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# Title: Exploring dementia care systems across the African-Caribbean diaspora: a scoping review and consultation exercise

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**Abstract**

**Background and Objectives**

Understanding the influences of marginalised cultural and social identities as experienced by the African-Caribbean diaspora within the context of dementia care is essential to minimise the gaps in current practice and policy in the health care setting. This study explores the impact of marginalised identities upon the meaning making process, access to services and experience of care provisions through a scoping review and consultancy exercises with key stakeholders.

**Research Design**

Fourteen databases were searched using key terms. Primary studies in English, any year, study design and country of origin were eligible. Titles, abstracts and full texts were screened for inclusion and data were extracted in stages. Thematic analysis was performed and the findings were discussed in a series of consultation meetings with people with dementia, carers and health care professionals in Manchester (UK) and Jamaica.

**Results**

The scoping review retrieved n=1989 research articles. Nineteen were included, most were qualitative (n=14), three quantitative and two mixed method. The findings revealed limited insight into cultural and multiple individual identities in explaining conceptualisation and service access. Consultation meetings confirmed these findings and highlighted differences in healthcare services and systems in the UK and Jamaica.

**Discussion**

This study suggests there is a complex interaction of socio-cultural processes that marginalise African-Caribbean persons in and across various national settings within the context of dementia care. The study highlights the importance of acknowledging and addressing how prevalent racialised- and class-based divides and related marginalised social locations are reflected in inequities in access to and use of dementia services.

## Background

The high prevalence of dementia among Caribbean populations is a concern for the Caribbean (Davis, Baboolal, Mc Rae, & Stewart, 2018; Molero, Pino-Ramirez, & Maestre, 2007) as well as for countries such as the United Kingdom (UK) (Adelman, Blanchard, Rait, Leavey, & Livingston, 2011) and United States of America (USA) (Mayeda, Glymour, Quesenberry, & Whitmer, 2016) where a high proportion of migrated Caribbean persons reside (Prince et al., 2013). According to 2011 UK census, 992,000 persons of foreign origin living in England and Wales identified themselves as Caribbean, making this group the second largest minority ethnic group (Adamson & Donovan, 2005; Adelman et al., 2011; ONS, 2012, 2015). Most of the Caribbean population that migrated to the UK during the post war period are reaching retirement age (Botsford, Clarke, & Gibb, 2012) and the older Caribbean population is estimated to grow to 3.8 million by 2051 (Lievesley, 2010).

The increasing number of Black, Asian and minority ethnic (BAME) people in the UK who are living with dementia (Prince et al., 2014) indicates the need for more community-centred and culturally-sensitive approaches. The 2015 UK policy paper titled *The Prime Minister's Challenge on Dementia 2020* presented a target of improving diagnosis rates for the BAME population (Parkin & Baker, 2016). Although this and related policy initiatives have likely contributed to addressing dementia care access and treatment in general in the UK (Pot & Petrea, 2013; WHO, 2012) there has been limited progress toward addressing the challenges and needs of BAME groups especially with a sensitivity to their intersectionality. By this we mean, an individual may experience disadvantage and discrimination along multiple dimensions (Burke, Owens, Serpe, & Thoits, 2003; Collins & Anderson, 1995) and not just according to mutually exclusive categories of social identity and location (e.g. race, social status, gender) (Sue, 2001). Current policy and practice are limited in such awareness and often fail to address cultural and social marginalisation that BAME persons face.

Studies exploring the role of marginalised cultural and social identities within dementia care systems are limited. This study focuses on the African-Caribbean diaspora. For the purpose of this study, the term 'African-Caribbean' refers to people of African ancestry who originate from the Caribbean countries (formerly known as 'The West Indies'), and other 'Caribbean Community and Common Market' (CARICOM) territories. With an attention to the positioning of African-Caribbean persons in their societies, this study explores their perceptions, influences upon making sense of dementia, experiences of care provisions, and their reports on the availability and accessibility of services. It examines key factors related to the experiences and preferences of African-Caribbean diaspora persons with dementia and their caregivers in gaining access to dementia-related health and social care information and services.

Scoping reviews are the most appropriate approach for this type of identification and mapping of available evidence (Munn et al., 2018). The scoping review was guided by the following questions: a) How do African-Caribbean people experience and conceptualise dementia? b) What formal and informal dementia services are available to and accessed by African-Caribbean people?

In this paper we first present findings from a scoping review of African-Caribbean persons' experiences, conceptualisations, and access and barriers to dementia services. Second, we compare and contrast the findings from the review and a consultancy exercise. Third, we discuss recommendations for policy, practice and future research.

## Methods

The present study consisted of two phases. First a scoping review was conducted to identify and map the available evidence. Second key findings were explored in stakeholder consultations in Manchester (UK) and Jamaica to assist with further synthesis. The scoping review was guided by Arksey and O'Malley's (2005) framework and refined by the Joanna Briggs Institute's (JBI) methodology (Peters et al., 2017). This included identifying a research question, identifying relevant studies, selecting studies, extracting the data and collating, summarising and reporting the results. Consistent with these frameworks, we aimed to obtain an overview of the key themes in the existing research. It is important to note that risk of bias assessments and other assessments of methodological limitations is not conducted in scoping reviews (Arksey & O'Malley, 2005; Mays, Roberts, & Popay, 2001). Stakeholder consultations assisted with interpreting the results after the review was completed (Arksey & O'Malley, 2005; Daudt, van Mossel, & Scott, 2013; Levac, Colquhoun, & O'Brien, 2010). Stakeholder groups consisted of healthcare professionals working in dementia services, African-Caribbean people with dementia and their caregivers.

### Searching for relevant literature

One of the authors (SB) conducted a search of electronic databases in March 2017. Another author (RL) repeated this search in May 2019. The search strategy was developed in consultation with the wider team and the systematic review service librarian (University of Manchester). SB and RL searched databases using the key terms 'dementia', 'Alzheimer', 'African-Caribbean' and their related terms (the detailed search strategy is available in supplementary table 1). Fourteen databases (AMED, Ovid Medline (R), PsycINFO, Embase, CINAHL, PubMed, NICE Evidence, Scopus, Open Grey, Web of Science, British Nursing Index, Applied Social Sciences and Abstracts (ASSIA), EBM reviews – Cochrane Central Register of Controlled Trials, EBM reviews – Cochrane Database of Systematic Reviews) were searched individually given their unique MeSH terms and thesaurus tools. SB and RL also applied lateral searching techniques such as cross-referencing search results across databases, utilising the 'cited by' tool in Google Scholar, searching 'related papers' and searching reference lists (Bunn et al., 2014).

Inclusion criteria were papers: originating from any country; written in any year; and written in English. Exclusion criteria were: epidemiologic and genetic studies; theses, books and other review papers; papers that did not present specific results for African-Caribbean participants; and papers lacking a focus on services for dementias.

### Selecting literature

Electronic search results were exported to EndNote bibliographic software and duplicate citations were removed manually. SB and RL screened the search results in two stages. First, abstracts and titles were screened. Second, full text articles were retrieved to assess for inclusion. The list of articles considered for full text screening and reasons for exclusions are available in supplementary table 2. Inter-library loans were sought for no access papers. Any disagreements in relation to the eligibility of articles were resolved at team meetings.

### Data extraction

Informed by JBI's (Peters et al., 2017) methodology, key information from the studies were extracted under the following headings: author, year of publication, study design, study setting, study population and sample size, aims and key findings. The study characteristics are available in table 1. More descriptive data on conceptualisation of African-Caribbean peoples' experiences of dementia, service access and the meaning making process were charted through an in-depth analysis by two researchers (SB & RL) independently. To ensure the study rigour, conceptual data were discussed at team meetings and compared against the key findings. A table with a list of studies selected for full text screening and reasons for inclusion or exclusion (see supplementary table 2) was shared with the wider team for further ratification of any bias in study selection and data extraction.

### Summarising & Expert consultation

Following Arksey and O'Malley's (2005) recommendations for thematic analysis, the team used an inductive approach to identify common themes (Braun & Clarke, 2006) and synthesise data. Key questions deduced from each of the themes helped to structure the stakeholder consultation meetings in Manchester (UK) and Jamaica with groups of people with dementia (Manchester n=18), carers (Manchester n=3, Jamaica n=3) and healthcare professionals (Manchester n=1, Jamaica n=4). Written feedback was collected from participants who were unable to attend the consultation meetings.

The papers extracted from a more recent search conducted in May 2019 are included in the overall reporting of the results. However, no new themes were generated from the four new studies included.

## Results

The search yielded 2045 papers with 1,989 unique citations after manual removal of duplicates. On screening titles and abstracts a further 1654 papers were excluded, leaving 19 for analyses for the scoping review. The four papers identified through lateral search are included. Details of articles excluded from the review can be found in supplementary table 2. Figure 1 presents the study selection procedure.

Most articles were qualitative studies (73%, n = 14), three (16%) were quantitative papers and two (11%) were mixed methods papers. Fifteen studies (79%) were based in the UK, two studies (10%) in the USA, and the remaining two (10%) in the Caribbean. Twelve studies recruited caregivers, eight studies recruited people with dementia, five studies recruited staff and two studies recruited African-Caribbean general adult population. Table 1 presents detailed study characteristics of the included papers.

## Thematic analysis

Using the Braun and Clarke (2006) framework to analysis that is described in table 2, the team identified the following four key themes: 1) Making sense of dementia; 2) Help-seeking –

Access and barriers; 3) Approaches to caring; and 4) Culturally sensitive services. The findings from the scoping review and stakeholder consultations are presented separately for each theme.

### Theme 1: Making sense of dementia

### The Scoping Review

A central aim of most studies (n = 10; 67%) was to explore how participants conceptualised dementia. Participants offered a range of explanations for dementia. Some explained dementia with reference to a biomedical model, i.e. impaired functioning or 'dying' of the brain (e.g. Adamson, 2001; Lawrence et al., 2011; Parveen, Peltier & Oyebode, 2017). Dementia was also described as a normal part of ageing, somewhat expected, influenced by lifestyle, life events and medications for co-morbid conditions (Berwald et al., 2016; Botsford et al., 2012; Cheston et al., 2017; Lawrence, Samsi, Banerjee, Morgan, & Murray, 2011; Mukadam, Cooper, Basit, & Livingston, 2011; Adamson, 2001). Some studies reported that participants felt there was insufficient information about dementia available to them in their community (e.g. Moreland, 2001; Moreland, 2003; Parveen, Peltier & Oyebode, 2016). Participants in studies also indicated that a lack of understanding about dementia contributed to their anxiety about the future (Lawrence et al. 2011). One study (Tappen et al., 2011) found that African-Caribbean persons scored low on cognitive screening and that the results were closely associated with levels of education.

Studies presented misconceptions and/or culturally specific beliefs about dementia. In one study, participants attributed dementia to 'too much aluminium in the brain'. In another, participants reported perceiving dementia as a 'white person's illness' i.e. unheard of in elders in the Caribbean and only becoming a problem following their migration to the UK. In some studies, participants explained dementia with reference to 'spirits' (All-Parliamentary Group on Dementia, 2013; Berwald, Roche, Adelman, Mukadam, & Livingston, 2016; Cheston et al., 2017). Dementia was described using stigmatising language such as 'madness' and 'mental' (Cheston et al., 2017; Lawrence et al., 2011; Moreland, 2001).

The data in the papers from which this theme was derived did not explicitly conclude that participants' gender or their age influenced their perceptions. A limited number of studies reported education/ professional background/ social class for participants according to ethnic group membership.

### The Consultancy Exercise

The UK consultation with persons living with dementia echoed the review finding of persons having a limited understanding of dementia, its causes, and how to help someone with the condition. Some persons living with dementia described dementia as a normal and expected part of ageing.

> Person living with dementia (UK): "There's no cure as far as I'm concerned but as you get older in your mind it change".

In both the UK and in Jamaica, in general the consultations with the informal carers offered conceptualisations of dementia that were consistent with review findings. They defined dementia as a decline in brain function and as a long-term illness with no cure. They noted that dementia might be a result of physical inactivity and a lack of cognitive stimulation. They also noted that life stressors, trauma and drastic changes in lifestyle could be potential causes.

A few female carers in Jamaica expressed that because of multiple caregiving roles they assume, women are less likely to have time for self-care, and that this in turn increased the risks of developing dementia.

While not communicated in the consultations with UK based informal carers, in Jamaica a family caregiver expressed dementia as inevitable, suggesting that most people develop dementia in their lifetimes, that it is hereditary, and that nothing can be done to prevent it.

> Informal carer (Jamaica): "Almost 80 to 90 percent of persons will get dementia, because everybody experiences some memory loss or symptoms of dementia…."

On discussion of review data which described dementia as a 'White person's illness', people living with dementia in the UK expressed that dementia is more prevalent in African-Caribbean people living in the UK as opposed to people living in the Caribbean. Some carers and health care professionals in the UK disagreed with this statement and suggested this view is probably due to lack of awareness about dementia in the Caribbean.

> Person living with dementia (UK): "In my country that I'm from we had a lot of old people and they lived so long, ninety, a hundred and we never heard of their forgetfulness with dementia, we never hear that name! and they lived for long! And die with good sense you know…"

Consistent with this, a health care professional in Jamaica explained that there are limited resources and poor awareness of dementia in the Caribbean.

Some carers from the UK and Jamaica attributed dementia to fate or luck. Reflecting on the use of stigmatising language discussed in the reviewed studies, the health care professionals and carers in Jamaica and the UK acknowledged that the formal diagnosis of dementia was in itself stigmatising.

> Health care professional (Jamaica): "We are far away from seeing dementia differently in Jamaica, not responding negatively such as saying 'that lady was so nice but went crazy."

Although the literature does not explicitly discuss identities within the socio-political environment, the data from the stakeholder consultations suggest gendered aspects to caregiving and that the external or societal environment plays a key role in conceptualisations of dementia.

### Theme 2: Help seeking – Access and barriers

#### The Scoping Review

Thirteen (72%) studies discussed services that persons living with dementia and their carers attended, attitudes towards services and barriers. Participants identified General Practitioners (GPs)/family doctors as potential gatekeepers to memory clinics (Parveen, Peltier, & Oyebode, 2017). Reservations about accessing GP service were often explained in relation to being worried about wasting the GP's time, costs, insufficient consultation time (Berwald et al., 2016; Cheston et al., 2017), and the GP's lack of awareness of cultural factors or adaptations needed for dementia services (Parveen et al., 2017; Roche, Mukadam, Adelman, & Livingston, 2018). Some male carers noted that previous unpleasant experiences at the GP and a lack of trust in services prevented them from seeking support (Berwald et al., 2016; Cheston et al., 2017). Some persons with dementia in the studies reviewed, particularly women living with dementia, noted that the diagnosis increased their fear of the future. The reviewed studies also reported that approaching health services evoked considerable fear of losing independence (Berwald et al., 2016), being taken away from family, being sectioned or 'locked up' (Baghirathan et al., 2018; Cheston et al., 2017), or being placed in a nursing home (Lawrence, Murray, Samsi, & Banerjee, 2008; Lawrence et al., 2011). However, a recent randomized control trial conducted in the UK suggested willingness among African-Caribbean older people –regardless of age and gender – to seek diagnosis if and when they faced memory problems. The study discussed organisational factors as potential contributory factors in delayed access to services (Roche et al., 2018).

