Accessing dementia care in Brazil: an analysis of case vignettes

Abstract

Background and Objectives: Despite the rapid increase in the number of people living with dementia in Brazil, dementia care is limited. This study describes how people living with dementia and their carers access care, treatment, and support, and identifies what characteristics are likely to enable or prevent access.

Research Design and Methods: We created ten vignettes to illustrate fictitious but realistic scenarios involving people living with dementia in Brazil. The vignettes explore a combination of socioeconomic and demographic variables. They were completed using an in-depth desk review of the dementia care landscape in Brazil; a Strengths, Opportunities, Weaknesses, and Threats (SWOT) analysis of the desk review; and expert knowledge. The analysis focused on identifying common sources of service provision, barriers of access to care and support, and specific issues experienced by some population groups.

Findings: access to a dementia diagnosis, care, and support for people living with dementia in Brazil is limited. Demographic and socio-economic circumstances play a role in determining the type of services to which a person might have access. Poor knowledge about dementia, lack of capacity in the health system, and lack of formal long-term care support are among the identified barriers to accessing timely diagnosis, care, and support in the country.

Discussion and Implications: Understanding the barriers and facilitators of access to diagnosis, treatment, and support for people with dementia and families with different demographic and socioeconomic characteristics is crucial for designing dementia policies that are context-specific and responsive to the care needs of different socioeconomic groups in Brazil.

Keywords

Dementia, access, care, support, pathways, Brazil, vignettes

Background and Objectives

Brazil has gone through a rapid increase in the number of people living with dementia, as a consequence of an ageing population (Melo et al., 2020). Recent epidemiological studies estimated that the burden of Alzheimer's disease and other dementias increased by 6% between 2000 and 2016 (Melo et al., 2020), and that about 1.8 million people were living with dementia in 2019 (GBD, 2022).

Access to a timely dementia diagnosis is crucial for a person to receive proper interventions from a team of health and social care professionals, leading to a positive impact on care and quality of life (Alzheimer's Disease International, 2021). Receiving a timely diagnosis may enable people living with dementia and their carers to access resources and information for themselves and others, destigmatize the condition, and plan for the future (Alzheimer's Disease International, 2021). However, dementia underdiagnosis rates worldwide are high; in Brazil, only about 1 in 4 persons receive a formal diagnosis (Nakamura et al., 2015).

Dementia is considered to be one of the most disabling disorders among older people (ADI, 2015), incurring high costs for families (Ferretti et al., 2018), demanding continuous and coordinated care at moderate to advanced stages. Such evidence has prompted the development of global policies aimed at improving the lives of people living with dementia and their families. Examples include the Global Action Plan on the Public Health Responses to Dementia 2017-2025, the World Alzheimer Report 2021, and the PAHO anti-stigma campaign (Alzheimer's Disease International, 2021; Reyes, 2019; World Health Organization, 2017). However, despite the emphasis these international policies have given to a timely diagnosis and person-centered post-diagnostic support, dementia care in Brazil has received limited attention from policymakers.

Currently, dementia care is still underdeveloped and a specific care pathway is practically nonexistent in the country. Typically, people living with dementia in Brazil receive care provided by the public health system (the *Sistema Único de Saúde, SUS*) or by the private health sector (Brazilian Ministry of Health, 2019). The SUS is universal, state-funded, and free of charge at the point of use. The private health system works through out-of-pocket payments from its users and established contracts with health care insurance companies. Some formal long-term care (for example, care homes and day centres) is provided by the

Unified Social Assistance System (SUAS). Access to the SUAS is mostly means-tested, often focused on people without financial resources to pay for their care or without family support (Brazilian Ministry of Citizenship, 2015).

People living with dementia are cared for under the broad umbrella of care for older people, which is regulated by national public policies and guidelines outlining levels of care associated with generic types of needs, regardless of any specific underlying diagnosis or condition (Brazilian Ministry of Health, 2006; Presidency of Republic of Brazil, 2003). At present, Brazil lacks a clear understanding of what services and support people living with dementia do access, when and how they access such services and move across different services and different sectors (e.g. health and long-term care), and of the contextual and individual factors that affect care access and use.

