











Brazilian National Front for Strengthening Long-Term Care Facilities for Older People: history and activities

Frente Nacional de Fortalecimento a Instituições de Longa Permanência para Idosos: histórico e ações realizadas

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ABSTRACT

In April 2020, the COVID-19 pandemic became a severe threat to long-term care facility patients worldwide. A national front was urgently organized to integrate regional oversight and workgroups, coordinate activities, and develop educational materials, meetings, and communication strategies with these institutions in Brazil. As of August 2021, the front's initiatives have demonstrated its relevance for helping long-term care facilities cope with the COVID-19 pandemic, as well as for the ongoing struggle to include this issue in the public agenda, given that these facilities are an indispensable link in the development of a national policy for continuing care. This paper describes the history and initiatives of the National Front for Strengthening Long-Term Care Facilities regarding the COVID-19 pandemic, as well as its successful volunteer initiatives regarding the care of institutionalized older adults.

KEYWORDS: homes for the aged; aged; coronavirus infection.

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Em abril de 2020, a pandemia de COVID-19 trouxe graves ameaças de morbidade e mortalidade aos residentes de instituições de longa permanência para idosos (ILPI) em âmbito internacional. No Brasil, em caráter de urgência, fez-se então necessária a organização de uma frente nacional que integrasse, por meio de coordenações regionais e de grupos de trabalho, as diferentes ações e desenvolvimento de materiais educativos, *lives* e estratégias de interlocução com essas instituições. Com as produções feitas até agosto de 2021, constata-se a relevância do apoio às ILPI no enfrentamento da COVID-19, bem como da luta permanente por sua inclusão na pauta pública, como um imprescindível locus do cuidado à pessoa idosa, atrelado à construção de uma política nacional de cuidados continuados. Apresentam-se neste artigo o histórico e a atuação da Frente Nacional de Fortalecimento às Instituições de Longa Permanência para Idosos (FN-ILPI) no enfrentamento da pandemia de COVID-19, além das ações exitosas de mobilização voluntária da sociedade civil no cuidado à pessoa idosa institucionalizada.

PALAVRAS-CHAVE: instituição de longa permanência para idosos; idoso; infecções por coronavírus.

INTRODUCTION

In March 2020, the World Health Organization declared COVID-19¹ a pandemic. News about the high COVID-19 mortality rates among European long-term care facility (LTCF) patients and the emergence of the first SARS-CoV-2 infection cases in Brazil led gerontologists to publish “COVID-19 and homes for the aged: care or an announced death?”.² This article led to a public hearing on April 7, 2020 by the House of Representatives’ External Commission for Combating COVID-19 about the situation of long-term care facilities for the older adults during the coronavirus pandemic (<https://www.camara.leg.br/evento-legislativo/59550>). On April 8, several older adult human rights groups organized an online group for text, audio, and video communication about how to quickly take action against the social and health threats to Brazilian LTCFs during the pandemic. As a result, the National Front for Strengthening LTCF (NF-LTCF) was established.

A number of initiatives were created or consolidated globally³⁻⁷ to fight COVID-19, particularly regarding care for the most vulnerable groups, such as older adults.⁸⁻¹¹ However, according to Abers and von Bülow,¹² due to politicization, the situation’s severity was not immediately perceived in Brazil: “in a context where the public authorities and some people deny this dangerous disease, movements had to fight to respond to emergency needs and build and disseminate a narrative that the threat is real” (our translation).

Due to the government’s lack of response to the pandemic, initiatives by non-governmental social and labor organizations, such as the NF-LTCF, helped health care facilities cope with these new challenges by providing robust scientific evidence, information bulletins, protocols for training sessions, reports, etc.^{10,13}

The NF-LTCF initiative grew organically, promoting strategic planning, activities, and research to strengthen LTCFs and create public policies about caring for older adults living

in LTCF. This article will outline the NF-LTCF’s initiatives to mitigate the COVID-19 pandemic, including the successful volunteer movement, which occurred despite opposition.