Across multiple studies, participants reported that they avoided or delayed seeking help for memory problems because of negative experiences with services, stigma associated with mental health services and previous experiences of race-based discrimination (Berwald et al., 2016; Lawrence et al., 2008; Moreland, 2003; Mukadam et al., 2011; Parveen et al., 2017). Some people with dementia and carers described their encounters with health care professionals and statutory services as unhelpful. They described professionals being dismissive and prejudicial in their interactions (Berwald et al., 2016; Moreland, 2003). The Parveen et al. (2017) and the Brown and Murphy (2018) studies noted that on receiving a dementia diagnosis families withdrew from the wider community and kept the diagnosis a secret. This withdrawal had implications for persons living with dementia and their carers not accessing community groups for support.

Cheston et al. (2017) and Baghirathan et al. (2018) indicated that people living with dementia relied upon their family to make initial contact with services. Studies also noted included that family members: were unable to recognise the symptoms (Adamson, 2001; Brown & Murphy, 2018; Mukadam et al., 2011); adapted to dementia-related changes (Botsford et al., 2012); and that they waited until the crisis point to seek help. Another barrier the studies discussed was denial on the part of the person living with dementia (Berwald et al., 2016; Botsford et al., 2012; Mukadam et al., 2011). In some UK studies, older people and notably older women, reported that having no family in the UK affected their care and was linked to their delay in help-seeking (Berwald et al., 2016; Lawrence et al., 2011). The Tuerk and Sauer (2015) study indicated that people of African-Caribbean descent present to services at an advanced stage of dementia. The Baghirathan et al (2018) and Cheston et al (2017) studies highlighted that, compared to women, Caribbean men are less likely to engage with services and often feel isolated. In their investigation of caregiver burden in Trinidad Baboolal and colleagues (2018) highlighted a significant association between men as carers and the caregiver burden, with their respondents noting that their health and wellbeing, financial and social life had been negatively impacted because of their role as carers.

On the topic of social care provisions, three UK-based studies discussed carers' concerns about the standard of care homes, overcrowding and the lack of culturally appropriate meals and daily activities (Brown & Murphy, 2018; Cheston et al., 2017; Lawrence et al., 2008). Carers reported that these factors made them consider care homes as a last resort. Regardless of their level of education, a majority of female carers in the Mukudam et al. (2011) study perceived external help as intrusive and preferred not to discuss their caring duties nor the diagnosis with anyone outside the family. The review findings also highlighted the need to make dementia specific and service related information culturally appropriate and easily available (Moreland, 2003).

**The Consultancy Exercise**

The stakeholder consultations in the UK with carers and health care professionals reiterated the review findings about GP services.

Stakeholders noted insufficient time for consultations and the GP's limited awareness of dementia services:

> Informal carer (UK): "There was definitely something wrong with my mum, but the GP said he couldn't do test straight away due to time."
>
> Health care professional (UK): "There is a Dementia Crisis Prevention Team who work within CMHT [Community Mental Health Team] but this support can only be accessed by referral from GP so relies on GP being aware of the pathway. Not all are."

In Jamaica, carers and health care professionals highlighted that some doctors were dismissive and were less likely to consider contextual information while making a diagnosis. This led the participants to question professionals' competencies.

> Informal carer (Jamaica): "…I got a psychiatrist to come and assess her, but he was very reluctant to say that there was a mental problem. He said she seemed fine after the interview. I had told him what was happening before the interview. I feel he should have used the information I gave him to understand her behaviours, and not just the interview."

Echoing the review findings, people living with dementia and carers from both the UK and Jamaica discussed dementia as a condition for which there is no cure and as a normal part of ageing. Health care professionals noted their observations of a significant amount of fear and stigma associated with dementia. They noted families' inability to understand symptoms and recognise the early stages, and people with dementia withholding their symptoms from family. These data support the review findings about delayed recognition and acceptance of early symptoms and point to a potential role for programs and services for transforming attitudes.

> Health care professional (Jamaica): "The culture makes the disease taboo…."

> Informal carer (UK): “after seeing it then early diagnosis is important. My dad kept it from us then eventually broke down to us.”

When they were presented with the review findings related to dementia care services, UK-based stakeholders identified funding cuts (APPG, 2013) to day care and befriending services as impacting their access to services.

> Informal carer (UK): “…not with services cut. Used to have befriending, not anymore.”

In addition UK-based stakeholders also confirmed lengthy diagnosis processes, GPs being overstretched, insufficient and inaccessible information regarding community services as some of the ongoing service-related challenges they face.

The consultancy group participants in Jamaica discussed other types of barriers that were also reflected in the literature. The barriers they focused on were around secrecy and not sharing information about a diagnosis or suspected case of such. They spoke about families and neighbours being over-protective, sympathetic and patronising. They noted that these attitudes and approaches were factors that influenced some carers to not share the diagnosis outside of the family and to not seek external support. Other carers noted that it was a part of their culture to keep the diagnosis within the family.

> Informal carer (Jamaica): "I didn’t want to say anything for a long time because of perceptions. I always heard…that dementia is worse than cancer. …People's reactions were often very dramatic and so it made me not want to share it. …People give you a sense of pity, that her life and my life is over, and that causes discomfort."

The stakeholders from Jamaica expressed that the communities are less empathetic towards people with mental illness. They discussed how a family’s financial situation and social class restricted access and shaped their choices for support. They noted too that financial situation and social class played a role in understanding of dementia because their built-in privileges provided some people access to relevant information and resources while people in other groups were not even aware of those resources.

> Informal carer, Male (Jamaica): “Information regarding dementia is really not that available.”
>
> Informal carer, Female (Jamaica): “…Certain classes who may have not had the education to know the symptoms and what [was] happening, what [was] serious and what [was] not."

Although some of the social factors discussed by groups in both locations were similar, none of the UK members presented social class or financial situation as a concern.

### Theme 3: Approaches to caring

### The Scoping Review

Caregiving was often framed as an important part of African-Caribbean culture. The majority of papers (n=10, 55%) examined aspects of confidentiality and privacy. Studies reported that family caregivers explained their caring role as a normal part of their relationships, their responsibilities, and their commitment towards family (Adamson & Donovan, 2005; Baboolal et al., 2018; Brown & Murphy, 2018; Mukadam et al., 2011). Mukundam et al. (2011) identified caregiving roles as more prevalent among the women compared to the men in their study, while noting that the had a majority of female participants. Carers in some studies explained that caring for parents was in some way reciprocating the care they received in childhood. They noted it was a virtue associated with being a "good Christian". Other carers reported that being a family carer meant they had lost their independence and caring duties were to be prioritised over their needs (Lawrence et al., 2008). The caregivers report in the Brown and Murphy (2018) study noted that a lack of support from the wider family made caregiving more challenging. They also stated that financial constraints pressed them to take up employment, that that limited their ability to provide care, and that in turn led to them feeling remorseful. The spouse caregivers of people with dementia in Botsford et al. (2012) study indicated that they supported their partner with dementia in most aspects of everyday living and did not wish to burden the wider family with caring responsibilities. People with dementia suggested that a person with dementia should rely on care professionals rather than family for practical assistance (Lawrence et al., 2011). Participants in various studies reviewed noted that apart from family, third sector organizations and churches were significant sources of support (e.g. Parveen et al. 2017). Support from care professionals was discussed in some studies. Findings in studies suggested that residential homes were considered as a last resort because they were seen to have unsatisfactory standards of care (Brown & Murphy, 2018; Moreland, 2001, 2003).

**The Consultancy Exercise**

The stakeholder consultations in the UK and Jamaica affirmed review findings. One of the key findings that were supported was that caring responsibilities were largely shared within a family and that the wellbeing of people living with dementia depended upon this shared familial care.

> Informal carer (UK): "They probably didn't have someone looking after them, that's why he got ill so quickly."

Some participants expressed particular satisfaction and pleasure with being able to look after their parents.

> Informal carer (Jamaica): "I'm grateful I'm here to care for my mother. Because I feel like that's what I'm supposed to do."

Some carers thought that the lack of family involvement led to rapid deterioration of health. HCPs in Jamaica indicated, regardless of whether the family lived close by or at a greater distance (even outside the country), the family took responsibilities to organise care for their loved ones. This topic of long-distance caregiving or organising relevant support was not explicit in the reviewed literature on dementia and African-Caribbean persons.

The data from the stakeholder consultations in Jamaica echo the review findings on the role of informal caregivers, particularly their responsibilities and support. Stakeholders indicated neighbours played an important role in caregiving for family members. The support system for family carers in Jamaica was described as inadequate. Stakeholders reported that this in turn contributed to carers feeling depressed, dealing with financial burden, and having to sacrifice their personal goals/ambitions. While discussing coping methods they suggested keeping busy with daily tasks.

> Informal carer, Female (Jamaica): "I was depressed, but not wallowing and locking myself away. So I kept myself busy with practical needs. I feel there's nothing I can do to change what is happening, so I may as well just do what I can to take care of her…."

Some carer stakeholders also mentioned turning to alcohol as a coping mechanism.

Although the reviewed literature did not explicitly discuss women being better suited for caring roles than men, during consultations stakeholders indicated that women were often regarded as better suited to caring roles compared to men.

Stakeholders in both the UK and Jamaica confirmed review findings about support services, noting that churches and third sector organisations were important parts of their social life and sources of information. Stakeholders also reiterated review findings about professionals' lack of understanding and sensitivity to the needs of people living with dementia and their failure to provide dementia friendly holistic care.

### Theme 4: Culturally sensitive services

#### The Scoping Review

Seven studies (47%) discussed the cultural needs of the African-Caribbean population within dementia services. People with dementia and carers in these studies emphasised the importance of seeking support from services that are respectful of cultural needs (APPG, 2013; Cheston et al., 2017; Parveen et al., 2017). However, it was also noted that these services were sometimes harder to access and more expensive. Participants also reported that they sought help from third sector organisations and local day centres. Churches were a particularly important source of support noted in some studies (Adamson & Donovan, 2005; Parveen et al., 2017). Studies described the benefits of having social groups/ dementia cafés and service providers with similar cultural background involved in delivering frontline care (APPG, 2013; Baghirathan et al., 2018; Cheston et al., 2017; Parveen et al., 2017). For example, in one study a participant described African-Caribbean people's reluctance to attend memory cafés noting that they do not want to 'stand out' and would prefer to share their experiences with people from a shared cultural background (Baghirathan et al., 2018; Cheston et al., 2017). In one paper, carers, persons living with dementia, and service providers suggested that it is important that services provide culturally appropriate cuisine (APPG, 2013). Language was also an important cultural consideration. Studies indicated that Standard English was not the preferred language for African-Caribbean persons living with dementia. In Cheston's (2017) study, Standard English was described as a 'performance language' for older generations. One study noted that there is no word for dementia in different Caribbean dialects or patois (Moreland, 2001) and that this may be linked to the difficulty that some African-Caribbean people have with conceptualising 'dementia'. Finally, the study also suggested that healthcare professionals were not always culturally competent, that they lacked confidence, and that some of the assessment tools were not fit for purpose for use with African-Caribbean persons living with dementia.

**The Consultancy Exercise**

Consistent with the scoping review findings, all stakeholder groups in the UK emphasised the need for dementia services to be culturally sensitive. For example, a carer reported that providing opportunities for people to reminisce with others from a shared cultural background, acknowledging the importance of religion, and providing African-Caribbean food during the meetings are factors that contribute to fostering a conducive environment for socialising and engagement with services.

> Informal carer (UK): "With some people the chance to talk about 'home' and reminisce about growing up and coming to England is beneficial. Preparation of home cooked food and taking a general interest in that person is vital."
>
> Health care professional (UK): “The majority of people here are from the West Indies, but they are from different part. They’re not all from the same place so it’s good. And they interact and they talk about where they’re from and so on so that’s good as well.”

Carers from the UK provided more socio-political context-sensitive ideas about why the shared cultural background is important to African-Caribbean people living with dementia. Noting that people living with dementia can often ‘go back thirty or forty years’, they pointed out that this means that they talk about their early memories growing up in the Caribbean and moving to England during the Windrush era. They spoke about this being a life event that is difficult to communicate with people who have not shared this experience but a context that is necessary to understand the African-Caribbean person living with dementia in the UK.

> Informal carer (UK): “They’ll be living in Jamaica, and when they first come over and they’ll be talking about what happened when they first come or whatever, but they could never talk about that with a white person because when they first come, what was it ‘no Blacks, no Irish, no dogs’? You know what I mean?”

Two UK stakeholders (one HCP and one informal carer) reported times where a person living with dementia did not want to attend a group activity because there were no other Caribbean people. One carer hypothesized that this might be because the person living with dementia would feel ‘singled out’.

> Health care professional (UK): "One family said that they didn’t want their dad going to a day service because there were too many women and no other African-Caribbean people there."

In response to the review findings about services in residential care settings, the informal carers and HCPs from Jamaica stated that the activities at nursing homes were not mentally stimulating and engaging.

> Health care professional (Jamaica): “I have been to nursing homes, and they [the persons living with dementia] do nothing but sit and stare at each other with the TV

> on in the background. In the States (USA) they were always stimulated. And I found they did not lose language as quickly."

While funding was not extensively examined in the reviewed literature, dementia services funding and funding cuts was discussed in the UK stakeholder consultations. Some carers in the UK highlighted ways in which the funding cuts affected their relative's wellbeing. They noted that the lack of funding meant the closure of pick up and drop off services to the group activities and that it increased reliance on unpaid volunteers. Some carers also mentioned dementia choirs as an essential service for persons living with dementia as it took the focus away from dementia, removed stigma, and helped the person living with dementia be a member of a group, and to engage in community activities. The little attention given to the topic of funding when compared to its prominence as a topic in the stakeholder consultations in the UK suggests that funding is an area for future research. It is worth considering how the political and economic landscape impact access to services, and more specifically, access for specific social groups. Such access is crucial to improving the quality of life for people with dementia.