This work aims to fill in these gaps and to generate information that could contribute to developing a dementia care pathway tailored for the Brazilian context. Specifically, this work intends to

1. Map the types of services for diagnosis, care, and support related to dementia available in Brazil for people in different socioeconomic groups and geographic locations
2. Understand when and how people access and use these services
3. Identify the enablers or barriers to service access and use
4. Identify policy options for improving the issues identified

Research Design and Methods

This work is based on a vignette approach. Vignettes are short stories based on a hypothetical person or scenario, and they are usually developed from previous research or examples of situations that reflect the local context (Gourlay et al., 2014; Mah et al., 2014). For this study, a set of ten vignettes, each describing the life of a fictitious person with dementia and their family carers living in Brazil, was developed and used to describe their likely care journeys.

This study is part of the STRiDE project – Strengthening Responses to Dementia in Low- and Middle-Income Countries (LSE, 2022), an international research program (2018-2022) aimed at generating evidence to support the development of dementia care policy and to inform practice in seven low- and middle-income countries (Brazil, India, Indonesia, Jamaica, Kenya, Mexico, and South Africa). A research team based in the UK and South Africa provided methodological support to the country teams.

The study was approved by the Research Ethics Committee of the London School of Economics and Political Science, by the Research Ethics Committee of UNIFESP, and the National Commission for Research Ethics in Brazil (CONEP) (CAAE: 12917019.3.0000.5505). Written informed consent to participate in the research study was obtained from study participants.

The vignettes were developed in five steps, as described in the following sections.

1. Creating the Vignettes

An initial set of five core vignettes (cases 1, 2, 3, 4, and 5; Table 1) was jointly developed by researchers from the seven country teams during a STRiDE workshop in March 2019. Each vignette aimed to sketch the life and circumstances of a person living with dementia in a way that could be both generic and realistic across the seven countries.

Each vignette included information such as: i) who the person with dementia was, ii) how their relationship was with family members, iii) what were the perceived signs and symptoms of dementia, and iv) what changes occurred in the person and family’s life. A detailed overview of the process used to create the core case vignettes can be found elsewhere (Lorenz-Dant et al., 2022).

The Brazil’s research team (FM, DO, EM, CF) recognized that some important features of the Brazilian context were not explicitly addressed in the five core vignettes and for this reason five additional vignettes were created to capture the country's cultural, demographic, and geographical heterogeneity.

2. Developing the vignette trajectories

The Brazilian research team (composed of a psychiatrist, a nurse, a physiotherapist, and a professor of applied linguistics who is also a caregiver of somebody living with dementia) convened to discuss each vignette and describe how each person with dementia would most likely access diagnosis, care, treatment, and support. This phase was guided by a set of probe questions aimed at framing the discussion around the trajectories of each vignette (Supplemental Material) (Lorenz-Dant et al., 2022).

This phase built also on two sets of information. First, we used the findings of a comprehensive desk review of the literature about the dementia care landscape in Brazil focussing on the country context, health and long-term care systems, policies, and services (Da Mata et al., 2022) complemented by a Strengths, Weaknesses, Opportunities, and Threats (SWOT) analysis of different aspects of dementia care in Brazil (e.g. care system, epidemiology and information systems, dementia awareness, and stigma) conducted in 2019 as part of the STRiDE project.

Second, we relied on data collected through interviews and focus groups carried out as part of a study within STRiDE with different groups of stakeholders from across the country. In total 57 individuals (7 persons living with dementia, 19 family carers, 11 healthcare professionals, 5 policymakers, and 15 members of the public) took part and discussed their views and attitudes towards dementia, and shared their understanding or lived experience of dementia care.

The findings of the desk review, SWOT analysis, stakeholder interviews, and focus groups were used as sources of information to describe the trajectories of the ten case vignettes. The authors (FM, DO, EM, CF) reviewed the completed vignettes and agreed on each of them.

3. Vignettes External Validation Process

We validated the vignettes in three successive steps.

First, we organized four online meetings with healthcare professionals (three psychiatrists, a gerontologist, a nurse, a physiotherapist, a psychologist), five academics, and two psychiatry trainees from Brazil. Vignettes were emailed in advance of the meetings so that attendees could familiarize themselves with them.

