

# Long-term care staff perspectives on the care of older people with dementia during the COVID-19 pandemic.

*Perspectivas dos profissionais de Instituições de Longa Permanência para Idoso sobre o cuidado de pessoas com demência durante a pandemia de COVID-19.*

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### Abstract

The Brazilian long-term care sector remains poorly structured and underdeveloped. During the COVID-19 pandemic, this sector faced many challenges which probably accentuated other common issues experienced by older persons living in Brazilian Long Term Care Facilities (LTCF), especially those with dementia. In this pilot study, we evaluated the staff perspectives toward the care of older people living with dementia during the COVID-19 pandemic. Twenty-four participants from seven different LTCF located in São Paulo State participated in this study. Opinions/experiences of the LTCF workers about the impact of the COVID-19-related changes in the care of and in residents with dementia themselves were collected through an online survey. Qualitative results highlighted concerns about the impacts of COVID-19, such as challenges related to the adequate following of precautionary measures and negative effects on behavioral and psychological symptoms related to dementia. COVID-19 precautionary measures, especially social distancing, had a negative impact on the care for and on persons living with dementia in LTCF. Limited awareness or understanding of the COVID-19 scenario seems to affect residents with dementia in different ways. In future similar scenarios, it is important to think about how to support the LTCF in the achievement of a balance between the protection and well-being of residents with dementia.

Key words: Dementia. Nursing Homes. COVID-19.



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## Introduction

Over the past two years, the COVID-19 pandemic has changed the world dramatically. The vulnerability of the population living in Long Term Care Facilities (LTCF) made them a high-risk group associated with increased morbimortality (THOMPSON et al., 2020). The LTCF sector adopted special measures worldwide to prevent the spread and mitigate COVID-19 in LTCF, like physical distancing and banning visitors. Beyond the fact of being characterized as residence, the sanitary crisis probably accentuated other common difficulties for Brazilian LTCFs, such as the care of patients living with dementia (PLWD). Thus, the present study aimed to explore LTCF staff's perspectives toward the care of PLWD during the COVID-19 pandemic in São Paulo State.

## Material and Methods

This is an exploratory qualitative study, conducted from October 2020 to April 2021. Workers from different LTCF in São Paulo State were invited to participate in the study. Due to sanitary restrictions, participants voluntarily responded to an online survey. The questionnaire was organized into four sections, as described by previously work from WE-THRIVE consortium (CORAZZINI et al., 2019). Each section included close and open-ended questions. The last collected the opinions/experiences of the LTCF workers about: 1) situations in which one or more aspects of the respective sections affected the care they provided to PLWD, 2) changes in the importance of the aspects of the care due to the COVID-19 pandemic and 3) the impact of the COVID-19 related changes in the care of PLWD. The content of open-ended questions was translated into English and back-translated to Portuguese for internal validity and cross-language equivalence. The content were then coded by the research team. After iteratively discussing and reaching a final set of codes, two experienced researchers in qualitative analysis reviewed all coding decisions to ensure that the researcher team reached conceptual alignment. Coding discrepancies were then solved by experienced researchers. Thematic framework analysis was carried out from the detailed and summarized discussion notes used. The study was approved by the Ethics committee board of the São Paulo State University under the C.A.A.E. number: 37612720.3.0000.5411.

## Results and Discussion

Twenty-four participants from seven different LTCF answered the electronic questionnaire. The majority (57.1%) of the LTCF were for-profit and the number of residents ranged between seven and 77 per LTCF. The prevalence of PLWD varied between 25.4% and 85.7%. The majority of responders were caregivers (52.2%) and had been working in long-term care for more than three years (58%). A summary of qualitative analysis is presented in table 1. The present results are in accordance with previous studies. Due to cognitive impairment, PLWD seem unable to understand, follow, or even remember the precautionary recommendations and, consequently have a high risk to contract COVID-19 (BROWN et al., 2020). Similarly, negative effects of routine changes and distancing measures on PLWD were also noticed by other authors (SMALING et al., 2022). As some recommendations can be viewed as a "double-edged sword"

for older adults, it is desirable to think about how to support LTCF in seeking for balance between protection and the well-being of residents in future similar scenarios.

**Table 1.** Themes, sub-themes and supporting quotations.

Theme 1: COVID-19 precautionary measures	
difficulty to understand the sanitary context	<i>"It is to make the old resident understand the disease itself and the safety measures as the main way to avoid getting infected. ... Sometimes they understand and other times they question why they are abandoned by the family."</i>
extra support with protocols	<i>"Yes, especially reinforcing hygiene, the use of a mask, and more frequent orientations to the residents."</i>
Theme 2: COVID-19 impacts on residents	
social aspects	<i>"With the pandemic, visits were suspended. ... This distance from family members had a negative effect on the residents. Some thought they were abandoned, others that their family members died."</i>
behavioral aspects	<i>"... for not understanding the circumstances, the patients with dementia became stressed and anxious making an impact in patient care."</i>
none	<i>"In general, those with dementia are not suffering much"</i>
Theme 3: COVID-19 impacts on care	
negative	<i>"The patients could walk freely without worrying about social distance among themselves. Now we have to keep them apart"</i>
positive	<i>"I believe that today we are more aware of the importance of hand hygiene among patients, what did not happen before"</i>
none	<i>"The pandemic has not affected the care for the old resident with dementia because they seem to be in a different reality"</i>

## Conclusion

COVID-19 precautionary measures, especially social distancing, had a negative impact on the care for and on PLWD in LTCF. Limited awareness or understanding of the COVID-19 scenario seems to affect residents with dementia in different ways.

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