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## **Title**

Perceptions of Dementia amongst the General Public across Latin America: A Systematic Review

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## Abstract

**Introduction:** Perceptions of dementia are important determinants of support, treatment and care received in the dementia community. Understanding these perceptions are vital for regions such as Latin America, where there is a rapid increase in people living with dementia. The aim of this study is to review and synthesise the general public's perceptions of dementia in Latin America, what factors are associated with these perceptions, and how they differ between countries in the region.

**Methods:** Searches were completed across five databases (Medline, SCOPUS, PsychINFO, SciELO, and WoS). Studies were required to capture attitudes or knowledge of dementia in the general public residing within Latin America. English, Spanish and Portuguese search terms were used. Results were synthesised narratively.

**Results:** 1,574 unique records were identified. Following lateral searches, de-duplication and screening, six articles (4 studies) met the inclusion criteria for this review. All the studies were quantitative research from Brazil (Median n = 722). There was evidence of a limited to moderate knowledge of dementia, though a significant minority had negative or stigmatising attitudes. Only higher levels of education were consistently associated with better attitudes and knowledge of dementia in the region.

**Conclusion:** There is a need for more in-depth research about attitudes of the general public across Latin America, particularly outside of São Paulo state, Brazil. There appears to be a greater need to raise awareness of dementia amongst less educated Latin American groups.

## Keywords

Health literacy; dementia literacy; Brazil; knowledge; attitudes; beliefs; adults

## Introduction

Perceptions of dementia are very important in determining whether people access and receive a diagnosis. Stigma, in particular, is a major barrier for seeking and accessing support, diagnosis, treatment, and information (Alzheimer's Society, 2008; Iliffe et al., 2005; Milne, 2010). As such, dementia awareness is a key component of the World Health Organisation's global plan on dementia (World Health Organisation, 2017).

Latin America (LA) is composed of 20 countries, which are linked geographically, and to some extent share history, culture and religion. There are approximately 71 million older adults in this region (2015)(National Academies of Sciences, Engineering, and Medicine, Division of Behavioral and Social Sciences and Education, Committee on Population, & Steering Committee for the Workshop on Strengthening the Scientific Foundation for Policymaking to Meet the Challenges of Aging in Latin America and the Caribbean, 2015; United Nations, Department of Economic and Social Affairs, Population Division, 2019), of which approximately 7.1%-8.5% of people aged  $\geq 65$  years have dementia (Nitrini et al., 2009; Prince et al., 2013). This is somewhat higher than other global estimates, which could be attributed to lack of access to primary care and lower education levels in the region (Custodio, Wheelock, Thumala, & Slachevsky, 2017). However, the number of people with dementia in LA is expected to increase nearly 4-fold by 2050 (Alzheimer's Disease International & BUPA, 2013). In part this is due to demographic characteristic and health transitions in LA (Bongaarts, 2009; Custodio et al., 2017), with an increasing number of people living to old age in the presence of a greater incidence of cardiovascular disease. Despite these figures, certain areas of dementia-related research in LA are lacking, with an urgent need to further explore the general public's perceptions and awareness about dementia (or 'dementia literacy') in the region.

Several studies have explored dementia perceptions of Latinos<sup>1</sup> in the USA. For example, focus groups with forty Latinos (predominantly Mexican Latinos) revealed people's beliefs that dementia was a normal part of aging and that there were no benefits from early diagnosis (Rodriguez, 2011). Participants in this study were able to correctly answer 17.6 (SD=3.4) out of 30 questions on the validated Alzheimer's Disease Knowledge Scale (ADKS)(Carpenter, Balsis, Otilingam, Hanson, & Gatz, 2009), which is generally lower than those reported by

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<sup>1</sup> In this instance, "Latino" was used to reflect the terminology used in the original paper, which is used to refer anyone with cultural ties to Latin America. The term is not intended to imply gender, or the strength and type of affiliation with Latin America.

older African Americans ( $M= 18.7$ ,  $SD = 3.7$ ) (Rovner, Casten, & Harris, 2013), general US older adults ( $M= 24.1$ ,  $SD = 3.0$ ), and US students ( $M=20.2$ ,  $SD = 3.6$ ) (Carpenter et al., 2009).

Studies investigating Latinos' perceptions about mental health issues in general often report misperceptions about such conditions. For example, Latino college students in the USA have been found with higher levels of mental health stigma and were less open to receiving support from mental health practitioners than students from other ethnic groups (Mendoza, Masuda, & Swartout, 2015). Older Latino Americans reported a greater embarrassment towards having a mental illness compared to other American groups, as they believe this could bring disharmony to the family (Jimenez, Bartels, Cardenas, & Alegría, 2013). Such evidence might not necessarily reflect attitudes specifically towards dementia, and instead might reflect a common Latino trait, called '*familism*' (or *familismo*), which "*places the family ahead of individual interests and development*" (Ingoldsy, 1991). Such attitudes can both have potential benefits (i.e. increased social support), but also increase risk of family conflict and strain (Calzada, Tamis-LeMonda, & Yoshikawa, 2013).