## Discussion

The reviewed studies discuss the meaning-making process of dementia, drawing on the perspectives and experiences of people living with dementia, informal carers, and healthcare professionals. These studies offer limited insight into the interactions of African-Caribbean persons' multiple identities and how these position them within their sociocultural contexts. Multiple Identities in this study refers to how individuals define their individuality by inferring to their self-knowledge, roles and position within the culture, family, background, education, skills, economy, class, ethnicity, race and situational contexts (Ramarajan, 2014). Although some of the studies address gender, class, and ethnicity as characteristics that influence dementia conceptualisation and service access (Adamson, 2001; APPG, 2013; Baghirathan et al., 2018; Botsford et al., 2012; Brown & Murphy, 2018; Cheston et al., 2017; Lawrence et al., 2011), they do not adequately discuss the implications of these intersecting social statuses for improving African-Caribbean peoples' experiences with dementia care. It is crucial to understand how people navigate and internalise status, class, ethnicity, roles and physical space in everyday life and the implications for conceptualising and addressing inequalities in dementia service availability and access. Furthermore, implementation of person-centred dementia care requires that the multiple marginalised positions they have experienced and still have to navigate is acknowledged and addressed in sensitive and effective ways. This involves going beyond the narrowly conceptualised influence of an often minimally defined ethnic 'culture' (Zubair & Norris, 2015), and considering instead how the varied intersections of 'race'/ racialization, ethnicity, social class, and gender may have an impact on the ensuing healthcare-related inequalities (Tang, Browne, Mussell, Smye, & Rodney, 2015) for African-Caribbean populations in different national contexts.

Recognising networks of social and situational identities can inform a better understanding of variations in perceptions observed in the reviewed studies. For example, the studies that discussed participants' descriptions of dementia as 'White person's illness' and as a normal process of ageing, (APPG, 2013; Berwald et al., 2016; Cheston et al., 2017) considered African-Caribbean peoples' ethnic identity. It might be useful to explore instead an analysis of intersecting influences of social class and varied levels of education of this ethnic group that is presumed to be homogenous but is quite heterogeneous (country of origin, profession, education attained, and gender). The stakeholder consultations in Jamaica and the UK indicated high levels of awareness regarding the risk factors for dementia. They also pointed to the ways in which stigma (Cheston et al., 2017; Moreland, 2003; Mukadam et al., 2011) and socio economic disparities (APPG, 2013; Brown & Murphy, 2018) may be barriers to service access. Thus, membership of a lower status and marginalised social position is likely to put African-Caribbean persons – whether living in the UK, USA or in a Caribbean country – at a greater disadvantage in terms of engagement with dementia services.

The reviewed studies which presented research evidence mainly from the UK and USA contexts, outlined a number of barriers to help-seeking. These factors included both general issues and those presumed to be culture-specific. Key barriers included: stigma; denial and non-recognition of symptoms; perceptions of external help as intrusive; fear of being institutionalized or locked up; specific religious beliefs; professionals' lack of cultural awareness; and professionals' dismissive attitudes (Adamson, 2001; Berwald et al., 2016; Botsford et al., 2012; Brown & Murphy, 2018; Cheston et al., 2017; Lawrence et al., 2011; Moreland, 2003; Mukadam et al., 2011; Parveen et al., 2017; Tappen, Gibson, & Williams, 2011; Truswell, 2016; Tuerk & Sauer, 2015).

A key socio-cultural barrier noted was African-Caribbean persons' negative experiences of racism with services as well as in the wider UK and USA society (Mukadam et al., 2011). Although the existing literature addressed barriers to dementia service access under the broader explanation of ethnic cultural differences, it engaged little with the discourse of identities. The significance of specific identities, process of internalisation, social locations and positioning as racialised and minority ethnic populations in the UK and USA contexts must be taken into consideration in the design and implementation of culturally-appropriate services. They are important contributory factors likely to result in the marginalised position of the African-Caribbean population in those contexts and their unequal access to services.

Much of the research literature from the UK and USA did not to sufficiently consider the significance of social class locations in conceptualising dementia and service access. The Jamaica stakeholder consultations highlighted social class as an important barrier to service access for those in that context, which has a health and social care delivery system different from that of the UK and the USA.

Some literature in the UK (APPG, 2013; Brown & Murphy, 2018) and the stakeholder consultations pointed to the impact of socioeconomic status upon people's choices. Having limited financial resources and being a member of a specific minority ethnic group placed people in a marginalised physical and social space. Additionally, cut back on government's funding provisions to support continuation of innovative services for minority ethnic populations in the UK meant discontinuity, chaos and a significant impact on the lives of these people living with dementia and their carers.

### Limitations and recommendations for future studies

There is a lack of research evidence on dementia relating to Caribbean populations in North America and the Caribbean region in particular. It is therefore difficult to examine national policies, cultures and resources and to make comparisons in these areas across countries.

The small but growing body of UK-based research literature has predominantly focussed on African-Caribbean ethnicity as an important factor influencing their understandings of dementia and access to dementia services. Our comparative focus involving participants living in the Caribbean suggests that in order to provide culturally appropriate access and services it may be useful to consider ethnicity as a context for exploring multiple intersecting factors that impact service access. Our findings indicate that barriers to service access in the UK are linked with experiences of racial, culture-based and socioeconomic exclusions; in the Jamaican context barriers appear to be informed by social class and financial resources. The role of inequalities, including systemic inequalities, is important in both national contexts. This understanding is reinforced for us through a comparative focus that considers race, ethnicity, class, gender, economy, education, profession, location, politics and social space as processes influencing identities in a given society and across various national contexts. Future comparative work on dementia care with and for African-Caribbean populations can further explore the complex and interlinked processes that disadvantage the diverse members of this population in terms of a lack of appropriate access to dementia services. Future studies can inform improvements to dementia care availability and access for this population by considering in their designs, implementations, and output the socio-cultural, political-economical processes that lead to marginalisation in dementia care-systems. They can also focus on interventions/ strategies that address such processes.

Some of the other limitations of this study include the lack of people with dementia at consultation events in Jamaica and limited feedback from healthcare professionals at the UK-based consultation events. The limited number of key stakeholder participants indicates that more customized community engagement approaches and strategies are needed to ensure that the voices of members of this population are included in the development and design of services and programmes that target them.

## Implications for practice and policy

The review data found that there was not a unanimous agreement among participants that caring was a manageable family duty; instead they reported that it was also an obligation that presented a considerable burden on families (Adamson & Donovan, 2005; Baboolal et al., 2018; Botsford et al., 2012; Brown & Murphy, 2018; Mukadam et al., 2011; Parveen et al., 2017). There is a stereotype that members of African-Caribbean communities perceive external professional help as undesirable. However, these review findings suggest that external or professional help may in fact be appreciated. The review findings indicated that what is resisted is services and help where African-Caribbean people feel discriminated against or do not experience culturally sensitive and appropriate service provision.

The issues of access and acceptability of dementia services, whether in the UK or in Jamaica are complex and go beyond a simple, singular, issue of cultural difference. This requires cultural sensitivity and improving access to quality mainstream person-centred dementia services. Some of the important aspects of quality improvement suggested in the overall findings involve better service integration, clearer referral pathways for dementia diagnosis and care, and appropriate education and training of healthcare professionals in relation to culturally informed person-centred dementia care (Manthorpe & Samsi, 2016).

Although NHS England's transformation framework for the dementia pathway (Department of Health, 2015) sets out standards for 'supporting well', 'living well and dying well with dementia', its application and implementation varies across regions. For example, the findings indicated GP services in some locations are perceived as unapproachable and not proactive in signposting families to dementia services, and that the lack of culturally appropriate assessment tools and outcome measures make diagnosis and intervention challenging. While the framework for the dementia pathway is robust, there is a gap in implementation. Understanding the impact of multiple marginalised identities in dementia care availability and access can influence diagnosis rates, service access, and culturally adapted implementation of proposed standards under the framework, particularly for BAME communities.

Ethnic identities and the ways they interact with other social identities are associated with multiple marginalizations. To address systemic inequalities in dementia care these intersections need to be considered at the level of both local services and at a national level (i.e. in terms of policy and clinical practice). Findings from this study suggest that uptake of and participation in community-based dementia services are determined by feelings of belonging, inclusion, similarity, approachability, and trust –not necessarily by expert knowledge of dementia as a condition. This points to the need for greater cultural sensitivity in community-based and charity-led services (dementia cafés, singing groups, book clubs, activity groups). There is currently little evidence to indicate how the UK's national policies and practice guidelines address wider inequalities around 'race', racism, and racialized identities and exclusions. Special attention needs to be paid to the UK's national policies to avoid placing certain racialised and minority groups in further marginalised positions and thereby being counter-productive in terms of building trust in the dominant healthcare services. Similarly, as social class appears to be a significant barrier to equitable service access within the Jamaican context, policy and practice in this context need to be responsive to wider systemic inequalities around social class and financial status. Services in Jamaica may also benefit from more public education about dementia and increasing the friendliness, approachability and person-centeredness of dementia-specific and general healthcare services.

## Conclusion

This study enhances the current literature by bringing to forefront the complex interaction of socio-cultural processes that marginalise African-Caribbean persons in and across various national settings. The study produces insight into the diversity of dementia experiences within the assumed homogeneity of the African-Caribbean group even within the Jamaican cultural context. Current policy and practice must address the inequalities linked with marginalised social locations and more specifically the powerful influence of the prevalent racialised and classed social divides and exclusions on access to information about dementia and dementia services.

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Figure 1: Study selection

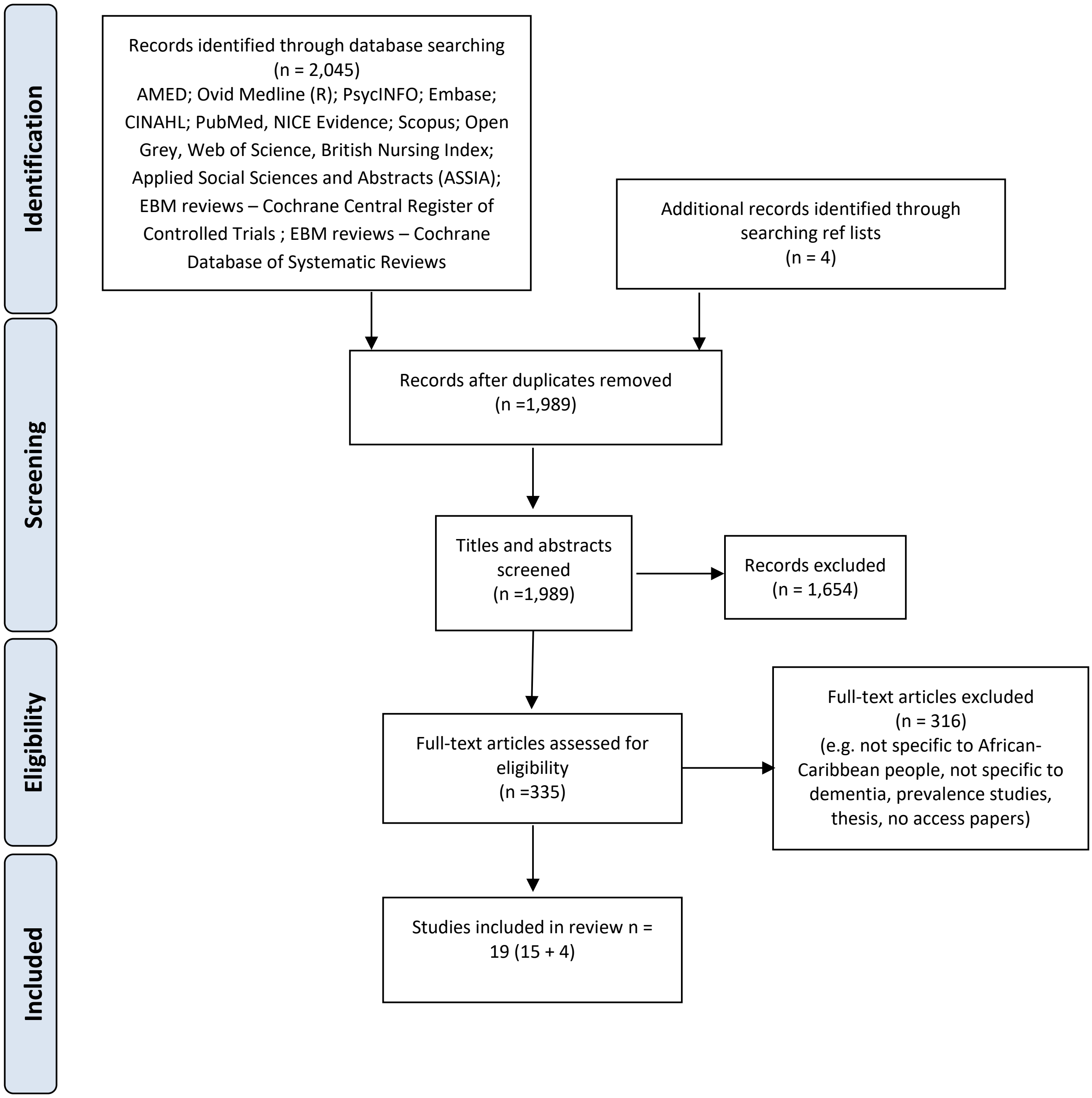

Table 1: Study characteristics

| Author (year) | Study design | Study setting | Sample | Aims | Key findings |
|---|---|---|---|---|---|
| Adamson (2001) | Qualitative | UK (England) | Total participants: 30 (carers) African-Caribbean: 18 (Female-15, Male -3; spouse-7, daughter-9, son -1, niece-1); South Asian: 12 | To explore African-Caribbean and South Asian carers' understanding of dementia and experiences of caring for their relative | African-Caribbean carers had some understanding of their relative's dementia but in some cases awareness of dementia was only acquired after their relative's formal diagnosis, which often lead to delays in help-seeking. |
| Adamson & Donovan (2005) | Qualitative | UK (England) | Total participants: 36 (carers)<br>African-Caribbean: 21<br>South Asian: 15 | To develop an understanding of African-Caribbean and South Asian people's experiences of informal caring of an older relative with dementia | Caring was described as 'normal disruption' and generally explained within a cultural framework whereby caring was viewed a pivotal part of family duty, moral obligation, and one's religious values. Most often, caring responsibilities belonged to a daughter with whom the PwD had previously shared a house with before they required care. |
| Baboolal et al., (2018) | Quantitative | The Caribbean (Trinidad and Tobago) | Total participants: 75 PwD- carer dyads<br>PwD ethnic groups: African: 36; East Indian: 13; Other: 26 | To examine potential cultural differences in caregiver burden in different ethnic groups in Trinidad and Tobago. The Zarit Burden Interview [ZBI] was used to measure caregiver burden and the General Health | Mean ZBI (burden) score was higher in carers of PwDs belonging to the "Other" ethnicity group (27.8) compared to carers of PwDs of African (20.7) and East Indian (18.2) descent. In summary, caregiver burden was significantly higher in male carers belonging to minority groups (In Trinidad and Tobago this would refer to individuals who are *not* of African or East Indian background). Additionally, |