During each meeting, two to three case vignettes were presented by the STRiDE Brazil team, followed by an in-depth discussion about the relevance and comprehensiveness of each case vignette. The discussions led to some changes in the previously designed trajectories of service use. For instance, we included services provided by traditional healers, a common source of help in some regions of Brazil. We also agreed that different routes of access greatly depend on the financial situation of the person living with dementia, and this was reflected in the final vignette.

Second, we invited the STRiDE Steering Committee (a group of 15 persons, including people living with dementia, family carers, neurologists, psychiatrists, government policy and decision makers, nurses, journalists) to revise and comment on the vignettes. Three persons from the committee agreed to participate (a journalist, a healthcare professional, a member of the government). We emailed each of them two case vignettes and received their responses in writing. Their feedback was mainly based on their work experience and led us to consider additional topics in developing the likely trajectories to be included in the vignettes, such as the need for trained healthcare professionals in dementia, and the need for more information on dementia to be delivered to the general public in Brazil.

Lastly, the vignettes were reviewed by members of the STRiDE team in other countries, including KL. Based on the feedback received, we added an overview of some of the services delivered in Brazil so that international readers could better understand the vignette case trajectory. The STRiDE Brazil team then incorporated the feedback received through the different validation routes into a final version of the vignettes; (see Supplemental Material and the STRiDE website) (LSE, 2022). Table 1 provides an overview of the main characteristics of each vignette.

4. Data extraction

These vignettes explore how people living with dementia and their families in different circumstances are most likely to navigate care pathways from the pre-diagnosis to potential diagnosis, treatment, and support in Brazil. We prepared a systematic, tabular overview following key questions outlined in the vignette guidance document (Lorenz-Dant et al., 2022) and based on the framework method, which allowed us to compare and contrast data across vignettes as well as within individual vignettes (Gale et al., 2013). The table helped us compare where people depicted in the vignettes access health and long-term care services, their likely family arrangements, and the impact of formal and informal care arrangements on their lives (e.g., social life, financial implications).

5. Analysis of the care systems through the vignettes

Building on the framework method (Gale et al., 2013), we charted the information from each vignette into a matrix (pre-prepared Excel table) following 13 *a priori* structured questions (Lorenz-Dant et al., 2022). After charting the data, we identified gaps and barriers that may have hindered access to diagnosis, treatment, and support for people with dementia and their families for each of the vignette scenarios.

Next, we compared the charted responses for each question across the ten vignettes to identify similarities and differences, then we reflected on whether these differences and similarities were likely due to some key *a priori* variables explored in the vignettes (see Table 1). For instance, we identified that, for most vignettes, primary care units are the first point of access to health care. Then, we identified that socioeconomic status, a key *a priori* variable in developing the vignettes, was a significant factor in determining access to care.

Findings

The ten case vignettes (available as supplemental material and at the STRiDE website [LSE, 2022]) helped us describe how a diverse set of people living with dementia and their family carers access and navigate (or are unable to do so) dementia diagnosis, treatment, care, and support in Brazil.

Below we present the results of the analysis of the care systems through the vignettes. The results are organized in three themes: (1) access to diagnosis, (2) access to ongoing care and support for people living with dementia, and (3) role of family carers. We selected these themes because we consider them a useful sequence to understand and present the gathered information on dementia care and support in Brazil.

1. Access to a diagnosis

The vignettes illustrate that the way in which people access a dementia diagnosis differs considerably across Brazil. Various factors can influence the routes through which people may get diagnosed, varying from whether an individual can access public (SUS) or private healthcare to cultural beliefs and economic factors.

In the SUS, the first consultation with a medical doctor generally occurs in a primary care unit. The consultation may happen via individual active help-seeking (in primary care units) or home visits. Vignette 1 depicts the case of an older couple with family support in rural Brazil with the wife showing symptoms of dementia. This case exemplifies home-based care delivered by the Family Health Strategy (FHS) team, a community-based program that integrates medical care, health promotion, and public health and involves community health workers who help connect the community to the primary care units.