From an international perspective, gaps in knowledge of dementia is commonplace (Glynn, Shelley, & Lawlor, 2017; Li et al., 2011; Van Patten & Tremont, 2018), though some countries appear to have a better understanding of dementia (McParland, Devine, Innes, & Gayle, 2012). The World Alzheimer Report 2019 (Alzheimer's Disease International, 2019), in the largest survey of dementia knowledge attitudes and knowledge to date, identified that two thirds people incorrectly think that dementia is part of normal aging. However, there are substantial variations in terms of attitudes between countries, for example 24.5% of the general public in the region of the Americas (World Health Organisation Region) would conceal their dementia diagnosis, which is higher than all over World Health Organisation Regions except for the European region (25.7%). Previous systematic reviews have confirmed that dementia knowledge and attitudes are generally poor internationally, particularly amongst ethnic-minority groups (Cahill, Pierce, Werner, Darley, & Bobersky, 2015; Cations, Radisic, Crotty, & Laver, 2018). However, due to somewhat restrictive nature of the literature searches, little to no research from LA has been identified in these reviews. As such, a more inclusive systematic review that allows for the identification of a broader range of outcome measures and of studies published in Spanish and Portuguese need to be conducted. In adopting a systematic approach, we ensure that the process is transparent and

minimises potential sources of bias, and allows researchers to replicate the search strategy in the future.

Understanding how the general public perceive dementia in LA may help identify whether there are gaps in their knowledge, or culturally-driven attitudes, that could potentially impact help-seeking behaviours, social support, or change in modifiable risk factors, for example. Therefore, this systematic review aimed to understand the perceptions about dementia in the general public in LA, the factors are associated with such perceptions, and to compare them between countries in the region.

## **Methods**

This systematic review is reported in line with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA framework: <http://www.prisma-statement.org/>). The review protocol was registered on PROSPERO (CRD42019129099).

### ***Eligibility criteria***

To be included, studies needed to:

- Originate from one or more LA countries;
- Include adults ( $\geq 18$  years old);
- Have a qualitative or quantitative design; and
- Explore the views, knowledge and/or beliefs regarding dementia.

Studies with the following characteristics were excluded:

- Participants with a diagnosis of dementia or mild cognitive impairment, as their attitudes and knowledge are likely to be influenced by their experiences of receiving a diagnosis;
- Samples restricted to healthcare students, healthcare professionals, care staff, or other specialist groups; and
- Perceptions about dementia were explored after an intervention.

### ***Information sources and Search Strategy***

Various iterations of syntax were used to search relevant databases (Medline, SCOPUS, PsychINFO, SciELO, and WoS), using combinations of MeSH terms and text words, with equivalent Spanish and Portuguese terms where appropriate. For example:

- TS=( belize\* OR "costa rica\*" OR "El Salvador\*" OR guatemala\* OR hondura\* OR mexic\* OR nicaragua\* OR panama\* OR argentin\* OR bolivia\* OR brazil\* OR chile\* OR colombia\* OR ecuador\* OR "French Guian\*" OR guyan\* OR paragua\* OR peru\* OR surinam\* OR uruguay\* OR venezuela\* OR "Latin America\*" ) AND TS=(demência OR Dementia OR Alzheimer OR Alzheimer's OR "Memory loss" OR "cognitive impairment" OR "cognitively impaired" OR "cognitive decline") AND TS=(Views or Opinions or Attitudes or Perceptions or Stigma or Knowledge or Information or Beliefs or Perspectives or Thoughts or Associations or concept or culture OR cultural OR idea or visualizações OR atitudes OR opiniões OR percepções OR stigma OR Conhecimento OR "Em formação" OR Crenças OR Perspectivas OR Pensamentos OR Associações OR conceito OR cultura OR cultural OR idéia)

To identify grey literature, we used electronic databases Opengrey.eu, CAPES, and hand-searched the references of relevant studies.

We only reported data that were included in the identified published studies.

### ***Study shortlisting***

All search results were downloaded and entered into Zotero where duplicates were identified and deleted. The remaining documents were then uploaded to the Rayyan web platform (Ouzzani, Hammady, Fedorowicz, & Elmagarmid, 2016), which allowed for titles and abstracts to be screened. Two researchers screened the records (JB and CKS). Between the two researchers, all the records were screened once, with 10% of all records being screened by both authors to ensure that they were applying the same eligibility criteria. Only eight conflicts (out of 157 screened) were identified at this stage, which were resolved upon discussion. Non-English language texts were reviewed by members of the broader multi-lingual team when needed.

### ***Study selection***

We collected full texts of all potentially eligible records. Then, two researchers independently established eligibility by applying the full inclusion/exclusion criteria. Decisions were tracked using a pre-piloted form and a dedicated table. There was good agreement between the researchers ( $k = 0.89$ ).

### ***Data extraction***

Data, defined as any relevant information about (or deriving from) a study were extracted from the full-texts of each of the included studies using a purposely designed, pre-piloted table of study design and conduction characteristics, main and secondary results. One of the researchers (RF) extracted all the relevant data, and a second researcher (DO) independently extracted a proportion of the data to check for consistency. Discrepancies and non-agreement that occurred during the data extraction was resolved with assistance from a third researcher (NF, JKB, or CKS).