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| | | | | Questionnaire [GHQ] assessed psychiatric morbidity. | carers who reported greater burden had increased GHQ scores. |
| Baghirathan et al (2018) | Qualitative | UK (England) | Total of 76 participants (carers & staff from voluntary organisations) -47 people from different South Asian communities (Muslim, Hindu and Sikh), 31 people from the Chinese community and 25 people from African Caribbean community. | To generate a grounded theory guided by the following questions: what experiences do people from three different BAME communities who provide care for people living with dementia in Bristol have of dementia-specific care? Secondly, why do they "think people might be reluctant to access dementia care services? | Caribbean men expressed visiting the doctor to discuss memory loss or other concerns was to risk being 'locked up. For some Caribbean participants the isolation of being the only visible person from a BAME community within a service thereby risked their cultural needs being ignored or disregarded. Many informants described a wish to hide the vulnerabilities that arose from dementia for as long as possible. Participants reported greater reliance on BAME led voluntary organisations and churches. |
| Berwald et al. (2016) | Qualitative | UK (England) | Total participants: 50 (4 carers, 4 people being assessed for memory problems, 2 support workers, 40 members of the public); Black African: 28; African-Caribbean:14;Black | To determine potential obstacles encountered by Black and African-Caribbean people when seeking help for dementia | Participants demonstrated an inability to recognise early warning signs, for example attributing forgetfulness to the normal ageing process. Dementia was described as a 'white persons illness'. Participants reported a reluctance to discuss problems due to concerns over time and privacy. It was also commonly reported that problems reached 'crisis point' before help was sought. Additionally, there was also a reluctance to seek help due to the |

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|  |  |  | British: 7;Indo-Caribbean: 1 |  | fear of losing independence or becoming ‘institutionalised’. |
| Botsford, Clarke & Gibb (2012) | Qualitative | UK (England) | Total participants: 13 (Female-6, Male-7; partners of people with dementia)<br>African-Caribbean: 6<br>Greek Cypriot: 7 | To examine the experiences of African-Caribbean and Greek Cypriot people in a relationship with a PwD | African-Caribbean participants tended to be more individual and couple-orientated. Participants reported that they initially adapted to the early warning signs exhibited by their partner, by attributing them to normal ageing and choosing not to seek help. In some cases, this meant that help was not sought after until problems reached crisis point. After acceptance of the dementia diagnosis, relationships followed a process of redefinition. This process included a dealing with the changes and developing coping strategies |
| Brown & Murphy (2018) | Qualitative | The Caribbean (Barbados) | Eight informal (family) care-givers of people living with dementia in Barbados | To explore the barriers of primary informal caregivers to caring for persons living with dementia (PLWDs) in Barbados | Four central themes were extracted from the interview data: imbalanced family dynamics, financial and time constraints, dissatisfaction with formal care services, and misunderstanding of complex symptomatology.<br>Family dynamics addressed issues of limited support from other siblings or adult children in caring for PwD, balance the challenges of own families while caring for PwD. |

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|  |  |  |  |  | Caregivers, whether employed or unemployed, admitted to not offering as much care as they would like and struggled financially.<br>Caregivers were concerned about overpopulation, and subsequent insufficiency and overmedication in formal care centres.<br>Limited/lack of recognition of symptoms at pre and post diagnosis stage that impacted PwD's behaviours were often the cause of conflicts and misunderstandings in relationships. |
| Cheston et al. (2017) | Qualitative | UK (England) | Total African-Caribbean participants: 10 (1 PwD, 8 family carers, one person concerned that they might have dementia). | To explore the understanding and experiences of dementia and services of three minority groups (African-Caribbean, Chinese & South Asian) | Participants reported services as oppressive and some people (particularly men) felt mistrustful of services for dementia. Participants voiced a need for culturally sensitive services that meet the needs of the African-Caribbean community. Most people had an awareness of the term 'dementia' but there were gaps in knowledge, for example viewing the condition as part of normal ageing. Some participants explained that caring for family 'until the very end' is an important part of their culture. People also explained that they avoided services because they were worried about the quality of care they would provide their relative with dementia. |

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| Cohen, Hyland & Magai (1998) | Quantitative | USA (Brooklyn) | Total participants: 286 (PwD); African-American: 164; African-Caribbean: 54; Caucasian: 68 | To assess whether any interracial and intra-racial differences are present in demographic variables, symptomatology and treatment of PwD living in a nursing home | The African-Caribbean group data was analysed to examine intra-racial differences. There were no significant differences in the clinical and social variables of the African-Caribbean and African-American groups. The only significant difference between groups was in marital status; that is, U.S.-born African Americans were more likely to have been widowed whereas African Caribbeans were more likely to have been separated/divorced or never have been married. This finding was trivial because the two groups had nearly equal rates of being unmarried and living alone at the time of institutionalization. While there are many cultural differences between U.S.-born African Americans and African Caribbeans, it is likely that the increased standardization of nursing home admission criteria along with their socioeconomic and racial similarities may have attenuated any potential differences. |
| House of Commons All-Party Parliamentary Group on Dementia report (2013) | Qualitative | UK (England) | Total participants: NR (PwD, carers and service providers)<br>Irish, Indian, Pakistani, African-Caribbean and Chinese | To determine understanding of dementia, service requirements and experiences faced by carers and people living with dementia within the BAME community | African-Caribbean participants had some misconceptions about dementia for example attributing it to 'spirits' or conceptualising it as 'a white person's illness' and suggested that dementia has only become apparent since Caribbean people moved to the UK. People also voiced a concern about a lack of culturally sensitive services and explained that people with dementia often become |

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|  |  |  |  |  | socially isolated because people within their social network do not know how to deal with the condition |
| Lawrence et al. (2008) | Qualitative | UK (England) | Total participants: 32 (carers)<br>African-Caribbean: 10<br>South Asian: 10<br>White British: 12 | To assess the needs of African-Caribbean, South Asian and White British informal carers, and their experiences of caring for a PwD | Carers were dichotomised into two distinct groups, those who viewed caring as natural and honourable (traditional) and those who viewed caregiving as unnatural and disruptive (non-traditional). Some African-Caribbean participants described caring as virtuous and an important part of their cultural identity, but others felt trapped, stressed, and thought of caregiving as a threat to their independence. |
| Lawrence et al. (2011) | Qualitative | UK (England) | Total participants: 30 (PwD)<br>African-Caribbean: 11 (Female-8, Male-3; single-1, married-3, divorced-2, widowed-5; living alone-4, with spouse-1, with family-4, sheltered accommodation-2); South Asian: 9; White British: 10 | To explore the experiences African-Caribbean, South Asian and White British PwD | African-Caribbean PwD commonly described dementia using stigmatising terms such as 'madness' or 'getting off your brain'. Most African-Caribbean PwD said that reliance for care should be placed upon healthcare professionals, although they also said memory services are often not suitable. Some participants said that informal family care is sometimes not available, for example in the case of children setting abroad or having work and family pressures of their own. Maintaining independence was also described as important, some participants felt concerned about ending up in a care home. |

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| Moreland (2001) | Qualitative | UK (England) | Total participants: 40 (20 community representatives; 20 carers and PwD)<br>African-Caribbean: 20 (n= 10 carers of PwD from the AC community, and n= 10 AC community representatives)<br>South Asian: 20 | To determine whether there are any people with dementia who are not seeking help. To explore the level of understanding of dementia and to discuss people's experiences of services for dementia. | Community leaders explained that dementia is commonly described by stigmatising terms within the African-Caribbean community. Participants also explained that there is no word for dementia in Patois language, which may make dementia difficult to conceptualise in older African-Caribbean communities. Some community representatives said they had no awareness of dementia, and when dementia was explained to them half of them thought of people who may be showing the early warning signs of dementia. There was a general lack of understanding of available services amongst community representatives. Carers explained stress they were under caring for a PwD and expressed a need for help with physical part of caring such as bathing and dressing. Carers also thought services should be more culturally sensitive, for example offering appropriate food at day centres. |
| Moreland (2003) | Qualitative | UK (England) | Total participants: 18 (10 community representatives, carers and PwD from Moreland (2001), and 8 service providers) | See Moreland (2001). In addition, study aimed to follow up participants who were previously interviewed to discuss the services accessed and whether their experiences had changed | Of the African-Caribbean PwD included in the sample, none lived with or were dependent on family members. The regression to childhood type behaviours typical of dementia meant that PwD often revert to the language and behaviour they associate with their earlier days in the Caribbean. This is one of the reasons carers suggested that culturally sensitive care is important. Carers also |

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| | | | | | thought that there was a lack of sharing of information between services leading to miscommunication. |
| Mukadam et al. (2011) | Qualitative | UK (England) | Total participants: 18 (carers, Female-13, Male-5)<br>White British: 4; South Asian: 5; Black African/Caribbean:5; White Irish: 1; White other: 1; Asian other: 1; Chinese: 1 | To explore understanding and pathways to care for dementia in BAME and indigenous carers | Participants from BAME groups were more likely not to seek help until the PwD was exhibiting severe symptoms and problems had become unmanageable. There were also delays on the part of the PwD refusing to accept help and carers viewing outside help as intrusive. Carers also voiced concern about the stigna surrounding dementia in African-Caribbean communities. The most common care pathway was through a GP but it was also common for the PwD to have only received their diagnosis after visiting a doctor for a separate physical problem. |
| Parveen, Peltier & Oyebode (2016) | Qualitative | UK (England) | Total participants: 175 (people living with dementia, carers and members of the public)<br>British Indian: 62 | To use 'Leventhal's Model of Self Regulation' to uncover the understating and experience of dementia of Caribbean, and East and Central European communities | African-Caribbean participants could describe common symptoms of dementia and assigned a biological cause but reported feeling they have a lack of knowledge about the condition. In terms of consequences of dementia, the African-Caribbean group were most concerned about the PwD wandering and getting lost. Participants also discussed the stigma surrounding dementia and how people are often ashamed to talk about it within their community. African-Caribbean people |

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| | | | African & Caribbean: 50<br>East and Central European: 63 | | mentioned a number of third sector organisations as well as GPs and family when they were asked about their awareness and use of services. Participants shared the negative experiences they had with GPs such as feeling and also voiced a concern about a lack of cultural sensitivity from services. |
| Roche et al (2018) | Qualitative & Quantitative | UK (England) | Total patients: 47<br>Patients from 5 GP practices.<br>Black African: 23<br>Black Caribbean (BC): 11 (Intervention- 6, Control-5)<br>Black British: 11<br>Asian Caribbean: 2<br>Having known (19/47, 40.4%), cared for (10/47, 21%), or worked with (10/47, 21%) someone with dementia. | To (1) develop a new intervention to facilitate timely diagnosis of dementia in BACE, and (2) evaluated its acceptability and (3) its delivery in a feasibility cluster randomised controlled trial (RCT). | 4/5 from the intervention group and 4/6 from the control group read the intervention leaflet. 4/5 & 3/6 said it made them think that either they or a relative or friend should visit their doctor about memory problems and six of them sought help.<br>Participants found intervention relevant, useful, helpful, informative, and educational. They have favourable attitudes towards help-seeking for dementia from doctors. Their late presentation to dementia services may be driven by other factors than culture and may include failings in health care service provision. |

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| Tappen et al. (2011) | Qualitative & Quantitative | USA (Florida) | Total participants: 72 (Participants undergoing cognitive screening); African American: 29; African-Caribbean: 23 (Female-20, Male-3); European American: 20 | To compare the explanatory models for Alzheimer's Disease (AD) of African-Americans, African-Caribbean and European-Americans | African-Caribbean participants (all first generation) had significantly more misconceptions about Alzheimer's Disease. Common misconceptions included AD is caused by 'aluminium' or a 'collapsed brain' |
| Tuerk & Sauer (2015) | Quantitative | UK (England) | Total participants: 460 (PwD); White British: 239; Black or Black British – Caribbean: 86; White other: 47; White Irish: 38; Black or Black British – African: 23; Asian or Asian British: 12; Other BME groups:15 | To assess whether there were any differences in referral rates, cognitive scores and severity of dementia in different ethnic entering a memory service in London, UK. | On average, African-Caribbean people were diagnosed with dementia (4.5 years younger than White British people). They were also more likely to receive a diagnosis of vascular or mixed dementia. Cognitive scores were significantly lower within the African-Caribbean group which could suggest that they are entering services later, after symptoms have become more severe. |

Abbreviations: PwD: Person/people with dementia; BAME: Black and minority ethnic; AD: Alzheimer's disease

Table 2: Thematic Analysis Framework

| **Stages** | **Process** |
|---|---|
| Familiarising | • Reading full paper<br>• Rereading and extracting key data |
| Generating initial ideas and themes | • Mapping papers for relevant data on conceptualisation and services access<br>• Comparing data across studies and summarising |
| Reviewing themes | • Reviewing the initial ideas and the overarching themes in relation to the extracted data by two researcher independently<br>• Discussing the themes and key data with the wider team |
| Describing and reporting | • Analyse the themes across the data set and synthesise the overall findings<br>• Examine the themes in relation to the study objectives and research questions. |

## Supplementary Table 1: Search Strategy

| Database | Date -last search performed | Search Terms | Results |
|---|---|---|---|
| CINAHL | 02/05/2019 | dementia/ or alzheimer/ and Caribbean/ Caribbean diaspora/ or African Caribbean/ or Afro Caribbean/ or Black Caribbean/ or West Indian/ or Jamaican | 76 |
| Pubmed | 03/05/2019 | ("dementia"[MeSH Terms] OR ("alzheimer disease"[MeSH Terms] OR ("alzheimer"[All Fields] AND "disease"[All Fields]) OR "alzheimer disease"[All Fields] OR ("alzheimer's"[All Fields] AND "disease"[All Fields]) OR "alzheimer's disease"[All Fields])) AND ((("west indies"[MeSH Terms] OR "caribbean region"[MeSH Terms]) OR "west indian"[All Fields]) OR jamaican[All Fields]) | 137 |
| Psychinfo | 02/05/2019 | 1. dementia.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]<br>2. exp PRESENILE DEMENTIA/ or exp DEMENTIA/ or exp SENILE DEMENTIA/ or exp AIDS DEMENTIA COMPLEX/ or exp SEMANTIC DEMENTIA/ or exp DEMENTIA WITH LEWY BODIES/ or exp VASCULAR DEMENTIA/<br>3. alzheimer*.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]<br>4. exp ALZHEIMER'S DISEASE/<br>5. 1 or 2 or 3 or 4<br>6. caribbean.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]<br>7. (caribbean adj diaspora).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures] | 103 |