In the private system, the person with memory concerns may choose to see a general practitioner first or directly book an appointment with a specialist. In vignette 8, describing a couple with the financial means to access the private system, for example, the specialist is consulted directly, leading the person living with dementia to be examined and diagnosed through the private health system in a relatively short period of time. In contrast, had he gone through a referral from a general practitioner, the process could have taken longer. However, it is possible for people not to receive a diagnosis, not have a diagnosis disclosed, or be misdiagnosed with another health problem. Vignettes 8 and 9 illustrate these situations.

Both in the public and private systems, people are often referred from a general practitioner to secondary care, for further investigation and diagnosis by a neurologist, geriatrician, or psychiatrist. Figure 1 shows possible health services pathways at primary and secondary levels of care as well as the factors that might influence this process. For instance, vignettes 1 and 6 show that a person living in a rural area and a person from an indigenous tribe living in a riverside community in the Amazon Forest might both use traditional healers as their first care choice. People in Brazil commonly believe that the symptoms of dementia are a natural part of aging, which often leads to further action being delayed or not being taken. This happens regardless of location, socioeconomic status, and type of health care system used (see vignettes 1, 2, 3, 5, and 7).

Table 2 shows the barriers to receiving a dementia diagnosis and the vignette characteristics linked to them. We found that all these barriers may delay the diagnosis or may lead to the possibility of someone never receiving a dementia diagnosis. However, we noted that the Brazilian SUS might facilitate access to a diagnosis if clinicians are aware of and trained in dementia. The supplemental figures 1 and 2 show likely common care pathways of people living with dementia in Brazil.

It is also worth noting that living arrangements and family circumstances may play a role in triggering (or not) the process of seeking a diagnosis. Signs and symptoms of dementia may go unnoticed for long periods among older people more isolated or living alone (e.g., after the death of the spouse), whereas they may be identified more promptly among people living with their adult children or relatives.

2. Access to long-term care and support for people living with dementia

Long-term care and support in Brazil are provided through health care, community-based, and residential care services. People living with dementia can access services provided by SUS or the private health care system at three levels of care (primary, secondary, and tertiary) depending on their health needs.

As part of primary care, people living with dementia in municipalities covered by the FHS may also seek help from this program. In the FHS, community health workers and nurses usually establish initial contact with those living in the community. Beyond primary care units, access to care is also possible through mobile services in remote areas, such as visiting teams travelling to indigenous communities by boat (see vignette 6). The FHS, including the GP, often become the main healthcare provider of people with dementia who access such services (vignettes 1 and 3).

As part of secondary care, diagnostic imaging, specialist doctors, and other health care professionals, such as speech-language therapists and physical therapists, are available through SUS and the private system through referral. However, people with dementia may not access these services due to non-referral and shortage of services. Non-referral might happen because of lack of knowledge by health professionals in associating these services with helping people living with dementia, as described in vignette 2. It may also occur due to the limited availability of therapies and infrastructure, mainly in public services and remote areas, as described in vignettes 7 and 9.

People living with dementia may access the tertiary level of care for more complex procedures or highly specialized treatments (vignette 9). In addition, vignette 3 shows that the FHS may also provide some home-based advanced health care support, such as help with a feeding tube and wound dressing. People with high socioeconomic status may access medical consultations, health checks, and domiciliary health care privately (vignette 8). Community-based services, provided by older people's and Alzheimer's associations, FHS teams, and primary healthcare units, offer psychosocial support to people living with dementia. Vignettes 2 and 5 show that these types of support are generally available in urban areas;

vignettes 1, 6, 9, and 10 show that psychosocial support in remote areas is almost nonexistent or when available is most likely unknown by the population.

Some informal support is offered within the community, as exemplified in vignette 6, where people living with dementia may receive help from their riverside community, and in vignette 7, where neighbors take care of a man living with dementia in a slum. Finally, the support received from family members and the community seems essential for people living with dementia regardless of socioeconomic status and geographical location. Lastly, use of long-term residential services is often stigmatized, as described in vignettes 2, 3, 4, and 8. There is a common belief that families should be responsible for caring for their older relatives. This belief, combined with negative views held towards long-term care facilities, makes these settings the last resort.

