da mesma forma, pesquisadores e entidades privadas colaboraram disponibilizando suas planilhas. Os dados foram colocados em planilhas para cada estado brasileiro. Excluíram-se as ILPIs que não atendiam a idosos (60 anos ou mais). Dados duplicados foram excluídos quando as sobreposições foram identificadas. **RESULTADOS:** Esta comunicação breve descreve a metodologia adotada para mapear a situação atual das ILPIs brasileiras. Apesar de suas ressalvas, este estudo representa um importante avanço na identificação, caracterização e monitoramento desses serviços em âmbito nacional. Um total de 5769 instalações foram encontradas no censo do SUAS de 2019. Após a exclusão dos estabelecimentos que não atendiam residentes idosos, esse total passou para 2381. A consolidação e filtragem das informações de múltiplas fontes de dados levaram à identificação de 7029 ILPIs para o país como um todo. **CONCLUSÃO:** A construção de um banco de dados sólido é fundamental para a formulação de uma Política Nacional de Cuidados de Longa Duração. Por incluir fontes múltiplas, o escopo desta pesquisa é muito maior do que todos os esforços anteriores e constitui uma experiência colaborativa sem precedentes no país, incluindo o potencial de se tornar o primeiro conjunto de dados nacional para o setor.

PALAVRAS-CHAVE: idoso; instituição de longa permanência para idosos; casas de saúde; instituições residenciais; Brasil.

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, LTCFs 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 affects not only the quality of care, but also the availability of minimal datasets and information on facilities' characteristics,[2,3] residents, and staff, particularly in low- and middle-income countries (LMIC).

Data from the latest Brazilian census, performed in 2009, suggest that LTCFs were present in only 29.9% of the country, totaling 3548 facilities.[4] Akin to other LMICs, however, Brazil likely had countless unregistered facilities that went unnoticed by 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 number and characteristics of their residents, seriously undermining the sector's organization. This basic information could serve to inform more effective public policies for dealing with, absorbing, and mitigating emerging threats such as the coronavirus disease 2019 (COVID-19) pandemic.
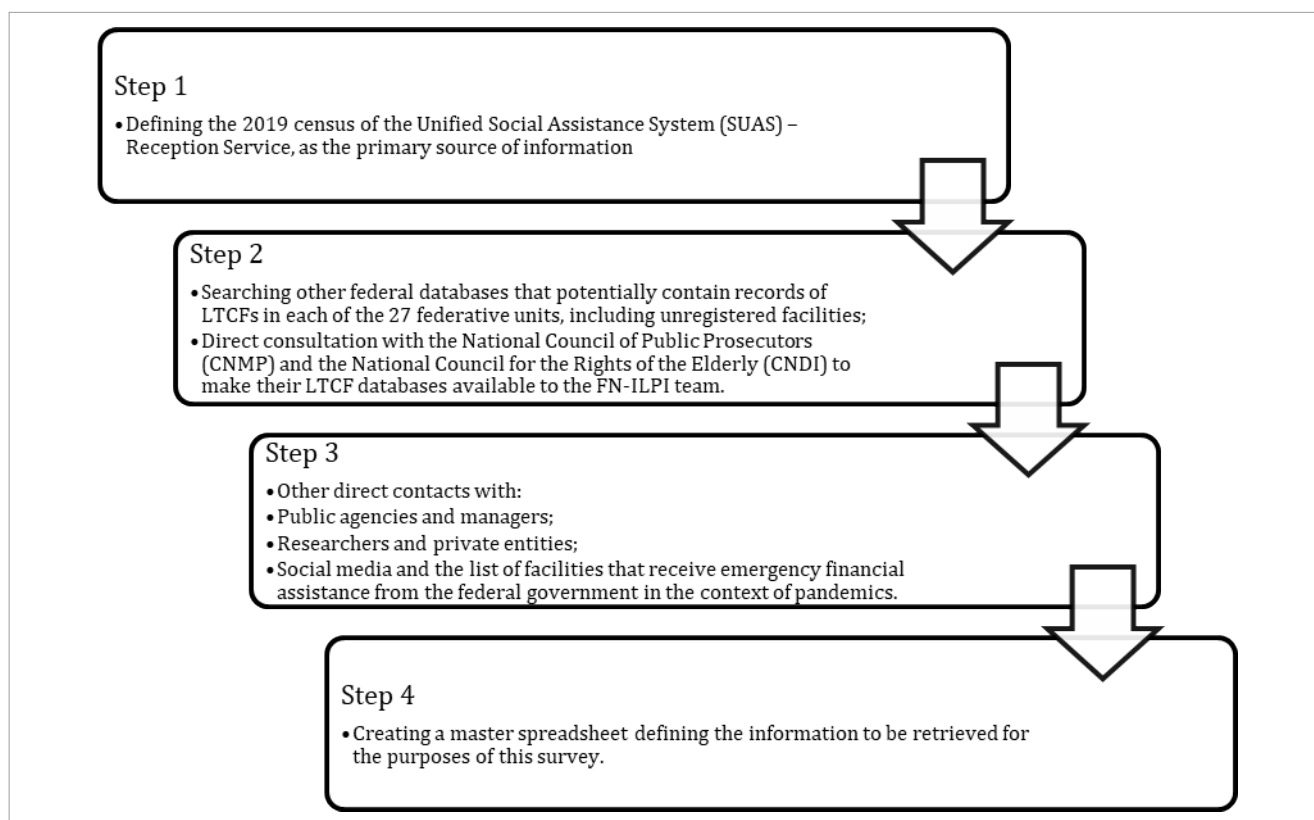
Created last April (2020) amid emergency issues related to coping with COVID-19 in Brazilian LTCFs, the National Front to Strengthen LTCF for Older Adults (Frente Nacional de Fortalecimento à ILPI [FN-ILPI]) comprises volunteers from all regions of Brazil and different areas of knowledge, including specialists, scholars, managers, and researchers in the areas of aging and public policies 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 this 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 LCTFs in the country.