### ***Data items***

Descriptive information about the methodology and outcomes used in the included studies were extracted, these included:

- Country
- Study design (e.g. qualitative)
- Sample size
- Inclusion criteria (e.g.  $\geq 65$  years old)
- Ethical approvals reported (Yes/No)
- Response rate (%)
- Non-response bias (Yes/No/Unclear)
- Outcomes and their measurement.

### ***Outcomes and prioritisation***

The primary outcome was attitudes or beliefs about dementia. The secondary outcome was knowledge of dementia.

### ***Risk of bias in individual studies***

As this review sought to include both quantitative and qualitative studies, the Mixed-Methods Appraisal Tool (MMAT) (Pluye, Gagnon, Griffiths, & Johnson-Lafleur, 2009) was used by two independent reviewers to assess the potential risk of bias of relevant papers. The MMAT was used to describe the studies and critique individual study findings, but none of



the relevant studies were excluded on the basis of its quality, in line with the author's guidance (Hong et al., 2018).

### ***Data synthesis***

Descriptive data were reported for all studies. The relevant information was synthesised narratively, with the initial plan to group by country, but this was not possible. Descriptive data was initially summarised, split by; a) knowledge and b) attitudes and beliefs.

Associations between outcomes and independent variables were reported and grouped in a similar fashion.

### ***Confidence in cumulative evidence***

There are no standardised or widely adopted tools to assess confidence in cumulative evidence in mixed-methods, observational studies.

## **Results**

On the 16<sup>th</sup> November 2018, 2,771 records were identified through electronic search (Figure 1). Following deletion of duplicates (n=1,993), 1,574 records remained for further screening. Two additional articles were identified through lateral searches. After screening, six papers reporting on four different studies met the inclusion criteria for this systematic review (Amado & Brucki, 2018; Blay, Furtado, & Peluso, 2008; Blay & Peluso, 2008, 2010; Matioli et al., 2011; Schelp, Nieri, Hamamoto Filho, Bales, & Mendes-Chiloff, 2008). All the included studies were conducted in Brazil, were published in English, had a quantitative survey design, and sample sizes ranging from 73 to 1,414 (Mdn=722).

*<Insert Figure 1 here>*

### ***Study aims and conceptual underpinnings***

Across the included studies, there were a range of aims, some of which were grounded in existing theory. Amado et al. (Amado & Brucki, 2018) aimed to better understand Brazilian public knowledge of dementia, as a first step to develop public health strategies, taking into account of the size of the country and variability of education levels.

Schelp et al. (Schelp et al., 2008) were interested in understanding public awareness of dementia in Botucatu, Brazil. The authors somewhat unclearly state that one of their aims was to “evaluate expectancy from the healthy-old age and scope dementia”.

Matioli et al. (Matioli et al., 2011) aimed to evaluate the worries about memory loss and knowledge of Alzheimer’s Disease in a literate elderly population from Santos (Brazil), and to find the associations with some sociodemographic characteristics.

Blay and colleagues (Blay et al., 2008; Blay & Peluso, 2008, 2010) had a series of aims, using a single survey of public stigma, knowledge and beliefs of Alzheimer’s Disease (AD), across three articles. In the first article (Blay et al., 2008), the authors used the Leventhal model of stress and coping (Leventhal et al., 1997) as a foundation for their research. The authors aimed to understand whether greater access to knowledge (due to a higher education) and previous experience with mental health problems is associated with greater agreement with a ‘medical model’ of dementia (help-seeking or in beliefs of treatment of Alzheimer’s Disease). The authors also aimed to understand the effect of age on treatment beliefs about AD. In the second article (Blay & Peluso, 2008), “mental health literacy model” (Jorm et al., 1997) was used as an underlying framework to refer to knowledge and beliefs about AD. The authors had four aims: to understand how the public identifies AD and its underlying causes; to understand whether previous experience with mental health problems mediates the relationship with health beliefs; to explore whether religion impacts the public’s AD knowledge; and to understand how age influences views about AD. In the third article, Blay and Peluso (Blay & Peluso, 2010) aimed to better understand the public stigma of AD and how this was associated with sociodemographic characteristics. The authors also explored whether stigma is associated with labelling AD as a mental illness, personal experiences of mental illness, beliefs about causes or personal reactions. Within this publication a theoretical model of stigma of Rush et al. (Rüsch, Angermeyer, & Corrigan, 2005) was used to underpin concepts of public stigma.