By and large, the SUS has shown strong capacity to reach out to highly remote areas and deliver domiciliary services (such as home-delivery medication) and home-based consultation. However, we identified through the vignettes some gaps and barriers that prevent access to ongoing care and support to people living with dementia, such as poor training in dementia among healthcare professionals and insufficient good quality public long-term care facilities (Table 2).

3. Role of family carers

Family carers are most likely to be women, particularly when providing personal care, with men taking up other responsibilities (e.g., transport and financial support). After diagnosis, living arrangements often change, for example when two generations move in together, as shown in vignettes 3, 4, 5, and 9. Vignettes 1, 2, and 9 show that taking on care responsibility without support can impact on carers' quality of life due to feelings of loneliness and unmet physical and mental health needs, and may lead to adverse health outcomes (such as depression, anxiety), tiredness, poor sleep. Female carers often give up their jobs, bringing financial vulnerability to this group.

Sporadic support for carers may be received from extended family members as shown in vignette 2 and the broader community as in vignette 6. The psychosocial support offered by NGOs and community health centers (provided by the public or the private sector) is more often located in urban areas. The FHS may also provide information and some health-related care at advanced stages of dementia (vignette 2).

In addition, help from private formal carers is available, as exemplified in vignettes 8 and 10; however, it is only accessible to those who can afford it. Our results also identified gaps in service provision to carers, such as limited opportunities to seek information about dementia and its care needs, no formal carers or respite care service funded by the government (Table 2).

Discussion and Implications

Our vignettes show the likely pathways for a set of people with dementia and their family, from the pre-diagnosis phase to the post-diagnosis phase, considering the influence of demographic variables and family arrangements.

In Brazil, access to diagnosis, care, and support is influenced by a number of factors, from the diverse geographical, social, and cultural conditions that characterize different areas in the country, to a general lack of investment in social care, lack of dementia-specific services and training for the healthcare workforce. These barriers often limit or prevent access to needed healthcare services (when existing), resulting in an increased risk of poor health outcomes and health disparities (Smedley et al., 2002). Moreover, considering the Covid-19 impacts on access to care and services, we discuss the likely impact of the pandemic on care and support for people living with dementia and their carers in Brazil.

The initial steps towards a dementia diagnosis in Brazil commonly start by seeking help from physicians within primary care services (via SUS), private systems, or traditional healers. In Brazil, around 70% of the population uses SUS as the first source of health care (Brazilian Institute of Geography and Statistics, 2020). In addition, the FHS is a key provider of primary care in the country (Macinko et al., 2019). In our study, we identified the following barriers to accessing a dementia diagnosis: poor awareness of dementia among the general population and health care professionals (such as misconception of dementia as a natural part of aging and poor training in dementia care among health care workers), stigma (e.g., no diagnosis disclosure), lack of family support, limited service coverage, and lack of good quality public transport to enable people to travel for healthcare appointments.

The 2021 World Alzheimer Report (WAR) showed similar barriers to the diagnosis of dementia worldwide, including lack of dementia knowledge and training among clinicians, lack of knowledge among the general public, and misconception that nothing can be done for a person living with dementia (Alzheimer's Disease International, 2021). In line with this, a systematic review has also revealed problems related to poor attitudes and knowledge about dementia, and system resources constraints as contributory factors for missed and delayed dementia diagnosis (Bradford et al., 2009). These barriers provide some explanations for the high proportion of dementia under-diagnosis that prevents people from receiving adequate care and support worldwide.

In our study, vignette characteristics such as geographical region, living in rural or urban areas, level of education, and socioeconomic status were linked to the identified barriers to a diagnosis. These are important social determinants of health (ODPHP, 2021) and may act as a direct deterrent to dementia diagnosis (Durgante et al., 2020; World Health Organization, 2021). Brazil offers healthcare services, community-based support, and residential services through public and private routes. Although no dementia healthcare coordination system clearly exists, people living with dementia may still access universal healthcare from the primary, secondary and tertiary levels of care.