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|  |  | 8. (african adj caribbean).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]<br>9. (afro adj caribbean).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]<br>10. (black adj caribbean).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]<br>11. (west adj indi*).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]<br>12. jamaica*.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]<br>13. 6 or 7 or 8 or 9 or 10 or 11 or 12<br>14. 5 and 13 |  |
| EMBASE | 02/05/2019 | 1. dementia.mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword, floating subheading]<br>2. exp HIV associated dementia/ or exp "mixed depression and dementia"/ or exp multiinfarct dementia/ or exp semantic dementia/ or exp dementia/ or exp presenile dementia/ or exp Pick presenile dementia/ or exp frontal variant frontotemporal dementia/ or exp senile dementia/ or exp frontotemporal dementia/<br>3. alzheimer*.mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword, floating subheading]<br>4. exp Alzheimer disease/<br>5. 1 or 2 or 3 or 4 | 529 |

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|---|---|---|---|
| | | 6. caribbean.mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword, floating subheading]<br>7. exp Caribbean/ or exp African Caribbean/ or exp "Caribbean (person)"/ or exp Caribbean Islands/<br>8. (caribbean adj diaspora).mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword, floating subheading]<br>9. (african adj caribbean).mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword, floating subheading]<br>10. (afro adj caribbean).mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword, floating subheading]<br>11. (black adj caribbean).mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword, floating subheading]<br>12. (west adj indi*).mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword, floating subheading]<br>13. jamaica*.mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword, floating subheading]<br>14. 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13<br>15. 5 and 14 | |
| Medline | 02/05/2019 | 1. dementia.mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading | 236 |

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|---|---|---|---|
|  |  | word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]<br>2. exp Dementia/ or exp Frontotemporal Dementia/ or exp AIDS Dementia Complex/ or exp Dementia, Vascular/ or exp Dementia, Multi-Infarct/<br>3. alzheimer*.mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]<br>4. exp Alzheimer Disease/<br>5. 1 or 2 or 3 or 4<br>6. caribbean.mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]<br>7. exp Caribbean Region/<br>8. (caribbean adj diaspora).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]<br>9. (african adj caribbean).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]<br>10. (afro adj caribbean).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]<br>11. (black adj caribbean).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept |  |

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|---|---|---|---|
| | | word, rare disease supplementary concept word, unique identifier, synonyms]<br>12. (west adj indi*).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]<br>13. jamaica*.mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]<br>14. 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13<br>15. 5 and 14 | |
| AMED | 02/05/19 | 1. dementia.mp. [mp=abstract, heading words, title]<br>2. exp Dementia/<br>3. alzheimer*.mp. [mp=abstract, heading words, title]<br>4. exp Alzheimers disease/<br>5. 1 or 2 or 3 or 4<br>6. caribbean.mp. [mp=abstract, heading words, title]<br>7. (caribbean adj diaspora).mp. [mp=abstract, heading words, title]<br>8. (african adj caribbean).mp. [mp=abstract, heading words, title]<br>9. (afro adj caribbean).mp. [mp=abstract, heading words, title]<br>10. (black adj caribbean).mp. [mp=abstract, heading words, title]<br>11. (west adj indi*).mp. [mp=abstract, heading words, title] | 1 |

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|---|---|---|---|
|  |  | 12. jamaica*.mp. [mp=abstract, heading words, title]<br>13. 6 or 7 or 8 or 9 or 10 or 11 or 12<br>14. 5 and 13 |  |
| Cochrane – Controlled trials | 02/05/2019 | 1. dementia.mp. [mp=title, original title, abstract, mesh headings, heading words, keyword]<br>2. Dementia/ or Frontotemporal Dementia/ or AIDS Dementia Complex/ or Dementia, Vascular/ or Dementia, Multi-Infarct/<br>3. alzheimer*.mp. [mp=title, original title, abstract, mesh headings, heading words, keyword]<br>4. exp Alzheimer Disease/<br>5. 1 or 2 or 3 or 4<br>6. caribbean.mp. [mp=title, original title, abstract, mesh headings, heading words, keyword]<br>7. exp Caribbean Region/<br>8. (caribbean adj diaspora).mp. [mp=title, original title, abstract, mesh headings, heading words, keyword]<br>9. (african adj caribbean).mp. [mp=title, original title, abstract, mesh headings, heading words, keyword]<br>10. (afro adj caribbean).mp. [mp=title, original title, abstract, mesh headings, heading words, keyword]<br>11. (black adj caribbean).mp. [mp=title, original title, abstract, mesh headings, heading words, keyword]<br>12. (west adj indi*).mp. [mp=title, original title, abstract, mesh headings, heading words, keyword]<br>13. jamaica*.mp. [mp=title, original title, abstract, mesh headings, heading words, keyword]<br>14. 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13<br>15. 5 and 14 | 8 |

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|---|---|---|---|
| Cochrane – systematic Review | 02/05/2019 | 1. dementia.mp. [mp=title, short title, abstract, full text, keywords, caption text]<br>2. alzheimer*.mp. [mp=title, short title, abstract, full text, keywords, caption text]<br>3. (Lewy adj bodies).mp. [mp=title, short title, abstract, full text, keywords, caption text]<br>4. (pick's adj disease).mp. [mp=title, short title, abstract, full text, keywords, caption text]<br>5. (creutzfeldt adj jakob).mp. [mp=title, short title, abstract, full text, keywords, caption text]<br>6. (normal adj pressure adj hydrocephalus).mp. [mp=title, short title, abstract, full text, keywords, caption text]<br>7. huntington's*.mp. [mp=title, short title, abstract, full text, keywords, caption text]<br>8. wernicke-korsakoff.mp. [mp=title, short title, abstract, full text, keywords, caption text]<br>9. 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8<br>10. caribbean.mp. [mp=title, short title, abstract, full text, keywords, caption text]<br>11. (caribbean adj diaspora).mp. [mp=title, short title, abstract, full text, keywords, caption text]<br>12. (african adj caribbean).mp. [mp=title, short title, abstract, full text, keywords, caption text]<br>13. (afro adj caribbean).mp. [mp=title, short title, abstract, full text, keywords, caption text]<br>14. (black adj caribbean).mp. [mp=title, short title, abstract, full text, keywords, caption text]<br>15. (west adj indi*).mp. [mp=title, short title, abstract, full text, keywords, caption text] | 78 |

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|---|---|---|---|
|  |  | 16. jamaica*.mp. [mp=title, short title, abstract, full text, keywords, caption text]<br>17. 10 or 11 or 12 or 13 or 14 or 15 or 16<br>18. 9 and 17 |  |
| NICE Evidence | 03/05/2019 | ‘Dementia and Caribbean’ | 572 |
| Scopus | 03/05/2019 | ( dementia OR alzheimer* ) AND ( caribbean OR "caribbean diaspora" OR "african caribbean" OR "afro caribbean" OR "black caribbean' OR Jamaican OR " west AND indi* ) AND NOT ( gene* ) | 111 |
| Web of science | 03/05/2019 | You searched for: TOPIC: (dementia OR alzheimer*) AND TOPIC: (caribbean OR "caribbean diaspora" OR "african caribbean" OR "afro caribbean" OR "black caribbean" OR "west indi*" OR jamaica*) | 260 |
| Open Grey | 03/05/2019 | Dementia and Caribbean | 1 |
| British Nursing Index | 03/05/2019 | (dementia OR alzheimer*) AND (Caribbean OR "Caribbean diaspora" OR "African Caribbean" OR "Afro Caribbean" OR "Black Caribbean" OR "West Indi*" OR "Jamaica*") | 90 |
| Applied Social Sciences Index & Abstracts (ASSIA) | 03/05/2019 | (dementia OR alzheimer*) AND (caribbean OR "Caribbean diaspora" OR "African Caribbean" "Afro Caribbean" OR "Black Caribbean" "West Indi*" OR Jamaica*) | 38 |

**Supplementary Table 2: Studies for full text review**

| Author | Title | Decision | Notes | References |
|---|---|---|---|---|
| Acosta et al. (2008) | The epidemiology of dependency among urban-dwelling older people in the Dominican Republic; a cross-sectional survey | Exclude | No specific information on african-caribbeans with dementia - dependency in domican republic | |
| Acosta et al. (2010) | The prevalence and social patterning of chronic diseases among older people in a population undergoing health transition. A 10/66 Group cross-sectional population-based survey in the Dominican Republic | Exclude | No specific information on african-caribbeans with dementia. No details of ethnic groups included in sample and just looking at prevalence of long term diseases such as | |
| Adamson (1999) | Informal care of a person with dementia in families of 'Asian' and 'African/Caribbean' descent | Exclude | Exclude, thesis. | |
| Adamson (2001) | Awareness and understanding of dementia in African/Caribbean and South Asian families | INCLUDE | African Caribbean people's Conceptualisation of dementia | |
| Adamson & Donovan (2002) | Research in black and white | Exclude | Nothing about african caribbeans with dementia specifically but might have useful background information. E.g. methodological issues surrounding conducting interviews with BAME groups | |
| Adamson & Donovan (2005) | 'Normal disruption': South Asian and African/Caribbean relatives caring for an older family member in the UK | INCLUDE | Carers experiences of looking after african caribbean person with dementia | |

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| Adelman et al. (2009) | A systematic review of the prevalence and covariates of dementia or relative cognitive impairment in the older African-Caribbean population in Britain | Exclude | Prevalence study, mixed samples included e.g. black african and african caribbean and mixed diagnoses e.g. dementia and depression. Useful background information | Cooper et al. (2010) |
| Adelman et al. (2011) | Need to identify modifiable risk factors of dementia in the older UK African-Caribbean population reply | Exclude | Letters | |
| Adelman et al. (2011) | Prevalence of dementia in African-Caribbean compared with UK-born White older people: Two-stage cross-sectional study | Exclude | Not including prevalence studies. Nothing about understanding/services for AC people with dementia. Useful background information | |
| Age UK policy document | Understanding the lives of older people living with frailty : a qualitative investigation | Exclude | No specific information on african-caribbeans with dementia - some useful background information | |
| Al Hadithy et al. (2008) | Pharmacogenetics of Parkinsonism, rigidity, rest tremor, and bradykinesia in African-Caribbean inpatients: Differences in association with dopamine and serotonin receptors | Exclude | Genetic study looking at physical parkinson's symptoms of AC people. Not related to dementia understanding/services | |
| Albanese et al. (2013) | Dementia and lower blood pressure in Latin America, India, and China | Exclude | study looks at the relationship between dementia and blood pressure (BP) in 8 low- and middle income countries. Nothing about AC and dementia understanding and/or services | |

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|---|---|---|---|---|
| Albanese et al. (2013) | Dementia severity and weight loss: A comparison across eight cohorts. the 10/66 study | Exclude | study looks at association between dementia severity and weight loss in countries with low and middle incomes. Nothing about AC and dementia understanding and/or services | |
| Ali & Josephs (2012) | Atypical and vascular Parkinsonism in Jamaica | Exclude | frequency, demographic and clinical features of atypical and vascular parkinsonism on the island of Jamaica - no information related to experiences, understanding or service use | |
| Ali & Josephs (2015) | Typical, atypical and vascular parkinsonism in Jamaica: An 8-year prospective study | Exclude | frequency, demographic and clinical features of atypical and vascular parkinsonism on the island of Jamaica - no information related to experiences, understanding or service use | |
| Almeida, Leite & Hildebrandt (2009) | Alzheimer's family caregivers: literature review | Exclude | Study of systematic reviews with the objective of analyzing the issues related to family caregivers of patients with Alzheimer's disease - nothing specific about african caribbean people with dementia | |
| Alzheimer Disease International (2013) | World Alzheimer report 2013 : journey of caring - an analysis of long-term care for dementia | Exclude | No specific information on african-caribbeans with dementia. Useful contextual/background information about dementia prevalence/incidence etc in caribbean | |

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| Amella (1997) | Amount of food consumed by elderly nursing home residents with dementia as a function of the quality of the reciprocal relationship between nurse aide caregivers and residents, caregivers' power and empathy | Exclude | Use of Social Exchange Theory to investigate mealtime interaction between caregiver and patient. Mixed caribbean and african american sample. Nothing related to AC understanding of dementia or services used. | |
| Arentoft et al. (2012) | Multidimensional effects of acculturation on English-language neuropsychological test performance among HIV+ Caribbean Latinas/os | Exclude | Study looks at associations between a multidimensional acculturation measure and neuropsychological performance among 82 HIV+ Caribbean Latina/o adults. Sample did not have dementia and not specific information about african caribbeans | |
| Arksey et al., (2005) | Review of respite services and short-term breaks for carers for people with dementia | Exclude | No specific information on african-caribbeans with dementia | |
| Ashby-Mitchell et al. (2015) | Life Expectancy with and without Cognitive Impairment in Seven Latin American and Caribbean Countries | Exclude | Only CI not dementia diagnosis in sample. No reporting of AC people | |

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| Baboolal, Davis & McRae (2014) | Trinidad and Tobago: A decade of dementia research | Exclude | Discuss- email author. Caregiving research may be relevant. Includes african descended patients and is focussed on caregiver burden but does not have any results for AC people specifically and cannot find the study's full paperNo Access | “The Plight of the Caregiver: A Study of the Burden Placed upon Caregivers of Patients with Dementia in Trinidad" ""The Prevalence of depression among the Elderly who attend Senior Activity Centres in Trinidad"" |
| Barnaby, Sewell & Lipps (2009) | Clinical presentations of patients attending a Dementia Clinic in Kingston, Jamaica | Exclude | Poster presentation, cant find published paper | |
| Barnes & Brannelly (2008) | Achieving care and social justice for people with dementia. | Exclude | Not much information about african caribbeans with dementia. A few sentences about one AC going into a residential care facility because of his presumed 'risk' | |
| Barnes et al. (2015) | Mixed pathology is more likely in black than white decedents with Alzheimer dementia | Exclude | comparison of the burden of neuropathology in black and white participants with clinical Alzheimer disease (AD). | |

