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USING INTERNATIONAL COLLABORATIONS TO SHAPE RESEARCH AND INNOVATION INTO CARE HOMES IN BRAZIL: A WHITE PAPER

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Abstract: The Brazilian care home sector is underdeveloped, and the limited available evidence suggests that care quality falls below international standards. Development of the Brazilian care home sector could be associated with better outcomes for those receiving care, and more efficient use of resources across health and social care. Research has an important role to play. This article summarises research priorities for Brazilian long-term care homes developed as part of an international workshop held in Brazil and the UK, and attended by 71 clinicians and researchers from 6 Brazilian Universities, supported by an international faculty of 8 Brazilian, 8 British, 2 Dutch and 1 Austrian academics. The research priorities identified were: understanding and supporting multidisciplinary working in care homes, with emphasis on describing availability of multidisciplinary teams and how they operate; dignity and sensitivity to cultural needs, with emphasis on collating accounts from Brazilian stakeholders about dignity in care and how it can be delivered; enriching the care home environment with art, music and gardens, with a focus on developing arts in the care home space in a way that is sensitive to Brazilian cultural identity; and benchmarking quality of care, with emphasis on exploring how international quality benchmarking tools can be adapted for use in Brazilian care homes, taking account of new initiatives to include person-centred outcomes as part of benchmarking. Instrumental to research in these priority areas will be establishing care home research capacity in Brazil.

Key words: Long-term care, aged, Brazil, research.

Introduction

In common with other BRICS (Brazil, Russia, India, China and South Africa) countries, Brazil is affected by rapid population ageing. In 2014, 14.6% of Brazilians were aged over 60 years, a proportion projected to grow to 33.5% by 2060 (1). Increases in average life expectancy have been accompanied by higher prevalence of multimorbidity and functional dependency, and unmet need for health and social care amongst older people.

All Brazilian citizens can access free healthcare at the point of delivery through a national health care system, the 'Sistema Único de Saúde' (SUS, or Unified Health System). This system, however, does not cover long-term care in care homes.

Care homes are facilities which provide 24 hour care, with or without specialist nursing input (2). They are a feature of most developed, and many developing, health and social care economies. They provide capacity to look after people with 24-hour care needs through support from dedicated staff, something which even the most generously funded healthcare systems struggle to reimburse in people's own homes.

In Brazil, a small number of care homes (7%) are state-funded (3). A small and developing private sector provides care in facilities, akin to residential or nursing homes seen in high income countries, but these remain beyond the means of many (4) The bulk of current provision comes from small, localised organisations which are funded precariously through a combination of older people's retirement benefits, community charities, and funding from municipalities.

The current estimated capacity of 100,000 beds across 3,549 institutions represents 0.03 beds per head of population over 80 years of age in Brazil (5). This differs considerably from England and the Netherlands, which have 0.12 and 0.23 beds per head of population over the age of 80 years respectively (6).

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All Brazilian care homes are led by Technical Directors, many of whom do not have a healthcare degree. There is no requirement for health professionals (doctors, nurses and allied health professionals) to be employed by care homes, and the structure of healthcare input to care homes is highly variable. Healthcare in Brazilian care homes is mostly provided by doctors without any formal postgraduate training in primary care, geriatric medicine, gerontology or old age psychiatry. A cross-sectional study using objective quality indicators adapted from the United States found that quality of care in Brazilian care homes was variable and fell some way short of international standards (7).

Research in Brazilian care homes is underdeveloped, has not been a particular focus of the academic community and has not been supported or funded in a strategic way. Against this background, the Improving care in LOng-Term Care InstitUtionS in Brazil and Europe through Collaboration and Research (LOTUS) consortium was formed to develop research in Brazilian care homes through international learning and collaboration. It comprised two workshops, the first held at UNESP Medical School, Botucatu, Brazil, in April 2019, and the second held at University of Nottingham, United Kingdom (UK), in August 2019.

The workshops comprised visits to Brazilian and UK care homes and round-table sessions to identify priorities for future research in Brazilian care homes, harnessing links with international institutions to accelerate progress. We present here a summary of the identified priorities, in part as a manifesto to drive our research programme forward, and in part to inform similar collaborations around long-term care between high-, low- and middle-income countries elsewhere.