### ***Study samples***

The characteristics of the study samples are given in Table 1. Four studies were conducted in Brazil, predominately in São Paulo state, including São Paulo (Blay & Peluso, 2008), Botucatu (Schelp et al., 2008), and Santos (Matioli et al., 2011) cities. One study utilised an online questionnaire and so was not limited to São Paulo state, but its recruitment through

memory clinics and social media makes it unlikely to be generalizable (36.4% were healthcare professionals, 13.9% were caregivers, and 87.3% were highly educated) (Amado & Brucki, 2018). Two studies used convenience samples (Matioli et al., 2011; Schelp et al., 2008), although one sample was recruited from two community locations with different ethnicities and socioeconomic statuses (Schelp et al., 2008). Only one study (Blay et al., 2008; Blay & Peluso, 2008, 2010) used multistage random sampling to minimise potential selection bias, as identified in the MMAT tool. In one instance, a study was limited to older adults only ( $\geq 60$  years) (Matioli et al., 2011). Generally, limited participant characteristics were reported. For example, only one study provided some form of description of the ethnicity of the sample, though no details were provided (Schelp et al., 2008). See Table 1.

<Insert Table 1 here>

### ***Risk of bias overview***

In most studies, the authors adopted questionnaires that did not appear to have been validated, nor provided any rationale for how the questions were decided upon. The only exception was a study using the ADKS (Carpenter et al., 2009), which was validated in English and translated into Brazilian Portuguese (Amado & Brucki, 2018). The authors did not provide evidence of cross-cultural adaptation or validation of this instrument for use in Brazil.

Only one study (three articles) attempted to reduce selection bias through the recruitment strategy used (Blay et al., 2008; Blay & Peluso, 2008, 2010), though none of the studies reported non-response rates, or controlled for non-response bias. It was also unclear how representative the samples were compared to the national statistics.

Across all studies, there was at least one item per study judged as “can’t tell” on the MMAT tool because the information was not explicitly reported to make a “yes” or “no” judgement, thus indicating the need for methods to be more transparent.

### ***Beliefs and attitudes***

Across the studies beliefs and attitudes varied depending on the outcome of interest. In particular, there appeared to be misconceptions about prognosis and causes of dementia, but

accurate beliefs about treatment and support. A significant minority had stigmatising attitudes towards dementia.

In the study by Blay et al. (Blay et al., 2008; Blay & Peluso, 2008, 2010), 500 participants were provided with a vignette depicting a case of a 70-year-old individual with AD, and then asked a set of structured questions about the case. For example, participants were asked what they believed caused the condition described in the case (Blay & Peluso, 2008). Participants were provided with a list of 18 conditions/situations and then asked to respond on 5-point Likert items (“completely agree” to “completely disagree”). Most participants perceived AD to be caused by isolation (29.7%), followed by drug use (19.2%) and by brain problems (13.1%). Other factors, such as lack of self-love, overwork, weakness of character, virus or infection, fate/predestination and influence/evil eye, were overwhelmingly perceived not to be the main cause (<1%). However, at least 25% of participants agreed that each of the 18 factors partly caused AD. Schelp et al. (2008) asked 73 participants questions about changes expected as a result of dementia and healthy aging. Memory impairment changes were more commonly associated with dementia (41.1%) than healthy aging (23.3%). However, 56% of participants believed that behavioural and mood changes were present in the general older population, compared to 32.9% who believed these symptoms were present in people living with in dementia.

Blay et al., (2008) also asked participants to rate how helpful or harmful 11 sources of help were for the AD case, alongside which option should be sought first (Blay et al., 2008). The first choice among participants was close family (27%), followed by psychologists (15%) and neurologists (13%). This was largely in line with opinion that psychologists (91%), self-help groups (91%), close family (87%) and neurologists (86%) were the most helpful sources of support (“would help a lot” and “would help a little”). Faith healers, sorcerers and pharmacists were not selected as the first choice to help people with AD, and were often seen as being a potential source of harm (44%, 59% and 88% respectively).

When asked about the perceived helpfulness of 17 different treatments, in which psychotherapy (96%), eating better (94%), keeping the mind busier (88%), and going to church/religious services (83%) were seen as the most helpful for the person described in the vignette. Whilst electroconvulsive therapy (92%), antibiotics (63%), and hospitalisation in a psychiatric hospital (58%) were seen as the most harmful. The first choice of interventions (i.e. >15%) for people with AD was psychotherapy (32%), physical exercise/sports (19%),

and keeping mind busier (16%). Irrespective of their choice of treatment, 95% of participants believed that the case described in the vignette would have partial or total recovery with treatment.

Blay and Peluso (2010) also used eight questions based on a previous study (Werner & Davidson, 2004) to evaluate emotional reactions based on the case vignette. Items were grouped into two factors; 'prosocial feelings' and 'avoidance and irritability'. Participants tended to have more prosocial reactions (desire to help 98.6%, warmth 93.4%, and friendliness 71.3%) to the AD case described in the vignette, whereas the rate of antisocial reactions (indifference, desire to be distant, fear and irritation) were less frequent (<25%). Three items were used to assess stereotypes, discrimination and prejudice towards the person described in the vignette. All response formats were "yes", "no" or "do not know". 41.6% expressed stereotypes, 43.4% demonstrated prejudice, and 35.5% demonstrated signs of discrimination. Based on an operationalised criteria for defining stigmatisation (i.e. participants who responded "yes" to all three domains), 14.8% met the criteria.

In the study by Schlep and colleagues (Schlep et al., 2008), participants generally believed that people with dementia had feeding difficulties (80.8%) and that they could not stay at home alone (89.0%).