METHODS

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

First, the database of the Unified Social Assistance System (Sistema Único de Assistência Social [SUAS]) census — Reception Services (available from https://aplicacoes.mds.gov.br/snas/vigilancia/index2.php) was consulted regarding the year 2019 and was adopted as the primary source of information. The SUAS census, performed 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 developed within

Figure 1. Research project flowchart. LTCF: long-term care facility; FN-ILPI: National Front to Strengthen LTCF for Older Adults; COVID-19: coronavirus disease 2019.

the scope of public social assistance units and organizations included in the Social Assistance Registry, as well as on the role of Social Assistance Councils. Government agencies completed this survey at municipal and state levels, including LTCFs 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 LTCFs 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 Prosecutor's offices. Researchers and private entities also collaborated by making their spreadsheets available to the working group for consultation.

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

The next step was to create and pre-test a master spreadsheet, defining the information to be collected for the present study: institution name; trading name; National Registry of Legal Entities (Cadastro Nacional de Pessoa Jurídica [CNPJ]) and 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 years 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 National Register of Health Facilities. 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 perform an 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 years or over, this number decreased to 2381 LTCFs.

The consolidation and filtering of information from multiple data sources led to the identification of 7029 LTCFs throughout the country. Of this, 4232 facilities were identified in the Southeast region, 1874 in the South region, 493 in the Northeast region, 351 in the Center-West region, 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.[6] In Brazil, akin to many LMIC, there is an evident shortcoming regarding the availability of public databases for this sector.[7] Although of vital importance, obtaining a single solid national dataset for the LTC sector poses a major challenge.

According to official SUAS data from 2019, after the exclusion of facilities not caring for residents aged 60 years or over, the number of LTCFs in the country totaled 2381, a figure not reflective of 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 LTCFs, revealing that about 1% of Brazilian older adults (around 90 000 people) were residing in 3548 facilities. Most of these LTCFs (65%) were non-profit philanthropic entities.[4]

A national survey based on the SUAS database from 2014 identified 1450 facilities, caring for approximately 51 000 older residents, most of whom were considered frail.[8] Although national regulations define LTCFs as "social shelters," this survey showed they 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 delivering care. A comparison of data from the 2014 survey with those of the 2019 SUAS census 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 COVID-19 pandemic. Insufficient and poor-quality national data act as a barrier to well-informed interventions. However, 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 this 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 the number of LTCFs over the 2010–2021 period, followed by the Northeast (104%), Southeast (94.4%), Center-West (34.7%), and North regions (40.2%). The largest increase according to legal status was found among private institutions. This increase supports 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 the supply of services in the public sector.[9]

Some limitations of this work should be considered. Although various sources have been consulted at federal, state, and municipal levels, including social media, 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. Despite recent efforts to regularize clandestine and unregistered LTCFs, including the support of Public Prosecutors from several Brazilian states, the lack of standardization of operational concepts and public policies for the LTC sector in the country continues to impair these advances.

Nevertheless, by including multiple sources, 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 LTCFs 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 collected so far. To this end, FN-ILPI researchers are conducting a research

project that adopts an updated version of the instrument applied by IPEA. Similarly, 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 deliver care to this vulnerable contingent of society.

ACKNOWLEDGMENTS

CONFLICT OF INTEREST

The authors declare no conflicts of interest.

FUNDING

AUTHORS' CONTRIBUTION

MARCD: conceptualization, data curation, formal analysis, investigation, methodology, project administration, validation, writing – original draft, writing – review & editing. PAW: conceptualization, investigation, methodology, writing – original draft, writing – review & editing. CBS: conceptualization, investigation, methodology, writing – original draft, writing – review & editing. LCSP: conceptualization, data curation, formal analysis, investigation, methodology, validation, writing – original draft, writing – review & editing. PFC: conceptualization, data curation, formal analysis, validation. PCLB: conceptualization, investigation, methodology, writing – original draft, writing – review & editing. SL: conceptualization, investigation, methodology, writing – original draft, writing – review & editing. VGM: conceptualization, investigation, methodology, writing – original draft, writing – review & editing. YAOD: conceptualization, investigation, methodology, writing – original draft, writing – review & editing. KCG: conceptualization, data curation, formal analysis, investigation, methodology, project administration, validation, writing – original draft, writing – review & editing.

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