Choosing the priority areas

Workshop attendance was free-of-charge. Delegates were invited using e-mail lists for Brazilian national gerontology and geriatric medicine organisations. Registration was via a public webpage in English and Portuguese, which was publicised using Twitter. Brazilian organisers, comprising eight academics from a range of disciplines, consulted widely to ensure the programme represented a broad constituency with an interest in care homes. Using this approach we recruited 71 clinicians and academics from six Brazilian universities, including healthcare professionals, social scientists, demographers, gerontologists, designers and architects. Eleven academics from six UK, two Dutch and one Austrian universities were invited based upon expertise which matched the programme prepared by the Brazilian committee. The first two days comprised small group workshops and plenary sessions which enabled delegates to share experiences, with a focus on opportunities and challenges that could be addressed by research. At the end of day 2, delegates were presented with a list of nine possible research domains drawn from discussions, which they were asked to rank in terms of priority. The topics chosen were discussed and developed more fully over the remaining one day of Brazilian and two days of UK-based workshops.

Priority area 1 – Understanding and Supporting Multidisciplinary Working in Care Homes

Caring for older people with complex needs requires a multi-domain approach recognising the contributions of mental and physical wellbeing, functional capabilities, social networks and environment to overall health and wellbeing. From a nursing and social care perspective this is reflected in the evidence-base for person- and relationship-centred care (8) From a medical perspective, it is expressed through the evidence for comprehensive geriatric assessment (CGA) (9). Whilst person-centred care and CGA have exponents in Brazil, they are not yet widely accepted. The extent to which care homes are set-up to deliver them is not clear.

Comprehensive care approaches draw upon expertise of multiple professionals working as a team. In high income countries, multidisciplinary teams can be based in and employed by care homes – as in the Netherlands – or can be composed of numerous visiting professionals – as in the UK and Austria. The latter scenario can present challenges around co-ordinating assessments by different professionals and managing their inputs to ongoing care, with the need to take account of remote working and asynchronicity of inputs (10).

Surveys of care homes in Brazil have focussed mainly on the structure of institutions and the profile of the residents who receive care, particularly focussing on health status, falls and frailty (11–13). Data have not been collected hitherto on how such institutions are staffed, in terms of the disciplinary background of staff involved in care, or how such staff integrate into a multidisciplinary team.

Following the LOTUS workshops, we have commenced a survey to establish how multidisciplinary teams operate across ten care homes, five not-for-profit/philanthropic and five for-profit, spread across five Brazilian cities in São Paulo State (Botucatu, São Paulo City, Ourinhos, São Carlos and Campinas). Following this we propose more detailed qualitative research to understand in greater detail how professionals from multiple backgrounds connect and interact in care homes. Given the variation in geography, climate, culture and economic resource between Brazilian states, an explanatory approach will be required to accommodate and understand variability.

Priority area 2 – Dignity and Sensitivity to Cultural Needs

Dignity is defined in the Oxford English Dictionary as 'the quality of being worthy or honourable; worthiness, worth, nobleness, and excellence'. The challenge lies in translating fine sentiments about maintaining dignity into care practice. Dignity can be complicated. For example, is it something that can be observed and measured objectively by meeting certain

standards, or is it subjective and perceived at an individual or interpersonal level? Two people may observe the same interaction, such as a visit to the toilet, and come to different conclusions about how dignified it was.

Three main interactional qualities have been described (14) that help to preserve care home residents' sense of dignity: experiencing love and confirmation; experiencing social inclusion and fellowship; and experiencing humane warmth and understanding within a caring culture, while being met as an equal human being.

There are several important cultural aspects of dignity (15). Staff and residents of care homes are often of differing backgrounds. This may include different socio-economic status, ethnic origins, speaking different languages, having differing sexualities or gender identities, or being of different faith. The linguistic issue, present in many countries due to dependence on migrant workers in long term care, can be particularly challenging in Brazil because, although Portuguese is the predominant language, the country is multi-lingual and not all older people speak Portuguese. Even where this is not the case, a care home of reasonable size will contain a diverse group of residents, with different educational and occupational experiences. They are likely to have different care preferences and needs. Some may observe a religion, others not. These aspects of individuality need to be understood and respected to support dignity in care.