### ***Factors influencing beliefs and attitudes***

Only Blay et al., explored factors influencing beliefs and attitudes towards dementia. The nature of the analysis revealed a range of factors significantly associated with different beliefs and attitudes.

Blay et al. (Blay et al., 2008; Blay & Peluso, 2008, 2010) carried out a number of analyses to explore factors influencing beliefs and attitudes towards dementia. Causal factors of AD were reduced using factor analysis into three factors, namely; 'psychosocial', 'religious/moral' and 'biologic' factors (Blay & Peluso, 2008). Higher income status (mean income > US \$200/month) were associated with attributing to cause to biological factors (Mean Difference (MD) = 0.20, p=0.02), whilst lower education levels (0-7 years) were significantly associated with attributing the cause to religious/moral factors (MD=0.50, p=0.001). Finally, being married (MD = 0.44, p=0.001) or previously married (MD=0.49, p=0.01) were more likely to attribute the cause to psychosocial factors.

A stagewise logistic regression was used to assess what factors were associated with the authors' definition of stigmatisation (described above)(Blay & Peluso, 2010).

Sociodemographic variables (block 1), personal and family experience with mental problems (block 2), and mental health literacy of AD (block 3) were included in the model. Only those with lower education were more likely to express stigma [Odds Ratio (OR) 2.35, 95% CI; 1.3, 4.26),  $p=0.005$ ]. No variables within block 2 were associated with stigma, those who believed in religious/moral causes for AD were more likely to express stigmatizing views within block 3 (OR=1.00; 95% CI=1.00, 1.00).

In a factor analysis of perceived helpfulness of treatment options for AD (Blay et al., 2008), two factors were retained; 'medical methods' and 'alternative methods'. Those who considered the person described in the case vignette as having a psychiatric condition (MD=0.44,  $p<0.0001$ ), those with a younger age (MD=0.26,  $p<0.03$ ) and those with fewer years of education (MD=0.45,  $p<0.0001$ ) tended to consider 'medical methods' more helpful. Being female (MD = 0.39,  $p<0.0001$ ) and being older (30-49 years old vs 18-29 years old) (MD=0.32,  $p=0.007$ ) were the only factors significantly associated with the perceived helpfulness of 'alternative methods'.

In the factor analysis of the perceived helpfulness of individuals (Blay et al., 2008), the 11 sources were reduced into three factors; 'medical help', 'religious help' and 'psychological and self-help'. Being able to identify the case described in the vignette as being a psychiatric condition was the only factor associated with perceived helpfulness of 'medical help' (MD=0.50,  $p<0.0001$ ). Perceived helpfulness of 'religious help' were associated with identifying the case as being a psychiatric condition (MD=0.25,  $p=0.01$ ), being Catholic vs. non-religious (MD=0.45,  $p=0.002$ ), and being Catholic vs Evangelical (MD=0.71,  $p<0.0001$ ). Finally, perceived helpfulness of 'psychological and self-help' was significantly associated with fewer years of education (MD=0.25,  $p=0.02$ ) and being Catholic vs No religion (MD=0.37,  $p=0.01$ ).

However, given that the total scores of the reduced factors and non-significant outcomes were not reported, it is difficult to interpret the strength of the effects of these factors in a meaningful way. Additionally, the use of multiple univariate ANOVAs to report significant findings may have introduced inflated error, whilst also potentially biasing the outcomes where multiple variables might have interaction effects or overlapping variance.

## ***Knowledge***

Overall, knowledge about dementia was limited across the studies, though variation existed depending on the aspect of knowledge measured.

Based on the validated ADKS, and after excluding healthcare professionals from the analysis, participants on average got 20.5 (SD = 3.51) out of 30 questions correct (Amado & Brucki, 2018). No ‘adequate’ level of knowledge has been established for this scale, though this is a “true” or “false” questionnaire and therefore participants could achieve 50% correct answers through random selection alone. It is worth noting that the total score also included caregivers of people with dementia, but being a caregiver did not significantly predict ADKS total score ( $p=0.49$ ).

Other studies used non-validated scales of dementia knowledge. In the study from Matioli et al., 69.5% ( $n=656$ ) subjectively reported that they knew what AD was and whether it was treatable or not (69.3%) (Matioli et al., 2011). However, this was based on perceived knowledge and did not assess participants’ actual knowledge. Over half of participants in the study by Schelp et al., (2008) were able to recognise all the given signs of dementia (57.5%), namely; forgetting obligations, forgetting the next commitment, unable to perform common tasks, feeding problems, changing names and parental status, unable to comprehend related facts and objects. However, only 4.4% of participants were able to correctly affirm that the person had dementia or AD (Blay & Peluso, 2008). The most common perceived causes were memory loss (46.6%) and ageing (26%), whilst 39.4% considered the person described in the vignette as having a mental illness. Studies also showed gaps in knowledge particularly related to risk factors ( $\geq 67.8\%$  incorrect responses) (Amado & Brucki, 2018) and age (42.5% thought that dementia only affected those  $\geq 60$  years) (Schelp et al., 2008).