METHODS

This experience report describes the activities of the NF-LTCF, considering its initial organization according to administrative region and, subsequently, in workgroups that gathered stakeholders nationwide. The initiatives reported herein refer to NF-LTCF activities from April 2020 to August 2021.

EXPERIENCE REPORT

NF-LTCF is a democratic network that through learning, researching, planning, and positioning promotes support initiatives for LTCF (whether private non-profit, private for-profit, or public), in addition to advocating stronger public policies about long-term care for older adults.

Established on April 8, 2020, after 122 deaths had been attributed to COVID-19, the NF-LTCF consists of people from every region in Brazil, including a broad plurality of fields and professional activities. The NF-LTCF employs virtual resources and digital platforms for all its activities. The NF-LTCF’s first group was called “LTCF Urgent”. This name was chosen to emphasize the need for a quick response to the considerable threat these facilities were facing. Regional subgroups were organized, but limited to 252 people per group, which demonstrates the great need for reliable information by institutional care providers.

As a result, the NF-LTCF’s first action was to organize nine workgroups to develop the Consolidated Technical Report,¹⁴ (https://sbgg.org.br/wp-content/uploads/2020/06/Relato%CC%81rio-final-FN_fichaC.pdf).

This document aimed to Support the Commission for the Defense of the Rights of Older Adults (CIDOSO) in its emergency efforts against the COVID-19 pandemic,

emphasizing institutional reception and gathering sufficient information to:

1. Produce a situational diagnosis for each LTCF with respect to the pandemic;
2. Implement efficient contingency measures against COVID-19;
3. Provide comprehensive care while coping with the pandemic.

The report described the main measures needed to avoid infection, provide early diagnosis, manage and isolate symptomatic patients, determine admission criteria, deal with deaths and palliative care, and maintain institutional functionality. It also included guidance about maintaining social and family connections during preventive isolation.

In May 2020, the NF-LTCF published a report on good LTCF practices for the House of Representatives' Commission for the Defense of the Rights of Older Adults.¹⁵ This material describes educational strategies that could improve training for managers of LTCF and group homes, as well as provide information for the family members of older adults and society in general.

Since it was important to disseminate the material in these two documents to stakeholders, several remote training programs were developed for LTCF staff, including managers, administrators, supervising technicians, caregivers, cooks, cleaners, nurses, rehabilitators, and social workers. Live nationwide webinars were held and later posted to NF-LTCF social network channels.

More than 1400 registered volunteers (experts, scholars, managers, and researchers on aging and public policy regarding the protection of older adults) were organized into thematic subgroups that worked on different strategies, creating new topics and support materials for LTCFs in several fields. The present experience report will be subdivided into national and regional actions. All described materials are available at www.frentenacionalilpi.com.br.

The NF-LTCF's Consolidated Report was published on the Brazilian Society of Geriatrics and Gerontology website on April 24, 2020, and was presented at a public hearing of the Commission for the Defense of the Rights of Older Adults in the House of Representatives on May 7, 2020. It was also presented to other bodies, such as the National Council of District Attorneys' Human Rights Group, State Councils for the Defense of the Rights of Older Adults, the National Association of District Attorneys for the Defense of Older Adults and People with Disabilities (AMPID). It also contributed to a Ministry of Citizenship ordinance¹⁶ regarding the Brazilian Unified Social Assistance System

(SUAS). The report was then translated into English and shared with international organizations, including the WHO Long-Term Care Workgroup, the International Longevity Center's Global Alliance,¹⁷ which operates in 17 countries, as well as Corona Older's Global Platform.¹⁸

Another result of the NF-LTCF was the establishment of the National Front of Councils for the Rights of Older Adults (FCC) in May 2020, given that coping with the pandemic required swift action to defend the rights of older adults efficiently and autonomously. Since then, the FCC has been sharing experiences and proposals for stronger councils, holding live diagnostic sessions, and providing support materials nationwide. Two reports with an updated diagnosis of the performance of councils for older adults have been produced and are available on partner websites (www.ilcbrazil.org.br).