Dignity is an important part of the realpolitik of care homes in developed countries. In the UK, for example, charitably funded national initiatives led by academics in partnership with care homes focus on dignity, whilst legislative and regulatory frameworks explicitly emphasise residents' right to dignified care. The concept of dignity is less established in Brazilian care homes. There is a high level of stigma attached to care homes and their residents. Stigma leads to ageism, exertion of power, isolation, seclusion, poor quality care, and high professional turnover, all of which may impact upon provision of dignified care and impair the ability of staff to see individuals behind negative labels and stereotypes. Dignity is not used as a measure of care quality in Brazil.

We need to understand the levers required in Brazil to promote culture change from the current preoccupation with meeting physical care needs to a more person- and relationship-centred approach. It is likely that the answer will lie in staff feeling empowered and valued, so that they can prioritise dignity in care (16). There will be organisational and cultural issues specific to Brazil that influence how to empower and support staff and residents. Research needs to examine the perceptions of different stakeholders about what constitutes dignity and what different priorities for change may be. We propose that the first step should be a scoping review of the Brazilian literature of long-term care and dignity, followed by qualitative interview studies.

Priority area 3 – Enriching the Care Home Environment with Art, Music and Gardens

The proportion of care home residents with dementia, internationally, ranges from 30-60% (17). Activities such as art interventions are helpful in supporting people with dementia (18) and are one of the few effective non-pharmacological strategies in dementia care. Music, for example, is associated with improvement in cognitive performance and mood of care home residents (19).

There is evidence that residents from Brazilian care homes are less able to access stimulating recreational activities than in higher income countries (20). This could relate, again, to the emphasis placed on physical needs within Brazilian care homes. Initiatives that have developed around recreational activities have been led by research teams. One such project involved working with participants from two care homes and two day centres using museum objects as a focus (21). Sensory strategies like smell, tactile and sound experiences were explored in addition to reminiscence. Eight to 15 people participated every week, with additional trips to museums every two months. This museum project also incorporated a music experience, using exhibits and photos in the museum. Although similar to initiatives conducted in other countries, a key learning point was how evocative and stimulating the smells, flavours and sounds of Brazil were for residents living with dementia. The smell of coffee, and the sound of "serestas" were associated with a particularly strong affective response.

Further work is required to work out how to enrich care home environments in ways which are sensitive to Brazilian culture and hence work. It is also clear that research is central to establishing such approaches in the mainstream of Brazilian care homes.

Priority area 4 – Benchmarking quality of care

Care provider organisations have a duty of care to protect the safety of clients and to ensure that care meets, and exceeds, minimum acceptable standards. Approaches to quality control and governance in care homes internationally vary and include: professionalism-based regulatory systems, where groups of professionals or provider organisations take responsibility for quality control; inspection-based regulatory systems, where statutory providers send independent staff inspect care homes; and data measurement and reporting based regulatory systems, where audit of minimum dataset submissions are used (5).

Regardless of the approach adopted, there is increasing emphasis across high-income countries on reliable metrics about quality of care, which can enable providers to understand areas which require improvement and to act upon them. A highly established approach uses the international Resident Assessment Instrument (interRAI), an interlinked suite of resources, whereby resident-level assessment conducted by care home staff can inform care protocols and also generate

institution level case-mix analyses and quality markers. There are, though, challenges associated with implementing such a detailed and comprehensive approach (22). A contrasting approach – adopted in the Netherlands, Austria, Switzerland, Turkey and one region of the UK – is the International Prevalence Measurement of Care Quality (in Dutch: Landelijke Prevalentiemeting Zorgkwaliteit, LPZ) – which takes a more straightforward, once-yearly audit-based approach to benchmarking and then uses the findings from these observations as the basis of quality improvement (23). These approaches are now being modified to take account of person- and relationship centred care, with inclusion of quality of care from the resident's perspective included in the Individually Experienced Quality of Long-Term Care (INDEXQUAL) framework, and its adaptations to take account of professional caregivers' and families' perspectives (24).