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| Basu & Brennan (2012) | Does living in a family slow cognitive decline in dementia? | Exclude | Research presentation, focus not on african caribbean people with dementia |  |
| Beard et al. (2009) | The two voices of alzheimer's: Attitudes toward brain health by diagnosed individuals and support persons | Exclude | No specific information on african-caribbeans with dementia |  |
| Beaubrun (1963) | Huntington's chorea in Trinidad | Exclude | Could not access full text but does not seem relevant |  |
| Berwald et al. (2016) | Black African and Caribbean British Communities' Perceptions of Memory Problems: "We Don't Do Dementia" | INCLUDE | Qualitative study of black african and caribbean people's attitudes towards dementia | Mukadam, Cooper & Livingston (2013); Regan et al. (2013) |
| Beverley et al., (2000) | Eliciting users' views of the processes of health care: a scoping study | Exclude | No specific information on african-caribbeans with dementia |  |
| Bhugra et al. (2014) | EPA guidance mental health care of migrants | Exclude | Not related to african caribbeans and dementia |  |
| Blansjaar et al. (2000) | Prevalence of dementia in centenarians | Exclude | Prevalence study in netherlands. No information about AC people |  |
| Boneham et al. (1997) | Elderly people from ethnic minorities in Liverpool: Mental illness, unmet need and barriers to service use | Exclude | Includes african caribbean people in sample but not much information AC with dementia specifically<br>Emailed author, No response - No access to paper |  |
| Bosch-Bayard et al. (2016) | Cuba's strategy for Alzheimer disease and dementia syndromes | Exclude | Discusses dementia services in Caribbean (Cuba) Exclude on the basis of meeting on 07/06/17, Cuba not included as CARICOM member |  |

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| | | | and not about AC people use of serviecs | |
| Botsford, Clarke & Gibb (2012) | Dementia and relationships: Experiences of partners in minority ethnic communities | INCLUDE | Qualitative study exploring the experiences of partners of people with dementia in two minority ethnic communities (African Caribbean and Greek Cypriot) | |
| Bowers et al., (2006) | The city 128 study of observation and outcomes on acute psychiatric wards | Exclude | No specific information on african-caribbeans with dementia | |
| British Academy report (2014) | If you could do one thing : nine local actions to reduce health inequalities | Exclude | No specific information on african-caribbeans with dementia | |
| Broughton, Keohane & Shorthouse (2012) | A future state of mind: facing up to the dementia challenge | Exclude | No specific information on african-caribbeans with dementia | |
| Buffel (2015) | Researching Age-Friendly Communities - Stories from older people as co-investigators | Exclude | Mixed ethnic groups, no information about understanding/services accessed by african caribbean people with dementia specifically | |
| Burke (1979) | Trends in Caribbean psychiatry. I: The problems | Exclude | Broad discussion of psychiatry in the caribbean, not specific to dementia | |
| Byrd, Sanchez & Manly (2005) | Neuropsychological test performance among Caribbean-born and US-born African American elderly: The role of age, education and reading level | Exclude | Not relevant - comparison of neuropsychological test scores of U.S.-born and Caribbean-born African American elders | |

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| Cabrera et al (2014) | Pathogenesis and current treatment of Alzheimer's disease | Exclude | No specific information on african-caribbeans with dementia | |
| Camacho-Mercado & Clara (2016) | Ethnicity or location? Differential clinical profile of Alzheimer's disease among Puerto Ricans | Exclude | No specific information on african-caribbeans with dementia | |
| Campion & Fitch (2015) - Joing Commissioning Panel for Mental Health | Guidance for commissioning public mental health services (policy document - December 2015) | Exclude | No specific information on african-caribbeans with dementia. | |
| Caparros-Lefebvre et al. (1999) | Creutzfeldt-Jakob disease in French West Indies | Exclude | No specific information on african-caribbeans with dementia | |
| Caparros-Lefebvre et al. (1999) | Possible relation of atypical parkinsonism in the French West Indies with consumption of tropical plants: a case-control study | Exclude | case-control study looking at potential link between tropical fruit consumption and atypical parkinsonism | |
| Carr (2014) | Social care for marginalised communities : balancing self-organisation, micro-provision and mainstream support (Policy document) | Exclude | No specific information on african-caribbeans with dementia | |
| Centre for Policy on Ageing | The ageing of the ethnic minority populations of England and Wales : findings from the 2011 census (A briefing paper from the Centre for Policy on Ageing) | Exclude | Review of census data, useful for background information | |

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| Chackkalackal (2014) | The value of peer support on cognitive improvement amongst older people living with dementia | Exclude | Possibly include -evaluation of three peer support groups for people living with dementia in extra-care housing schemes. Caribbean people included in sample but no results per ethnic group. Emailed author - No response | |
| Chakkalakal & Kalathil (2014) - Mental health foundation doc | Evaluation report : peer support groups to facilitate self-help coping strategies for people with dementia in extra care housing | Exclude | No specific information on african-caribbeans with dementia | |
| Charity funded report | Dementia Equity and Rights | Exclude | No specific information on african-caribbeans with dementia - cites some potentially relevant papers | Clayton et al. (2013); Age UK 'fit as a fiddle'; Truswell & Taverna (2015) |
| Chaudhuri (unpublished) | Non motor symptoms (NMS) of people with Parkinson's in black African/Caribbean and South Asian population in London: case control study and biomarkers and non motor subtypes evaluation | Exclude | Ongoing trial but does not look relevant - comparison of white, african caribbean and south asians non-motor parkinson's symptoms including dopaminergic scans of the brain (DatScan) and also in a subgroup collect blood sample for future genetic and enzyme analysis | |
| Chaudhuri et al. (2000) | Atypical parkinsonism in Afro-Caribbean and Indian origin immigrants to the UK | Exclude | Study looking at frequency, pattern and prevalence of parkinson's disease in Afro caribbean and Indian people in the UK. | |

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| Chenoweth et al. (2015) | Organisational interventions for promoting person-centred care for people with dementia | Exclude | Services used by african caribbean people with dementia | |
| Cloos et al. (2010) | Active ageing: A qualitative study in six Caribbean countries | Exclude | Services for ageing, not services for AC people with dementia. | |
| Cohen (2000) | Racial differences in neuropsychiatric symptoms among dementia outpatients | INCLUDE | Comparison of african american and african caribbean sympoms of dementia. Symptomatelogy ethnic differences not in eligibility criteria | |
| Cohen, Hyland & Magai (1998) | Depression among African American nursing home patients with dementia | Exclude | Experiences of dementia - black people in USA. Would need to find out if there were african caribbean people included in study | |
| Cohen, Hyland & Magai (1998) | Interracial and intraracial differences in neuropsychiatric symptoms, sociodemography, and treatment among nursing home patients with dementia | Exclude | Study looks at interracial (black & white) and intra racial (african caribbean & african caribbean) differences experiences of depression, psychosis and agitation in a nursing home | |
| Conference abstratcs | Abstracts of the 7th World Research Congress of the European Association for Palliative Care (EAPC) | Exclude | No specific information on african-caribbeans with dementia | |
| Davis et al. (2007) | Potential biomarkers for dementia in Trinidad and Tobago | Exclude | biomarkers - vascular dementia and alzheimer's disease | |
| Davis, Baboolal & McRae (2016) | Dementia prevalence in the oldest old in trinidad and medical comorbidities | Exclude | Poster presentation - prevalence study | |

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| De Jesus (2013) | Aging and dementia: Implications for Cuba's research community, public health and society | Exclude | Exclude (meeting 07/06/17) Cuba not CARICOM country and no focus on AC people. Review focussing on need for epidemiological research to obtain greater knowledge of the disease, improve health services, promote actions for prevention and early diagnosis, and implement a national strategy to address dementia in the Cuban population. | |
| De Jesus (2017) | Cuba's aging and Alzheimer longitudinal study | Exclude | No specific information on african-caribbeans with dementia | |
| Dementia UK guide | Dementia: workers and carers together. A guide for social care workers on supporting family and friends carers of people with dementia (dementia UK guide) | Exclude | No specific information on african-caribbeans with dementia | |
| Demirovic et al (2003) | Prevalence of dementia in three ethnic groups: the South Florida program on aging and health | Exclude | Prevalence study african caribbeans not included | |
| Dening, Jones & Sampson (2012) | Preferences for end-of-life care: A nominal group study of people with dementia and their family carers | Exclude | No specific information on african-caribbeans with dementia | |
| Department of Heath Policy document | Closing the Gap: Priorities for essential change in mental health | Exclude | Not related to african caribbeans and dementia | |

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| Devi et al. (2000) | Familial aggregation of Alzheimer's disease and the influence of apolipoprotein E genotype in Caucasians, African Americans, and Caribbean Hispanic populations in northern Manhattan | Exclude | Study comparing the familial aggregration and lifetime risk of AD to the age of 90 years in the first-degree relatives of patients with AD and unrelated controls among caribbean hispanics, african americans and whites |  |
| Dickens (2009) | Public awareness of dementia : what every commissioner needs to know - alzheimers society policy doc | Exclude | No specific information on african-caribbeans with dementia |  |
| Dixon-Woods et al., (2005) | Vulnerable groups and access to health care : a critical interpretive view | Exclude | No specific information on african-caribbeans with dementia but may be useful for broader info about african caribbean interactions with mental health services. Under useful papers tab |  |
| Dominguez et al. (2006) | Is B vitamins deficiency associated with prevalence of Alzheimer's disease in Cuban elderly | Exclude | Vitamin D as a risk factor for high prevalence of AD in Cuba. No specific information on african-caribbeans with dementia |  |
| Eduar Herrera Murcia et al. (2015) | Empathy in Huntington's disease families: Study in the Colombian Caribbean | Exclude | Conference abstract, not AC people with dementia |  |
| Edwards & Morris (2007) | Alone and confused: community-residing older African Americans with dementia | Exclude | African caribbeans not specified in sample |  |
| Eldemire (1996) | Level of mental impairment in the Jamaican elderly and the issues of screening levels, caregiving, support systems, carepersons, and female burden | Exclude | Have received paper - checked for inclusion at meeting. Not enough information about dementia |  |

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| Eldemire-Shearer et al. (2011) | Chronic disease and ageing in the caribbean: Opportunities knock at the door | Exclude | Not about AC people and dementia, about chronic disease generally, but might have useful background/contextual information |  |
| Elliot (2016) | Poverty and mental health : a review to inform the Joseph Rowntree Foundation’s Anti-Poverty Strategy | Exclude | No specific information on african-caribbeans with dementia |  |
| Elvish et al., (2012) | Psychological interventions for carers of people with dementia: a systematic review of quantitative and qualitative evidence | Exclude | No specific information on african-caribbeans with dementia |  |
| Erol, Brooker & Peel (2015) | Women and dementia : a global research overview - Alzheimers disease international | Exclude | Not much information on caribbean people and dementia but useful background informaiton |  |
| Evaluation of the Workforce Development Innovation Fund | Three-year evaluation of the Workforce Development Innovation Fund, 2011/12-2013/14 | Exclude | No specific information on african-caribbeans with dementia |  |
| Ferri & Prince (2010) | 10/66 dementia research group: Recently published survey data for seven Latin America sites | Exclude | Letter about prevalence study |  |
| Ferri et al. (2011) | Tobacco use and dementia: Evidence from the 1066 dementia population-based surveys in Latin America, China and India | Exclude | Study assessing the association between tobacco consumtion and dementia. No information about african caribbean people |  |

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| Ferri et al., (2009) | World Alzheimer report 2009 | Exclude | Exclude as not specific information on african-caribbeans with dementia but does include useful for background information e.g. prevelance in different caribbean countries | |
| Figueroa et al. (2008) | Geographical differences in the occurrence of Alzheimer's disease mortality: United States versus Puerto Rico | Exclude | No specific information on african-caribbeans with dementia | |
| Forbat (2004) | The care and abuse of minoritized ethnic groups: the role of statutory services | Exclude | Abuse in care relationships and institutional racism. Case study of african caribbean person and housing, nothing specific about dementia/helathcare systems . | Forbat (2003) |
| Forbat & Nar (2003) | Dementia's cultural challenge | Exclude | Short article, mentions Jamaican woman with dementia experience of services. Cites potentially relevant DoH policy document | Department of Health (1998) |

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| Friedemann & Buckwalter (2014) | Family Caregiver Role and Burden Related to Gender and Family Relationships | Exclude | Mixed sample but not reported by ethnic group, nothing specifically related to african caribbean/dementia, more related to gender differences in caregiving - the final sample included 38.6% White non-Hispanic caregivers; 12.2% Blacks, predominantly from the Caribbean; 30.6% Cubans; and 18.6% caregivers from other Hispanic countries in Central and South America, Mexico and Puerto Rico | |
| Gibson, Martin & Neita (2010) | Mental illness and public health: Exploring the role of general hospital physicians at a teaching hospital in Jamaica | Exclude | mental health services in Jamaica, mention of dementia. Decided at meeting to exclude but use for background information | |
| Ginneken et al. (2013) | Non-specialist health worker interventions for the care of mental, neurological and substance-abuse disorders in low- and middle-income countries | Exclude | Not AC people & dementia | |
| Glasby et al. (2013) | Who knows best? Older people’s contribution to understanding and preventing avoidable hospital admissions | Exclude | No specific information on african-caribbeans with dementia | |

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| Glover (2013) | Running self-help groups in sheltered and extra care accommodation for people who live with dementia : a guide (Resource pack for mental health foundation) | Exclude | Services attended by caribbeans but not specifically for african caribbean people with dementia. Case study mentions caribbean patient. Exclude, very little information about AC and dementia | |
| Glymour & Manly (2008) | Lifecourse Social Conditions and Racial and Ethnic Patterns of Cognitive Aging | Exclude | lifecourse framework. Mention of caribbean and dementia. Exclude, not dementia, cognitive aging and focus on African Americans, no mention of Caribbean background | |
| Goldstein et al. (2014) | Validity of the montreal cognitive assessment as a screen for mild cognitive impairment and dementia in African Americans | Exclude | Assessing validity of a measure with african americans. Exclude. | |
| Gonzalez et al. (2014) | Building capacity for dementia care in Latin America and the Caribbean | Exclude | Excude on the basis of meeting 07/06/17 - no focus on AC people. Useful paper for background info though. Latin America and the Caribbean - reviewing existing initiatives and provided examples of actions taken to build capacity and improve the effectiveness of individuals, organizations, and national systems that provide treatment and support for people with dementia and their caregivers. However not specifically about african caribbean people and their experiences with services | |