In June 2020, the Everyone for Health Movement (TPS), which received BRL 1.2 billion in funding from Banco Itaú to reduce the impact of the pandemic in Brazil, requested permission to use the NF-LTCF's Consolidated Report as a basis for training visitors to monitor the development of COVID-19 cases in 620 selected LTCF. In September 2020, the TPS invited the NF-LTCF to develop material for its training program for LTCF professionals. This program included a further 1000 LTCF, which received materials to mitigate the pandemic. In October 2020, the NF-LTCF organized a training program based on everyday stories of facilities that addressed patient care and management, social and family networks, and functionality, engaging LTCFs managers and collaborators. Approximately 13,000 professionals watched its live online sessions.

In May 2020, the NF-LTCF worked directly toward the passing of Law 14.018/2020, which made BRL 160 million available to LTCF on an emergency basis. With the motto "The life of every older adult living in LTCF matters", the NF-LTCF spearheaded a broad campaign to encourage both public and private LTCFs to apply for these funds. However, it was later determined that only non-profit LTCFs could apply.

In May 2021, in celebration of the one-year anniversary of NF-LTCF, a webinar was held on Corona Older's Global Platform.¹⁸ The NF-LTCF also staged a national seminar for LTCFs called "Building partnerships". The seminar's 37 speakers consisted of volunteers, family members, and researchers. A total of 3188 participants registered for the event. This event addressed LTCF management, care, and financing issues. On a national level, as of August 2021, the NF-LTCF has participated in 8 public hearings at the House of Representatives about the coronavirus pandemic and the need to strengthen the LTCFs.

The NF-LTCF's activities have benefitted from a partnership with the Proqualis program of the Oswaldo Cruz Foundation and the Federal University of Minas Gerais, which led to live online courses on "Health care and safety in long-term facilities for older adults in the context of COVID-19" and the "Oral health refresher course: training in professional care for older adults".

REGIONAL GROUP ACTIONS

The NF-LTCF also worked in regional subgroups to encourage dialogue and the sharing of experiences between LTCF in the same region. Each of these subgroups had at least one volunteer coordinator who directly facilitated communication between the NF-LTCF, volunteers, and other institutions, which led to a consolidated report of regional initiatives. This organization was more active from May to June 2020 and is described in Figure 1.

PRODUCTION OF EDUCATIONAL AND TRAINING MATERIALS

The NF-LTCF is using communication app groups, social networks, live online sessions, and its website to share materials digitally. Figure 2 shows a summary of the NF-LTCF's output and its national and international scope.

Social networking is handled by the NF-LTCF's communication staff, which allows for nationwide coverage. Materials can be accessed through Facebook, YouTube,

and Instagram, and facilities can contact the group through WhatsApp groups, e-mail, or by telephone. The splash screens and menus of these media outlets were designed to provide a friendly, stimulating, and encouraging experience.

All NF-LTCF materials consider the cultural diversity of the region for which they are produced. Care is taken that event billboards and other artwork are inclusive and didactic,

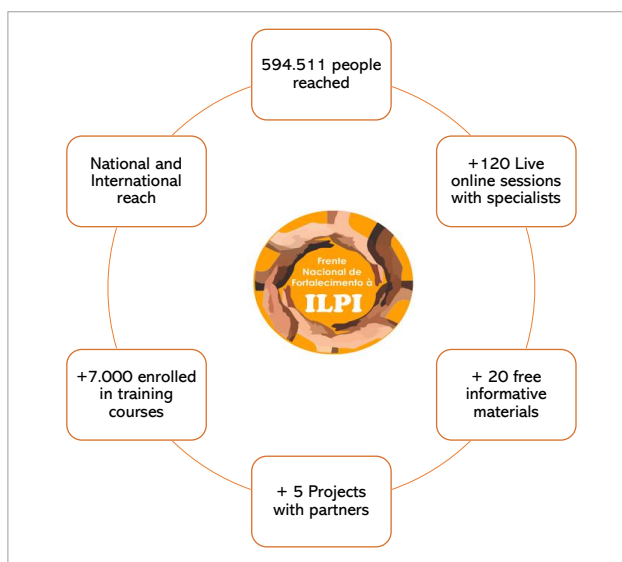


Figure 2. Summary of National Front for Long-Term Care Facilities output from April 2020 to August 2021.