Very little benchmarking data are available in the Brazilian care home sector. Benchmarking using a sub-component of the interRAI has been conducted on a small scale basis as part of a study in 35 homes conducted in Rio Grande do Norte State of Brazil (7). It is therefore feasible within the context of a cross-sectional research cohort study. Further work is required to consider the wider role of benchmarking, its feasibility, its implementation in routine practice, and how it can be used to drive quality improvement. As with other domains described above, the shift to resident- and relationship-centred benchmarking will need specific adaptation to the Brazilian cultural context.

Discussion

Each of the above priority areas is challenged by the relative under-development of the Brazilian care home sector. It is well established that effective research in care homes requires collaboration, and co-design, between residents and relatives, staff from the care home sector, and academics. There are specific challenges to recruitment and retention of care home staff and residents in research, and to data collection and analysis in care home cohorts, that require sector-specific expertise which takes time to develop.

There is good evidence that an established care home research network can help cultivate the necessary competencies in academic and care home staff, and that the resulting research can drive up standards of care, and generate the case for capacity in the care home sector (25). A highly structured model, such as the South Holland Nursing Home Research Network (26), may be challenged by the limited capacity and relative under-development of Brazilian long-term care as it stands. Other examples, though, are available, such as the UK National Institute of Health Research Enabling Research in Care Homes (EnRICH) model (27), where care homes are recruited as research opportunities become available, with a network slowly developing over time. This might better suit the Brazilian situation.

Most of the work required to address the above priority areas will comprise mixed-methods research. Whilst both positivist biomedical research and inductive qualitative approaches are established in Brazil, researchers from these different backgrounds have not frequently come together. Relationship and team building will be required. In addition, new approaches that can make sense of complex interactive systems, need to be imported. Realist enquiry, with its ability to describe how context affects the mechanisms at play within complex systems, to deliver outcomes that matter, could be useful (28). Implementation science, with its insights into how to implement and sustain evidence-based approaches to care, will be able to provide approaches which can make sense of the wide variation in approaches to care home services across Brazil (29).

As we write this paper, the world in general, and Brazil in particular, is still in the grip of the COVID-19 pandemic. This pandemic has been associated with significant mortality in the care home sector. We do not yet fully understand the extent to which it has impacted upon the Brazilian care homes (3) Internationally COVID-19 has challenged models of healthcare delivery to care homes, remuneration and funding models, how data are collected and collated on care home residents, how staff are trained, and how buildings are designed to maximise quality of life and wellbeing for residents (30). Most of these areas of uncertainty are highlighted by the research priorities which we had already identified in our workshop before the arrival of COVID-19. That they have been reinforced by the pandemic highlights how research to understand each of these domains is central to the development and delivery of good care. The pandemic has laid bare how devastating it can be for care home residents, and society more generally, if we do not prioritise and focus upon these research areas.

Implications for practice and research

This document is presented to provoke discussion and thought. It makes no claims to be representative of all Brazilian academics with an interest in care home research. The strengths of our approach included the use of two face-to-face workshops, one held in Brazil, free-to-attend and publicised through national academic and clinical practice networks. Advanced planning and an open discursive approach at the meeting was designed to give full voice to Brazilian academics from diverse backgrounds, and to enable them to set the agenda and priorities going forward. Limitations are that Brazil is a large country and running our workshop in one city in São Paulo State may have limited the ability of colleagues from more remote parts of the country to attend. Not all Brazilian representatives were able to attend the second workshop in the UK. Brazilian colleagues are not all fluent in English and the workshop may have given prominence to the ideas of those who were most conversant in this language. Laying out in this paper the ideas developed through the workshop programme,

represents a further opportunity to discuss important topics and to generate dialogue. We hope that colleagues that we have not hitherto engaged with, will feel empowered to join the debate.

We have highlighted in this paper the need for rapid development in the Brazilian long-term care sector. Close collaboration between care providers and researchers has the potential to accelerate the development of the sector, drive up standards and improve efficiency and effectiveness of care. International collaboration can help accelerate the development of a Brazilian care home research community to support this process.

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Ethical standards: This international collaborative workshop was exempt from the need for ethical approval under the guidelines of the host countries (Brazil and UK)

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