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| Gonzalez et al. (2015) | Global comparisons for developing a national dementia registry in Cuba | Exclude | Excude on the basis of meeting 07/06/17 - no focus on AC people and Cuba not a CARICOM member. Paper addresses the Cuban proposal for an automated national dementia registry, comparing it to others internationally | |
| Gottesman et al. (2015) | Brain Aging in African-Americans: The Atherosclerosis Risk in Communities (ARIC) Experience | Exclude | Exclude, African American sample, no mention of AC people/dementia. Review discusses the experience in the Atherosclerosis Risk in Communities (ARIC) study evaluating racial disparities relating to stroke, subclinical brain infarction, leukoaraiosis, as well as cognitive change and dementia | |
| Grant (2016) | Using Multicountry Ecological and Observational Studies to Determine Dietary Risk Factors for Alzheimer's Disease | Exclude | Study looks at cross cultral dietary practices and risk of AD. No reference to AC people and dementia | |
| Gray et al. (2014) | Satisfaction with social care services among black and ethnic minority populations : exploring satisfaction with adult social care services amongst Pakistani, Bangladeshi and white British people (NatCen social research document) | Exclude | No specific quotes about african caribbean people with dementia, but included in sample/focus group. Email for further info? | |

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| Greene, Pugh & Roberts (2008) | SCIE Research briefing 29: Black and minority ethnic parents with mental health problems and their children | Exclude | The briefing does not include older people (those aged 65 and over), dementia, detailed evaluations of services and interventions, or experiences of particular services. | |
| Greenwood et al. (2016) | Qualitative focus group study investigating experiences of accessing and engaging with social care services: perspectives of carers from diverse ethnic groups caring for stroke survivors | Exclude | Mixed ethnicity focus group, related to stroke survivors not focussed on dementia experiences and services | |
| Grelotti et al. (2015) | A Pilot Initiative to Deliver Community-based Psychiatric Services in Rural Haiti after the 2010 Earthquake | Exclude | Not specific to dementia but evaluation of psychiatric care in the caribbean | |
| Guartazaca Gerrero et al. (2016) | Behavioral and psychological symptoms in elderly patients with dementia: A 5-year cohort follow up | Exclude | Exclude, poster presentation and not AC people. Follow up of patients with dementia in cuba to assess patterns of behavioural and psychological symptoms. | |
| Hall et al. (2000) | Community screening interview for dementia (CSI 'D'); performance in five disparate study sites | Exclude | Exclude, cross cultural evaluation of a measure | |
| Hall et al. (2011) | Feasibility, acceptability and potential effectiveness of Dignity Therapy for older people in care homes: A phase II randomized controlled trial of a brief palliative care psychotherapy | Exclude | Exclude, no focus on AC/dementia | |
| Harvey et al., (2005) | Measuring outcomes for carers for people with mental health problems | Exclude | Review of outcome measures, no specific information on african caribbeans with dementia | |

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| Hasan et al. (2015) | The UK's contribution to health globally : benefiting the country and the world - A report by the All-Party Parliamentary Group on Global Health | Exclude | Discusses building public health capacity twinning PHE with the Seychelles, Sierra Leone and Trinidad and Tobago (through the Caribbean Public Health Association, CARPHA, and linking to other countries in the Caribbean), also involving Canada as a partner |  |
| Health & Social Care Information Centre | Focus on dementia | Exclude | No specific information on african-caribbeans with dementia |  |
| Health & Social Care Information Centre | Focus on the Health and Care of Older People - June 2014 | Exclude | No specific information on african-caribbeans with dementia |  |
| Hendrie (2009) | Diagnosis of dementia and Alzheimer's disease in Indianapolis and IBADAN: Challenges in cross-cultural studies of aging and dementia | Exclude | Taken from a research symposia - challenges related to cognitive assessments for different cultural groups |  |
| Hendrie et al. (1996) | Cross-cultural perspectives: Caribbean, Native American, and Yoruba | Exclude | Review of cultural differences in relation to behavioural disturbances and treatment approaches for dementia - Jamaican sample. Email author for more information? |  |
| Hendrie et al. (2015) | Statin use, incident dementia and Alzheimer disease in elderly African Americans | Exclude | Not specific to AC people with dementia. Looks at the association between statin use, incident dementia, and Alzheimer disease (AD) in a prospective elderly African American cohort. |  |

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| Hinojosa et al. (2009) | Racial/ethnic variation in recovery of motor function in stroke survivors: role of informal caregivers | Exclude | Related to motor function and caring for stroke survivors. Mixed ethnicity sample. Cites potentially relevant paper | Janevic & Connell (2001) |
| Hoban et al. (2011) | Voices on well-being: A report of research with<br>older people | Exclude | No specific information on african-caribbeans with dementia | |
| Honyashiki et al. (2011) | Chronic diseases among older people and co-resident psychological morbidity | Exclude | psychological morbidity with chronic diseases across Cuba, dominican rep, peru, venezuela, mexico, china and india | |
| House of Commons All-Party Parliamentary Group on Dementia report (2013) | Dementia does not discriminate: the experiences of black, Asian and minority ethnic communities | INCLUDE | Include? Different BAME groups but Includes results specifically about african caribbean people's experiences of dementia and engagement with services. | |
| House of Commons Committee of Public Accounts | Improving access to mental health services. Sixteenth Report of Session 2016-2017 | Exclude | No specific information on african-caribbeans with dementia but useful for intro | |
| Housing LIN' case study | The benefits of extra care housing on the quality of life of residents: The impact of living in Campbell Place, Fleet | Exclude | No specific information on african-caribbeans with dementia | |
| Huxley et al., (2011) | Integration of social care staff within community mental health teams (NIHR report) | Exclude | No specific information on african-caribbeans with dementia | Robertson-Hickling, Abel & Hickling (2008) |
| Jackson et al., (2012) | The Mental Health Act 2007 : a review of its implementation | Exclude | No specific information on african-caribbeans with dementia | |

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| Joint Commissioning Panel for Mental Health | Guidance for commissioners of mental health services for people from black and minority ethnic communities | Exclude | Focusses on African caribbeans experiences and services related to psychosis, nothing specifically about dementia? | |
| Jolley et al. (2009) | The 'Twice a Child' projects: learning about dementia and related disorders within the black and minority ethnic population of an English city and improving relevant services | Exclude | Overview of the three 'twice a child' projects - reviews and interviews with african caribbean and asian communities in Wolverhampton. Include full papers - see ref lists. This is an overview of the projects, include full papers in review, use this for discussion of twice a child projects | Moreland, Jolley & Read (2005); Dementia plus (2001; 2003; 2007) |
| Jordanova et al. (2007) | Markers of inflammation and cognitive decline in an African-Caribbean population | Exclude | Biomarkers/inflammatory processes and dementia - prospective association between levels of three markers of inflammation, plasma interleukin-6 (IL-6), serum C-reactive protein (CRP), serum amyloid A (SAA), and cognitive decline in an African-Caribbean community population | |
| Josephs et al. (2016) | Frontotemporal dementia in patients of African descent | Exclude | Conference abstract - brain anatomy african descended people with dementia | |

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| Jutlla (2013) | Ethnicity and cultural diversity in dementia care: a review of research | Exclude | Could not access full text but potential include. Gained access 19/05/17 nothing additional about AC and dementia. Cites twice a child projects. Useful background/contextual information though | |
| Kalaria et al. (2008) | Alzheimer's disease and vascular dementia in developing countries: prevalence, management, and risk factors | Exclude | No specific information on african-caribbeans | |
| Karlawish et al. (2011) | What Latino Puerto Ricans and non-Latinos say when they talk about Alzheimer's disease | Exclude | Not AC people/dementia. Latino Puerto Ricans and Non-Latino White caregivers | |
| Katzenschlager et al (2003) | Unclassifiable parkinsonism in two European tertiary referral centres for movement disorders | Exclude | Study looking at non classifiable parkinsons patients. Not related to dementia/AC people | |
| Keane (2005) | A comparison of the Boston Naming Test and Miami Naming Test in an Afro-Caribbean population over the age of 55 | Exclude | Thesis - african caribbean sample but just looks at scores on two different measures | |
| Keane et al. (2015) | Comparison of African American and Afro-Caribbean older adults' self-reported health status, function, and substance use | Exclude | Useful background information but no information about dementia | |
| Keating et al., (2006) | Research priorities for service user and carer-centred mental health services : a synthesis of the literature | Exclude | No specific information on african-caribbeans with dementia | Keating et al., (2002) |

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| Kelley (2005) | Gendered elder care exchanges in a Caribbean village | Exclude | Exclude, focus is on gender differences and care of the elderly. Nothing about AC people and only one mention of alzheimers. Elderly care in a village in St Lucia although not reported to be dementia services specifically | |
| Khan & Venneri (2011) | Fewer paris, parrots peaches: Interpreting cross-cultural semantic fluency deficits in Alzheimer's assessment | Exclude | Poster presentation, Differences in fluency deficits in caribbean and british people with dementia. Include? Different experiences of dementia | |
| Khan & Venneri (2012) | Culture matters: Clarifying the effect of ethnicity on memory and attention and its implications for assessment of Alzheimer's disease | Exclude | cultural differences in neuropsychological assessments - british and caribbean participants | |
| Khan, Shanks & Venneri (2009) | The influence of education and ethnicity on mini mental state examination (MMSE) scores | Exclude | Not AC experiences/services - dementia | |
| Knight et al., (2007) | Mental health and physical health of family caregivers for persons with dementia: a comparison of African American and white caregivers | Exclude | African caribbeans not specified in sample | |
| Koss-Chioino (2003) | Jung, spirits and madness: Lessons for cultural psychiatry | Exclude | Not AC experiences/services - dementia | |
| Lai et al. (2012) | Special care units for dementia individuals with behavioural problems | Exclude | Not AC experiences/services - dementia | |

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| Lannuzel et al. (2015) | Clinical varieties and epidemiological aspects of amyotrophic lateral sclerosis in the Caribbean island of Guadeloupe: A new focus of ALS associated with Parkinsonism | Exclude | Not related dementia - experiences of/services. ALS association with Parkinsons in Guadeloupe | |
| Lawrence et al. (2008) | Attitudes and support needs of Black Caribbean, south Asian and White British carers of people with dementia in the UK | INCLUDE | Includes information about carers of African Caribbean people with dementia | Milne & Chryssanthopoulou (2005); Dilworth-Anderson & Gibson (2002); Lawton et al. (1992); Connell & Gibson (1997); Haley et al. (1996); Atkin & Rollings (1992) |
| Lawrence et al. (2011) | Threat to Valued Elements of Life: The Experience of Dementia Across Three Ethnic Groups | INCLUDE | Experiences of dementia: AC, south asian and white british | |
| Levine et al. (2015) | Does Stroke Contribute to Racial Differences in Cognitive Decline | Exclude | Not related to AC dementia/experiences of services. Study looks at whether racial differences in cognitive decline are explained by differences in the frequency or impact of incident stroke between blacks and whites | |
| Lievesley & Midwinter (2013) | Wellness : prevention and the sustainability of health and well-being in older age | Exclude | No specific information on african-caribbeans with dementia. | |

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| Lipman & Manthorpe (Age UK policy document) | Gearing up: Housing Associations' responses to tenants with dementia from black and minority ethnic groups, October 2015 | Exclude | Exclude, mention of a services used by african caribbean people with dementia. Limited information though | |
| Lippa (2011) | Review of issue: Caregiver depression and a plan to manage resistance to care | Exclude | Nothing related to african caribbeans and dementia but cites Tappen (included paper) | |
| Livingston (unpublished) | Improving dementia care in African and Caribbean minority ethnic groups | Exclude | Project relevant but in process. No access | |
| Livingston et al. (2001) | Mental health of migrant elders - the Islington study | Exclude | Exclude (prevalence study) but useful background information. Study compares prevalence of dementia and depression in older migrants with those born in the UK. Compared with those born in the UK, the prevalence of dementia was raised in African-Caribbeans | |
| Livney et al. (2011) | Ethnoracial Differences in the Clinical Characteristics of Alzheimer's Disease at Initial Presentation at an Urban Alzheimer's Disease Centre | Exclude | Exclude due to reported sample - African American, Latino (primarily of Caribbean origin), and white non-Hispanic (“WNH”) subjects | Manly & Mayeux (2004) |
| Llibre (2011) | Dementia and other chronic diseases in older adults in Havana and Matanzas: the 10/66 study in Cuba | Exclude | Looks at prevalence of risk factors. Includes structured physical and neurological exams | |
| Llibre Guerra et al. (2016) | Prevalence, incidence and associations between APOE genotype, cardiovascular risk factor and dementia in the Cuban population | Exclude | Prevalence/genetic study. Not AC experiences/services - dementia | |

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| Llibre Jde et al. (2009) | Prevalence of dementia and Alzheimer's disease in a Havana municipality: A community-based study among elderly residents | Exclude | prevalence study, not AC people | |
| Local government association | Working with faith groups to promote health and wellbeing | Exclude | No specific information on african-caribbeans with dementia | |
| Maayan, Soares Weiser & Lee (2014) | Respite care for people with dementia and their carers | Exclude | not AC people/dementia | |
| Maestra & Nitrini (2014) | It is time to focus on an underestimated epidemic | Exclude | Editorial re. dementia epidemic in LAC. Exclude, nothing related to AC people/dementia experiences/services. Includes countries not in CARICOM | |
| Maestre (2008) | Dementia in Latin America and the Caribbean: An overlooked epidemic | Exclude | Comment but suggests resources that are needed to prevent and treat people with dementia in LAC, use for background information? Nothing about AC people | |
| Mak, Kim & Stewart (2006) | Leg length, cognitive impairment and cognitive decline in an African-Caribbean population | Exclude | Exclude, not related to AC/dementia/services. Looks at early life/trauma, leg length and cognitive reserve. 'In a community population of African-Caribbean elders, in whom leg length had been measured, study seeks to compare associations with cognitive impairment at baseline and cognitive decline over a three-year follow-up period.' | Stewart & Richards (2002) |

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| Manes (2016) | The huge burden of dementia in Latin America | Exclude | Correspondance - exclude but useful background information | |
| Manly et al. (2008) | Frequency and course of mild cognitive impairment in a multiethnic community | Exclude | Nothing specific to AC/dementia | |
| Manly et al. (2011) | Telephone-Based Identification of Mild Cognitive Impairment and Dementia in a Multicultural Cohort | Exclude | Study looks at accuracy of a telephone interview in classifying people with dementia. Not related to AC/dementia specifically | |
| Marcheco et al. (2003) | Attitudes and knowledge about presymptomatic genetic testing among individuals at high risk for familial, early-onset Alzheimer's disease | Exclude | Exclude, Attitudes of Cuban family before diagnosis of alzheimers | |
| Maurer (2011) | Education and Male-Female Differences in Later-Life Cognition: International Evidence From Latin America and the Caribbean | Exclude | Nothing specific to AC/dementia | |
| Mavrodaris, Powerll & Thorogood (2003) | Prevalences of dementia and cognitive impairment among older people in sub-Saharan Africa: A systematic review | Exclude | Nothing specific to AC - sub saharan africa | |
| Maxwell (2005) | Extra care housing options & older people with functional mental health problems (DoH fact sheet) | Exclude | No specific information on african-caribbeans with dementia, related to people's long-standing Functional Mental Health problem such as depression, schizophrenia and anxiety as they get older. | |
| McCracken et al (1997) | Prevalence of dementia and depression among elderly people in Black and ethnic minorities | Exclude | Exclude, no results for AC specifically. Focus of paper is on | |