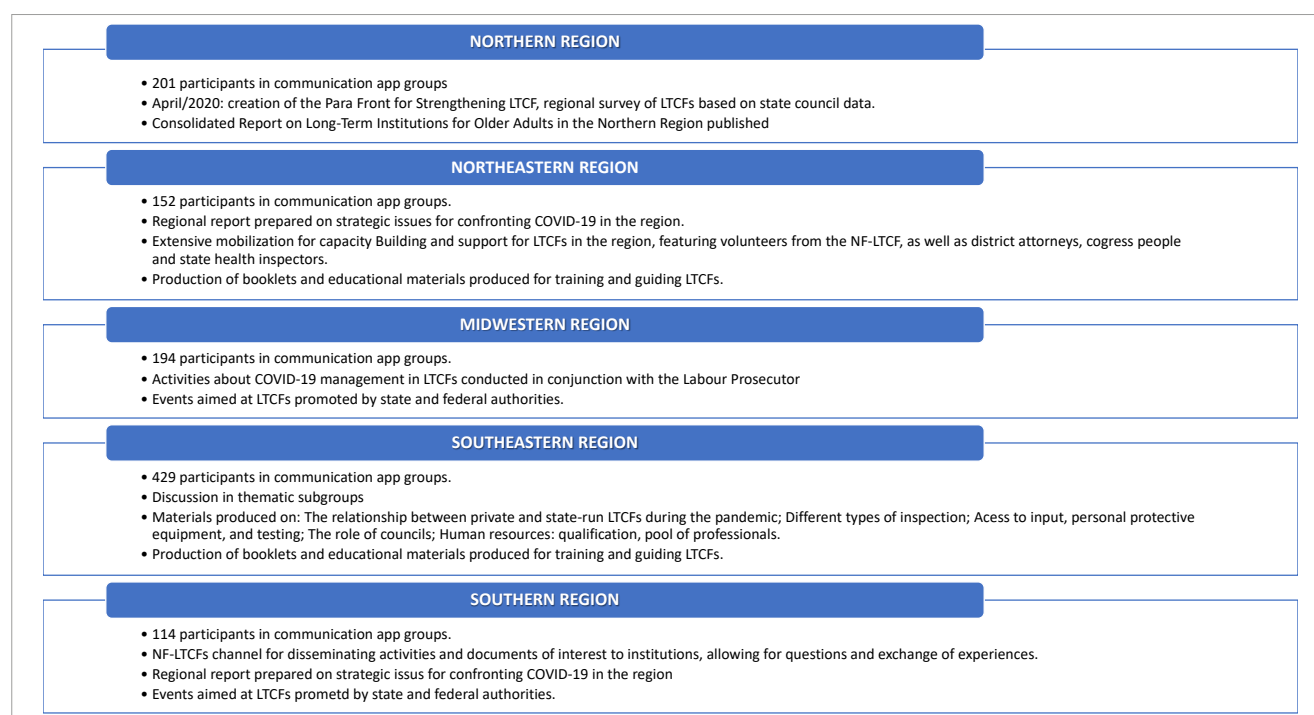


Figure 1. Initiatives of the regional groups of the National Front for Strengthening Long-Term Care Facilities.

considering guests and representatives of the different regions in the live online events. These initiatives have reached more than 594 000 people.

The NF-LTCF has produced more than 20 educational materials, including “Managing COVID-19 in LTCF”, which was made available between June and August 2020, and “Visiting LTCF Management”, which was made available between October and November 2020. These two materials led to a number of synchronous virtual training sessions for LTCFs throughout Brazil, with more than 7000 professionals participating. The public’s active participation in training and live online sessions is encouraged, and any questions posted on the YouTube or Facebook channels are answered in the training sessions. Public participation in the live online sessions led to the production of new informative materials to respond to frequently asked questions.