## ***Factors influencing knowledge***

Knowledge about dementia was compared against a range of sociodemographic characteristics (e.g. age, gender, education level). Across the studies, only higher education levels were consistently associated with better knowledge.

Three studies found a significant association between better knowledge and higher educational levels (Amado & Brucki, 2018; Blay & Peluso, 2008; Matioli et al., 2011). Gender was not associated with perceived knowledge of what AD was (Matioli et al., 2011),

whether it would be classed as a mental illness (Blay & Peluso, 2008) or overall knowledge scores (Amado & Brucki, 2018), but was associated with perceived knowledge of whether it was treatable (Matioli et al., 2011). The influence of age was mixed, with one study reporting better knowledge in younger people (Amado & Brucki, 2018), one reporting no differences (Blay & Peluso, 2008), and in the final study finding better perceived knowledge of whether AD was treatable with younger age, but no significant differences in perceived knowledge of what AD was (Matioli et al., 2011). Lower socio-economic status were significantly associated with identifying AD as a being mental illness (OR=2.59; 95%CI 1.03,2.46) (Blay & Peluso, 2008), whilst religion, personal experiences of mental health problems and marital status did not significantly predict knowledge about dementia in the model.

See Table 2 for an overview of the associations reported.

<Insert Table 2 here>

## **Discussion**

This is the first systematic review to explore the general public's knowledge and attitudes of dementia across Latin America. This systematic review identified a paucity of research on most of LA countries about the views, knowledge and/or beliefs regarding dementia within the general public. Only six articles from Brazil were included in the results, and hence we unable to compare attitudes and knowledge of dementia between countries. Regarding attitudes and perceptions, beliefs were mixed, with predominantly prosocial attitudes reported but a substantial minority also expressed stereotypical perceptions, stigma and discrimination. Only one study reported factors affecting attitudes, and identified a number of demographic factors and beliefs about causes that influenced perceptions regarding sources of help and treatments. Levels of knowledge about dementia reported can probably be described as moderate, but few were able to identify a case vignette of AD. Educational level was consistently associated with knowledge, but the effects of age and gender were mixed across studies and other factors were generally not widely explored.

A common theme across the studies was the presence of misconceptions and a lack of basic knowledge about dementia. Whilst nearly 70% of Brazilian older adults self-reported knowing what AD is (Matioli et al., 2011), less than 5% of a younger sample presented with a



vignette of AD knew the condition (Blay & Peluso, 2008). Dementia literacy appeared to be generally poor across the samples included, particularly regarding the risk factors for dementia, its cause and forms of treatment. These findings seem to align with evidence from a US Latino sample (n=120) who believed that stress was a risk factor for AD and who were less likely to believe that mental activity was a protective factor against AD compared to white respondents (Ayalon, 2013). However, it is difficult to compare between studies as they often use different outcome measures. Only one of the studies included in this review adopted a validated measure (ADKS), in which the results were slightly higher than a US Latino sample (M= 20.5 vs. M= 17.6 out of 30, respectively) (Rodriguez, 2011). However, when compared to other Western samples, the scores were marginally lower, such as US white adults (M=22.5, SD=4.1, N=498)(Carpenter, Zoller, Balsis, Otilingam, & Gatz, 2011) and an Icelandic sample (M=21.2, SD=4.4, N=1,002) (Eyjólfsson, 2016).

One of the more interesting findings were related to perceived helpful interventions for dementia. Whilst psychotherapy was seen as helpful for the case described in an AD vignette, non-medical interventions such as eating better, keeping the mind busier and attending church/religious services were also seen as helpful by the majority of participants (Blay et al., 2008). Such views may reflect cultural/religious patterns in LA as approximately 92% of older Latin Americans are affiliated with a religion (Pew Research Center, 2014; Reyes-Ortiz, Pelaez, Koenig, & Mulligan, 2007), and 79.9% feel that their religion is important (Reyes-Ortiz et al., 2007). The value of religion in health and dementia has been discussed widely elsewhere (Büssing & Koenig, 2010; Cummings & Pargament, 2010; Killick, 2004; Krok, 2015; Nagpal, Heid, Zarit, & Whitlatch, 2015), but religion, religiosity and spirituality should certainly be considered in its role in shaping attitudes and beliefs within LA. In the study by Blay et al., family was perceived as the most important source of help for someone with AD, even more so than seeking the help of healthcare professionals (i.e. psychologists and neurologists). This could be due to the potential cultural importance of family, as highlighted in 'familism' (Ingoldsy, 1991), but could also be a result of lack of knowledge about the benefits of seeking professional help, or limited access to healthcare. Within Brazil, where all the included studies were conducted, 15% of respondents on the Brazilian National Health Survey (2013) underutilised the freely available healthcare system (defined as either never visiting a physician, dentist, or never having had their blood pressure or blood glucose checked) (Boccolini & de Souza Junior, 2016). In the same survey, factors such as low levels of education, low socioeconomic status and being non-white were associated with

underutilisation of the healthcare system. Previous research has identified there is a lack of trust in healthcare and associated state institutions by the general public in LA (Almeida, 2008), which may affect the perceived value of accessing care.