Our study showed the relevance of primary care as the first point of access for people to seek other levels of care through the public health system in Brazil. The FHS seemed to be of great value as a bridge between the healthcare system and the persons living with dementia and their families. The program is one of the largest primary care programs in the world and has shown to improve health outcomes among the population (Ferreira-Batista et al., 2022). However, national data from 2019 revealed that the frequency of FHS's monthly visits was low, reaching only 38% of the registered households (Brazilian Institute of Geography and Statistics, 2020). This low rate reinforces the need to expand primary care services nationally as a possible way to overcome gaps and barriers to dementia care. We highlighted that non-referral of persons living with dementia to other levels of care and support was common, which was linked to a lack of knowledge by clinicians towards dementia care or restrictions in the availability of therapies and infrastructure. According to the WAR 2021, personal testimonies from people living with dementia and their carers indicated unsatisfactory knowledge received at the point of diagnosis about the available support for their condition (Alzheimer's Disease International, 2021).

Regarding community-based services, not many options were identified through the vignettes. Our findings showed that psychosocial support is more commonly available in urban areas and most often only through dementia-focused non-governmental organizations, such as FEBRAz. Additionally, informal support may be received from people in the community through neighbors and friends. Services such as state-funded day centres are very limited or non-existent. These services might be accessed privately; however, they are expensive for the majority of the population.

Long-term care facilities in Brazil are provided mainly by the philanthropic sector (65.2%), followed by the private (28.2%) and the public/SUAS (6.6%) sectors (Alcantara et al., 2016). Besides, there is limited and insufficient availability of these services in all geographical regions, with the majority concentrated in the better-off South and Southeast regions (Lacerda et al., 2021). Our results showed that long-term care facilities are considered a last resort measure regardless of being private, public, or philanthropic. In addition, private long-term care settings are generally unaffordable for the vulnerable population. Barriers for accessing care and support included lack of trained formal carers, public day centres, public transportation, and state-funded long-term care facilities. Our study showed that these factors primarily affected those living in rural or remote areas and the socially disadvantaged.

As the severity of the individual’s condition progresses and because of the lack of opportunities for training and support, family members find themselves without the required training to take on a more demanding caregiver role. Women seem to be critical in the carers' role, mainly when providing personal care, which might be related to a widespread patriarchal belief that caring is a natural women’s task (Sharma et al., 2016).

In line with that, the literature points out that caring might result in changes in carers' living arrangements and abandonment of their professional lives, which brings about adverse health and quality of life outcomes (Schulz & Sherwood, 2008; World Health Organization, 2021). Moreover, data from a study in Brazil showed that roughly a quarter of family carers of people with some care needs have to stop working or studying to provide care (Giacomin et al., 2018). Our findings suggest that the community, NGOs, and healthcare professionals are offered training about dementia and psychosocial and physical support, however, to a limited extent.

Identified barriers to caregiver support include lack of awareness about the carers' needs by the carers themselves, lack of a proper diagnosis disclosure, limited opportunities to seek information, lack of respite care services funded by the government, and absence of social safety nets. These barriers were observed regardless of sex, geographical region, rural or urban areas, educational level, socioeconomic status, public or private systems. In addition, stigma often prevents family carers from seeking the help and support they need (Alzheimer’s Disease International, 2021).

The issues identified by this work have been amplified or worsened by the Covid-19 pandemic, which has challenged how healthcare professionals work and led to the implementation of new approaches to healthcare delivery (Feter & Leite, 2021; PAHO, 2021). For instance, most likely access to diagnosis has been further delayed and hampered in most of the vignette scenarios, as suggested by the WAR 2021(Alzheimer's Disease International, 2021). In particular, we anticipate that delays in access to a diagnosis are likely to have happened due to pandemic mainly in situations of limited internet access, such as in remote areas or among people with lower educational levels and socioeconomic status.

Moreover, while dementia help-seeking might have changed due to social isolation resulting in an overload of functions for many family carers (Masterson-Algar et al., 2021), in other cases, this might have been facilitated with some families moving in together, which may have relieved a few primary carers from the challenges of caring alone. Conversely, the shortage and closure of services during the pandemic have strained family members who rely on professional carers, paid support for house chores, or community-based services (Mok et al., 2020). Still, the pandemic made residential care homes more cautious with new admissions (FN-ILPI, 2021). Additionally, people with dementia were at higher risk of SARS-CoV-2 and disease-related morbidity and mortality when compared with those without dementia. The long periods of isolation, for example, increased the risk of worsening neuropsychiatric symptoms and severe behavioural disturbance (Numbers & Brodaty, 2021).