The following educational materials are available on the NF-LTCF website:

- How to support older adults in LTCF: the role of family and friends
- Taking care of caregivers
- LTCF multidisciplinary teams: comprehensive care during the COVID-19 pandemic
- Emergency guidelines about visiting LTCF during the COVID-19 pandemic
- Clinical Management and COVID-19 control in LTCF: physical therapy guidelines, hygiene guidelines, oral health guidelines, and cognitive stimulation guidelines.

The Brazilian Nursing Association’s Scientific Department of Gerontological Nursing partnered with NF-LTCF in 2020 to produce two educational primers for LTCF: “Preventing injuries from personal protective equipment and clothing in long-term institutions for older adults” and “Preventing pressure injuries in institutionalized older adults during the COVID-19 pandemic”.

The NF-LTCF works with more than 100 WhatsApp groups to disseminate information, provide support for training platforms, interact with and strengthen local LTCF, send materials, and help with other tasks. The NF-LTCF’s activities in WhatsApp groups and live online sessions, as well as its digitally distributed materials have given it broad credibility. Its work has been presented in national and international events, universities, associations, and congresses. As Fernandes et al.¹⁰ point out, NF-LTCF productions stand out as the most well-developed materials for LTCF in the pandemic context.

WORKGROUPS

In September 2020, due to the requests from technical supervisors and LTCF collaborators, workgroups were established in four areas to speed up NF-LTCF training, legal support, care quality, research, and diagnostic activities.

Training workgroup

The Training Workgroup was developed after members from the southeast region began using guidelines for preventing and managing COVID-19 that focused on social and family networks. These participants held a number of virtual meetings via WhatsApp to plan further primers and workgroup training sessions. Work on 5 fronts led to the production of tools, primers, and documents, all available on the NF-LTCF website, which address practical clinical management criteria through an algorithm, an institutional overview spreadsheet based on the Kanban system, and a pocket guide to help interdisciplinary teams classify LTCF residents with a suspected or confirmed COVID-19 infection. These materials have been used as point of reference for LTCF and government agencies in decision-making and national recommendations.

Legal support workgroup

This workgroup held live online sessions for LTCF about new legal demands that appeared with the pandemic, changes that affect management (specifically labor issues), how to address restricted visitation issues, and a protocol for dealing with employees or residents who refuse the COVID-19 vaccine. This workgroup supports other groups with respect to best practices in the legal management of LTCF and provides timely guidance to institutions that need help with specific cases.

Care quality workgroup

This group emerged to answer the following question: “What can we do to improve care quality in LTCF?” The Participants in the Care Quality Workgroup seek to develop and practical routines so that LTCF can offer quality resident-centered care. Its main concern is helping the staff of these institutions believe, support, and achieve older adult-centered care. Quality care is defined as “the degree to which health services increase the likelihood of desired health outcomes for individuals and populations and are consistent with current professional knowledge”.¹⁹ Besides helping organize the training offered by the NF-LTCF, this workgroup created the Care Quality Manual for LTCFs (Figure 3), which consists of 20 chapters written by 54 collaborators from different fields involved in LTCF.²⁰

Research and diagnosis workgroup

The Research and Diagnosis Workgroup developed a task force to identify whether or not changes in the profile of Brazilian LTCF had changed since their origin. The Study, Research, and Diagnosis Group for Older Adults (GPED-LTCF) was formally established in November 2020. It was linked to the School of Arts, Sciences, and Humanities of the University of São Paulo, a pioneer in LTCF-related issues. This group was registered with the National Council for Scientific and Technological Development (CNPq) and consisted of 16 researchers and 23 volunteers from all regions of Brazil.