Education levels appeared to be the only reoccurring factor associated with varying knowledge and perceptions of AD. Lower levels of education were associated with higher levels of stigmatizing beliefs towards AD, more incorrect responses on AD knowledge questions, less perceived knowledge of what AD is and whether it is treatable, believing that religion/morality being the cause of AD, and identifying AD as a mental illness. This corroborates many studies internationally which have linked higher education levels with higher dementia literacy (Cahill et al., 2015; Hamza, Mousa, Abdul-Rahman, & Abd Elaziz, 2014; Li et al., 2011; McParland et al., 2012; Zhang et al., 2017).

It is worth highlighting, that with the exception of a single study (Schelp et al., 2008), all the other studies explored knowledge or attitudes towards AD only (or a vignette describing someone with AD), rather than dementia more broadly. This may have affected participants' responses as they might not have been familiar with the AD term. Within focus group discussions amongst Latinos living within the US, for example, there was a general preference to refer to the symptoms of dementia as "dementia" or "memory loss", and Spanish speaking Latinos were not able to identify that AD was one type of dementia (Rodriguez, 2011). It has previously been demonstrated that different countries might use different terminologies, for example, "disease of old people" (Tanzania) (Mushi et al., 2014), and "disease of forgetting" (Pakistan) (Farina, Zaidi, Willis, & Balouch, 2019).

The findings reported in this review may not represent the views from people in LA as a whole, not least because the data is derived exclusively from Brazil. In fact, due to much of the literature deriving from São Paulo state, no conclusions can be drawn regarding the broader Brazilian public, particularly as many authors did not provide extensive detail on participant characteristics and the generalisability of their samples. The MMAT risk of bias assessment also indicated that response rates were not reported in any of the studies. Future research is needed to explore the attitudes and knowledge of dementia amongst other countries in LA, and also with a particular focus subgroups of participants, such as 45 million indigenous people that live there (Economic Commission for Latin America and the Caribbean, 2014). It has previously been noted that indigenous populations may have

different attitudes to and knowledge of dementia (Johnston, Preston, Strivens, Qaloewai, & Larkins, 2019).

Most studies used quantitative methods; hence, there was an absence of in-depth qualitative research into the general public's perceptions of dementia. As such, it might not be possible to explore the role of *familism*, but also other LA values including *marianismo*, *machismo*, *personalismo*, *simpatía*, and *dignidad y respeto* (Abdullah & Brown, 2011; Mascayano et al., 2016). In addition, the synthesis and interpretation of our findings were somewhat limited because of the heterogeneity between the outcome measures used, but also through the adoption of non-validated, self-created instruments. Only a single study used a validated dementia knowledge measure (Amado & Brucki, 2018), even though the psychometric properties of the ADKS has been previously criticised (Annear et al., 2016) and the measure did not appear to be rigorously cross-culturally adapted for use in Brazil. There is a general absence of measures that have been psychometrically tested across settings; however, efforts are underway to fill such gaps. For example, the Dementia knowledge assessment scale (DKAS) has been confirmed to be valid and reliable in an English speaking international cohort (Annear et al., 2017).

## **Conclusions**

This review suggests that public health information and awareness interventions would be best targeted towards people with lower levels of education, and that there may need to be a focus on identifying symptoms of dementia and what are some of the potential risk factors. However, as these findings are primarily relevant to São Paulo state, the extent to which they apply to the wider Brazilian population and LA is unclear. Whilst the review identified that there is evidence of both lack of knowledge and negative perceptions of dementia across the studies, it is important that further research occur in LA, using validated scales and in-depth qualitative methods. This may be partially resolved through upcoming research from the STRiDE project (<https://www.stride-dementia.org/>).

## **Disclosure of Interest**

The authors report no conflict of interest.