Finally, another consequence of the pandemic is that families have been facing severe financial constraints (Almeida et al., 2021). This situation was also observed in the vignettes and adds another layer of complexity, as people living with dementia and carers have limited or non-existent social protection in Brazil. Once more, socioeconomic inequities seem to determine how people coped with the pandemic, especially among vulnerable individuals such as people living with dementia (Rocha et al., 2021).

There are several possible ways to overcome the challenges people living with dementia and their carers currently face to access care in Brazil. Some of these include raising the political profile of dementia care, developing long-term care system capacity, and implementing evidence-based care and interventions to reduce widespread stigma. Dementia is gradually gaining attention in the country as the National Policy of Integrated Care for People Living with Alzheimer's Disease and Other Dementias was approved by the Senate House in 2021 but is awaiting the Chamber of Deputies' approval and the President's sanction (Brazilian Federal Senate, 2021). Additionally, national policies aiming at preventing modifiable risk factors and supporting family carers of people living with dementia could be expanded (Livingston et al., 2020).

Good-practice examples to address identified gaps in dementia care pathways in Brazil do exist. For example, two different educational programs to support carers of people living with dementia were tested in India and Peru, respectively, and could be adapted and implemented in Brazil (Dias et al., 2008; Guerra et al., 2011). Besides, Brazil is currently implementing the iSupport-BR, a Brazilian version of the dementia-training program developed by the WHO for carers of people living with dementia (UFSCar, 2021; World Health Organization, 2019). Moreover, occupational therapists' interventions in Brazil and China have shown positive results regarding reduction in neuropsychiatric symptoms, caregiver challenges, improvement in cognitive functions, daily living ability, and quality of life (de Oliveira et al., 2019; Zhao et al., 2018). Evidence from cognitive stimulation therapy (CST) has shown clinical benefits among people living with dementia in Brazil (Marinho et al., 2021).

Strengths and limitations

To our knowledge, this is the first study aiming to describe and explore the dementia care pathways in Brazil. We used a novel approach to conceptualize and develop case vignettes to depict a diverse range of people living with dementia and their carers embodying a variety of individual, family, and social circumstances.

By including several case vignettes depicting individuals in different situations, we systematically aimed to compare a range of possible care pathways in Brazil and bring more information for orientating policy decision-making. Although the list of barriers to care access may not be exhaustive, it highlights the multi-dimensional nature of care access and its underpinning factors.

From a methodological perspective, this work builds on a comprehensive desk review of the literature and a SWOT analysis, complemented by expert knowledge to overcome gaps in the evidence base. The vignettes were also validated by a diverse group of national and international experts, including experts by experience.

Although people living with dementia have not been directly involved in validating the vignettes, their views gathered with focus groups and interviews for other STRiDE components were embedded in developing the vignettes.

Moreover, although we tried to include different situations through the vignettes, we know that only some scenarios were represented in the study. For instance, due to stigma and discrimination, people living with dementia and their carers who identify as sexual and gender minority may face barriers to accessing and using care and support services, including long-term care. These issues should be addressed in policy and practice (for example, by raising awareness around this area) and should be explored also in research (for example, by exploring the care needs among people from the LGBT community living with dementia, or their experience of navigating through dementia and supporting services).

Policy implications

In Brazil, not only is the importance of person-centred dementia care still poorly understood and dementia care and services almost non-existent, but there is also limited information on which services are accessed by people living with dementia and their families.

This study investigated the most likely care routes that people living with dementia may take, identified barriers and gaps in the services and accessing them, and linked sociodemographic characteristics that might influence service access in Brazil.

The vignettes created in this study can be used broadly as educational material as they are also available at STRiDE website, may serve as a foundation or starting point for future research, and be used to support modeling work. Understanding how people living with dementia and their carers access services and where they face difficulties is crucial for policymaking. Therefore, with this study, we aimed to contribute to the evidence that can be used to support the development of an integrated dementia care system in the country. In addition, this study may work as a first step to start discussions towards developing feasible dementia policies considering different socioeconomic realities in Brazil.

Declaration of conflicting interests

The Authors declare that there is no conflict of interest.

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