This workgroup developed a research project called “National Mapping of Long-term care facilities for Older Adults”, which was inspired by a 2010 census-based study by the Institute for Research and Advanced Studies. Its starting point was when issues arose in the NF-LTCF related to the number, location, legal nature, and identification of the existing Brazilian LTCF. The lack of a unique registry with this information led to the construction of the three-step research project:

Step 1 - Preparation: This period began in September 2020, aiming to produce a literature survey and a preliminary

registry of all LTCF with data available in publicly accessible databases, such as the Unified Social Assistance System, Municipal and State Social Assistance and Health Secretariats, Councils for the Rights of Older Adults in the three branches of the government, and municipal and state health surveillance agencies. This preliminary search revealed a considerable increase in LTCF in Brazil between 2010 and 2021: from 3 548 to 7 029 (ie, a 100% increase in about a decade). These facilities were found through tax records (CNPJ) or in the previously mentioned databases. Furthermore, LTCF distribution was heterogeneous among regions, with alternating growth and decline. These findings are due to the legal nature of LTCF (public, private, or non-profit) and the applicable requirements and norms that must be observed to guarantee assistance and care for institutionalized older adults in each region. All data will be described in detail in a future NF-LTCF publication.

Step 2 - Census-Based Survey: A census-based survey is expected to occur between 2021 and 2022 to reach all LTCF in the consulted databases.

Step 3 - Questionnaire: At this stage, data will be collected through an online form based on the 2010 Institute for Research and Advanced Studies questionnaire, adapted to measure the impact of COVID-19 on institutions.

The Research and Diagnosis Workgroup also promoted reflection on the following questions:

1. “What is the identity of LTCF for older adults in Brazil?”
2. “What are the bureaucratic, legal, and health barriers to an adequate characterization of these facilities?”
3. “How can the LTCF, which are legally configured as such, adapt to current legislation?”

FINAL CONSIDERATIONS

The development of the NF-LTCF has supported LTCF nationwide. With a level of collaboration seldom seen among these facilities, it created a culture of support for managers and professionals, which has led them to overcome their insecurity and share daily issues, whether in the context of management or care, as well as resolving questions about the existing legislation through the NF-LTCF communication channels.

It is important to understand how to provide support. The daily debate and shared experiences, contacts, and documents have been cited as another distinctive characteristic of the NF-LTCF, whose volunteers have spared no effort to help LTCF. The NF-LTCF’s multidisciplinary presence ensures rich discussions and guidance for participants in



Figure 3. Care Quality Manual for Long-Term Care Facilities, produced by the Care Quality Workgroup.

their constant search for real-time answers to questions and challenges. The Brazilian LTCF are invisible to the public authorities and society and, thus, are victims of prejudice. They are not recognized as facilities that promote social well-being and a locus of care for their residents and the community.

Furthermore, throughout its history, the NF-LTCF has assembled activists from other movements interested in improving LTCFs, such as the District Attorney's Office, health inspectors, congressmen, and experts in different areas: doctors (geriatricians, public health specialists, and psychiatrists), nurses, caregivers, gerontologists, psychologists, speech therapists, nutritionists, dentists, physical therapists, social workers, lawyers, technology and communication professionals, architects, and physical educators. It is a movement with broad and open participation, including anyone who wants to contribute to its mission.

If, on the one hand, Brazil has severe problems that require responsible action by the government, it also has volunteer movements that address urgent causes. The COVID-19 pandemic has been a catalyst, revealing the invisibility and vulnerability of older adults in LTCF and leading to the development of the NF-LTCF. The movement needs all of its supporters and participants to persevere in confronting prejudice against these facilities, defending the life of every older adult residing in them, and relentlessly seeking support for a national continuing care policy.

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CONFLICTS OF INTEREST

The authors declare no conflicts of interest.

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NCH: Conceptualization, writing – original draft, writing – review & editing. PJFVB: Conceptualization, writing – original draft, writing – review & editing. AFSC: Conceptualization, writing – original draft. SVST: Conceptualization, writing – original draft, writing – review & editing. GCC: Writing – review & editing. ACA: Methodology, writing – original draft. MMTT: Conceptualization, writing – original draft. WCBA: Writing – original draft, writing – review & editing. EHS: Writing – review & editing. KCG: Project administration, conceptualization, writing – original draft, writing – review & editing.

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