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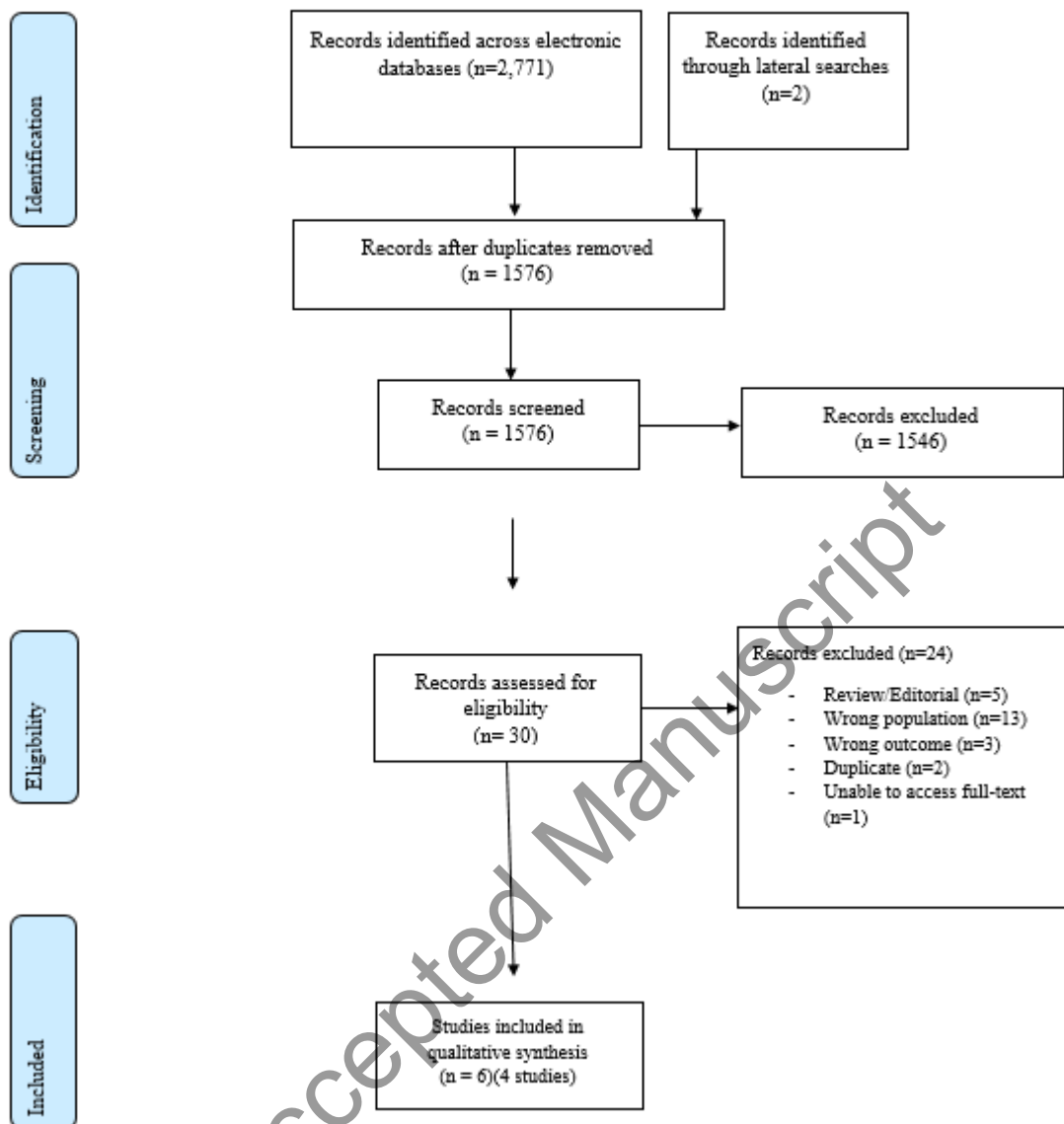


Figure 1. Flow chart of systematic review process.

**Table 1. Summary of studies included in the review**

<b>Study</b>	<b>Amado et al. 2018</b>	<b>Blay et al. 2008a; Blay and Piza Peluso, 2008, 2010</b>	<b>Matioli et al. 2011</b>	<b>Schelp et al. 2008</b>
<b>Country</b>	Brazil	Brazil	Brazil	Brazil
<b>Location</b>	26 federative units of Brazil	Sao Paulo, Sao Paulo	Santos, Sao Paulo	Botucatu, Sao Paulo
<b>Recruitment strategy</b>	Online questionnaire distributed by email to patients and relatives of a tertiary memory clinic and through social media	The study was based on a multistage random sampling	Convenience sample	Convenience sample within the community
<b>Participant criteria</b>	Aged $\geq 18$	Aged 18-65	Aged $\geq 60$ years	Not Reported
<b>Sample size: N</b>	1,414	500	944	73
<b>Age: Mean (SD)</b>	42.3 (not reported)	39.1 (SD=13.83)	72.2 years (SD=7.2)	Not reported
<b>Gender: Female: N (%)</b>	1,076 (76.1%)	252 (50.4%)	453 (47.9%)	36 (49.3%)
<b>Ethnicity: N (%)</b>	Not reported	Not reported	Not reported	Not reported

<b>Dementia knowledge and attitudes</b>	ADKS – Portuguese version	Self-created questionnaires on knowledge and attitudes (causes, sources of help, treatments)	Two item self-created questionnaire about self-perceived knowledge of dementia	Seven item self-created questionnaire about dementia knowledge
<b>Response Rate</b>	Not reported	No reported	Not reported	Not reported

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ADKS = Alzheimer's disease knowledge scale

N = number of participants

SD = Standard Deviation

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Table 2. Summary of associations between better dementia knowledge and other factors. Associations reflect data reported within included studies only.

	<b>Amado et al. 2018</b>	<b>Blay et al. 2008a; Blay and Piza Peluso, 2008, 2010</b>	<b>Matioli et al. 2011</b>	<b>Schelp et al. 2008</b>
Age	-	x		x/-
Gender: Male	x	x		x/-
Education levels	+	+		+/+
Profession: University level	+			
Relative with dementia	+			
Socioeconomic: higher		+		
Religion: Yes		x		
Personal experience of mental illness		x		
Marital status: Married		x		

x = No significant association, + = significant positive association, - = significant negative association