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| Mcintosh (2008) | Under the radar | Exclude | Short article discussing the lack of mental health services for black and minority ethnic older people. The article does include a relevant service though - the Caribbean Dementia Cafe run by Leeds Black Elders Association | |
| McKenzie & De Santi (2011) | Beliefs about cognitive loss among older African-and caribbean-American adults | Exclude | Poster presentation - No access to full paper | |
| McNally (2015) | Levels of cognitive impairment among elders in cuba: Findings from the survey on health, well-being, and aging in latin america and the caribbean (SABE) | Exclude | Poster presentation - assessing cuban elders for cognitive impairment | |
| Mehta & Yeo (2017) | Systematic review of dementia prevalence and incidence in United States race/ethnic populations | Exclude | Prevalence study, no data for AC populaton | |
| Mental Health Foundation. (2016) | Fundamental facts about mental health 2016 - policy document | Exclude | No specific information on african-caribbeans with dementia | |
| Mitrani et al. (2005) | Adapting the structural family systems rating to assess the patterns of interaction in families of dementia caregivers | Exclude | Development pf a measure (SFSR-DC) using sample of Cuban Americans and white non hispanic participants | |

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| Mitrani et al. (2008) | Conflict resolution and distress in dementia caregiver families: Comparison of Cubans and white non-hispanics | Exclude | Study investigates the role of family conflict resolution as a mediator of the relationship between ethnicity and psychological distress in dementia caregivers. | |
| Molero, Pino-Ramirez & Maestre (2007) | High prevalence of dementia in a Caribbean population | Exclude | Prevalence study - caribbean people in the caribbean. Useful background information | |
| Moriarty (2008) | The health and social care experiences of black and minority ethnic older people | Exclude | Information about african caribbean is not relevant e.g. about hypertension and relevant information is a replcation of findings of other ncluded studied e.g. Lawrence | Moriarty & Butt (2004); Rai-Atkins et al., (2002) |
| Moriarty & Manthorpe (2012) | Diversity in older people and access to services - an evidence review, 2012 (age UK report) | Exclude | Limited information on african-caribbeans with dementia, information about experiences of BME groups broadly. Useful contextual/backgroup paper | McLeod et al., (2008); 'Cass Business school' (2012) |
| Mukadam, Cooper & Livingston (2010) | A systematic review of ethnicity and pathways to care in dementia | Exclude | systematic review including different ethnic groups but has data specifically related to AC people with dementia | Hinton, Franz & Friend (2004) |
| Nadkarni et al. (2011) | The psychological impact of heavy drinking among the elderly on their co-residents: The 10/66 group population based survey in the Dominican Republic | Exclude | Not related to AC people with dementia. Study examines prevalence of heavy drinking amongst the elderly in dominican republic and severity of | |

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| | | | psychological and behavioural symptoms | |
| Neal & Barton Wright (2009) | Validation therapy for dementia | Exclude | cochrane systematic review of validation therapy, nothing specific to AC people with dementia | |
| Neita et al. (2014) | The prevalence and associated demographic factors of dementia from a cross-sectional community survey in Kingston, Jamaica | Exclude | Prevalence study, nothing specific to AC people with dementia. Broadly looks at prevalence in a jamaican population and western european population | |
| Nervi et al. (2008) | Comparison of Clinical Manifestations in Alzheimer Disease and Dementia With Lewy Bodies | Exclude | Exclude, study looks at neuropsychological profiles in DLB and AD among Caribbean Hispanic family members and participants in a population-based epidemiologic sample using extended neuropsychological test batteries and to explore whether these differences were related to heritable factors. | |
| Network for mental health - policy doc' | Mental Healthwatch handbook : improving mental health with your community | Exclude | No specific information on african-caribbeans with dementia | |
| Newbronner et al. (2013) | A road less rocky: supporting carers of people with dementia (carers trust guide) | Exclude | No specific information on african-caribbeans with dementia. | |

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| Ngandu, Mangialasche & Kivipelto (2014) | The Epidemiology and Prevention of Alzheimer's Disease and Projected Burden of Disease | Exclude | Not related to AC people with dementia. | |
| Nguyen et al. (2008) | Life course socioeconomic disadvantage and cognitive function among the elderly population of seven capitals in Latin America and the Caribbean | Exclude | study looks at life course socioeconomic disadvantages (SED) on cognitive function in later life - caribbean and latin america. Nothing specific abou AC people | |
| NHS report | Compassion in practice : two years on | Exclude | Not related to african caribbeans and dementia | |
| NHS report | The five year forward view mental health taskforce : public engagement findings - A report from the independent Mental Health Taskforce to the NHS in England September 2015 | Exclude | No specific information on african-caribbeans with dementia | |
| Nicholson et al., (2008) | Croydon Rethink African and Caribbean Carers Support Group - Mental Well-being Impact Assessment (MWIA) | Exclude | Write up of a support group meeting for african and caribbean carers. Exclude, not focussed on dementia and mixed black african and caribbean population | |
| Nielsen & Waldemar (2016) | Knowledge and perceptions of dementia and Alzheimer's disease in four ethnic groups in Copenhagen, Denmark | Exclude | AC people not included in study. Native Danes, Polish, Turkish and Pakistani immigrants | |
| NIH bypass budget proposal for fiscal year 2018 | Stopping Alzheimer's disease and related dementias: advancing our nation's research agenda. NIH bypass budget proposal for fiscal year 2018 | Exclude | No specific information on african-caribbeans with dementia | |

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| O'Shea et al. (2015) | Examining the association between late-life depressive symptoms, cognitive function, and brain volumes in the context of cognitive reserve | Exclude | Not related to dementia, AC people not included in sample. Hispanic, African American, and non-Hispanic White sample. | |
| Orr (2010) | The pursuit of certainty in diagnosing dementia: Cognitive testing, childishness and stress in two British memory clinics | Exclude | Not related to AC people with dementia. | |
| Oxford Dementia Challenge Group - evaluation paper | Evaluation of Oxfordshire dementia-friendly communities project | Exclude | No african caribbean people included in sample | |
| Pagan-Ortiz et al. (2014) | Use of an online community to provide support to caregivers of people with dementia | Exclude | Development of a website for spanish speaking caregivers. Not AC population. | |
| Paradise et al. (2009) | Systematic review of the effect of education on survival in Alzheimer's disease | Exclude | No results specific to AC population with dementia | |
| Parsons et al., (2010) | Self-management support among older adults : the availability, impact and potential of locally based services and resources | Exclude | No specific information on african-caribbeans with dementia | |
| Parveen, Peltier & Oyebode (2016) | Perceptions of dementia and use of services in minority ethnic communities: a scoping exercise | INCLUDE | Culturally specific dementia awareness roadshows. British Indian, African and Caribbean, East and Central European attenders. Has results/quotes from AC people experiencing dementia/caring for someone with dementia | Johl, Patterson & Pearson (2016) |

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| Perez et al. (1996) | Towards community diagnosis of dementia: Testing cognitive impairment in older persons in Argentina, Chile and Cuba | Exclude | No information about african-cairbbeans with dementia | |
| Perry, Barner & England (2013) | A review of values-based commissioning in mental health (network nsun for mental health report) | Exclude | Exclude, does mention that there should be more reseach into older african caribbean people's mental health but limited information | |
| Pierre & Meastre (2013) | Dementia care in haiti: Needs and opportunities for capacity building | Exclude | Exclude, Poster presentation. Assessment and experiences of people in Haiti with dementia, nothing about AC people. | |
| Policy doc - department of health and human services centers for disease control and prevention | Trends in aging -- United States and worldwide | Exclude | No specific information on african-caribbeans with dementia | |
| Policy doc - NHS Quality Improvement Scotland 2005 | Report of the Scoping Study Group on the Provision of Spiritual Care in NHS Scotland Sep 2005 | Exclude | No specific information on african-caribbeans with dementia | |
| Policy document - carers UK | Half a million voices : improving support for BAME carers | Exclude | Exclude, experiences of african caribbean carers, useful background information | |
| Policy document - DoH | New Horizons: A shared vision for mental health: EqIA (DH) | Exclude | No specific information on african-caribbeans with dementia | |
| Policy document - Nuffield Council on Bioethics | Dementia : ethical issues | Exclude | No specific information on african-caribbeans with dementia | |

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| Policy document - WHO | Equity, social determinants and public health programmes | Exclude | No specific information on african-caribbeans with dementia |  |
| Policy document - WHO | Global health and aging | Exclude | No specific information on african-caribbeans with dementia |  |
| Prakash (2011) | Need to identify modifiable risk factors of dementia in the older UK African-Caribbean population | Exclude | Exclude, Correspondance - critiique of adelman's prevalence study. Could be useful for discussion/background info |  |
| Prince (2009) | Treatment for patients and caregivers in the developing world | Exclude | Plenary, no data AC/dementia |  |
| Prince et al. (2003) | Dementia diagnosis in developing countries: a cross-cultural validation study | Exclude | No results specific to AC population with dementia |  |
| Prince et al. (2004) | Care arrangements for people with dementia in developing countries | Exclude | Use for background information. NOthing about ethnic background of the samples and more focussed on Latin American countries. A descriptive and comparitive study of dementia care, caregiver characteristics, the nature of care provided, and the practical psychological and economic impact upon the caregiver in 24 centres in India, China and South East Asia, Latin America and the **Caribbean** and Africa |  |
| Prince et al. (2007) | The protocols for the 10/66 dementia research group population-based research programme | Exclude | Incidence study.  No results specific to AV people & experiences of dementia |  |

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| Prince et al. (2011) | A brief dementia screener suitable for use by non-specialists in resource poor settings--the cross-cultural derivation and validation of the brief Community Screening Instrument for Dementia | Exclude | Development of dementia screener. No results specific to AC people & experiences of dementia | |
| Prince et al. (2011) | Leg length, skull circumference, and the prevalence of dementia in low and middle income countries: a 10/66 population-based cross sectional survey | Exclude | Study carried out in India, China, Cuba, Dominican Republic, Venezuela, Mexico and Peru. Nothing specific to AC people with dementia | |
| Prince et al. (2011) | The association between common physical impairments and dementia in low and middle income countries, and, among people with dementia, their association with cognitive function and disability. A 10/66 Dementia Research Group population-based | Exclude | Study carried out in India, China, Cuba, Dominican Republic, Venezuela, Mexico and Peru. Nothing specific to AC people with dementia | |
| Prince et al. (2012) | Dementia incidence and mortality in middle-income countries, and associations with indicators of cognitive reserve: A 10/66 Dementia Research Group population-based cohort study | Exclude | Incidence study. No results specific to AV people & experiences of dementia | |
| Prineas et al. (1995) | South Florida Program on Aging and Health. Assessing the prevalence of Alzheimer's disease in three ethnic groups | Exclude | Prevalence study, not specified AC people - African American, Cuban American and white non-Hispanic American | |

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| Rait et al. (2000) | Screening for cognitive impairment in older African-Carribeans | Exclude | Useful background information but paper not relevant. Testing the efficacy of measures in an AC community - MMSE & AMT | |
| Rankin (2005) | Mental health in the mainstream | Exclude | No specific information on african-caribbeans with dementia | |
| Rawlins (2001) | Caring for the chronically ill elderly in Trinidad: The informal situation | Exclude | Cant access full text but abstract could be relevant. Includes afro-trinidadian carers. Not sure whether study looks at dementia though. Checked in meeting not related to dementia care specifically, exclude | |
| Rawlins et al. (2015) | Attitude towards Alzheimer's disease among undergraduate students of university of the West Indies, Trinidad and Tobago | Exclude | Attitudes/conceptualisation of dementia in west indies. Not related to AC people and dementia | |
| Razzouk et al. (2008) | Challenges to reduce the '10/90 gap': Mental health research in Latin American and Caribbean countries | Exclude | Not specific to AC with dementia. Mental health research generally across latin america and caribbean | |
| Rechel et al., (2011) | Migration and health in the European Union (policy document) | Exclude | No specific information on african-caribbeans with dementia | |
| Regan (2016) | The interface between dementia and mental health : an evidence review | Exclude | No specific information on african-caribbeans with dementia | |
| Report from the WHO European Ministerial Conference | Mental health: facing the challenges, building solutions | Exclude | No specific information on african-caribbeans with dementia | Mclean, Campbell & Cornish (2003) |

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| Repper et al., (2008) | Family carers on the margins : experiences of assessment in mental health | Exclude | Some discussion of african caribbeans experiences with services generally.  Nothing specific to african caribbean patients or carers and dementia | |
| Ribeiro et al. (2016) | Non-pharmacological strategies used to manage the behavioral alterations in the elderly with dementia | Exclude | Selected conference abstract. Not relevant AC/dementia | |
| Richards & Brayne (1996) | Cross-cultural research into cognitive impairment and dementia: Some practical experiences | Exclude | Includes discussion of african caribbean migrants to UK and dementia.  Focus on cognitive impairment rather than dementia but may have useful background information | Richards et al. (1995) |
| Richards et al. (2000) | Cognitive function in UK community-dwelling African Caribbean and white elders: A pilot study | Exclude | Exclude, as per other Richards paper, focus on cognitive impairment but may be useful for background infromation. Assessments with african caribbean and white elders. Rated by a psychiatrist blinded to ethnicity | |
| Rodriguez et al. (2008) | The Prevalence, Correlates and Impact of Dementia in Cuba | Exclude | Not relevant AC/dementia | |
| Ross et al., (2009) | The professional experience of governance and incentives: meeting the needs of individuals with complex conditions in primary care | Exclude | No specific information on african-caribbeans with dementia | |

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| Roush et al. (2013) | Exemplars of geriatric education centers in geriatric psychiatry programming on mental health issues in later life | Exclude | AAGP annual meeting' not relevant AC/dementia | |
| Rowe et al. (2014) | Alzheimer's disease and other dementia in sub-Saharan Africa and the Caribbean | Exclude | Letter to editor not specific to AC people. Mainly focussed on death rates in Subsaharan africa & caribbean | |
| Sachrajda (2011) | Dementia care in London (policy document - institute for public policy research) | Exclude | No specific information on african-caribbeans with dementia - useful background info | |
| Salazar, Dwivedi & Royall (2017) | Cross-ethnic differences in the severity of neuropsychiatric symptoms in persons with mild cognitive impairment and Alzheimer's disease | Exclude | Not AC with dementia. Hispanics vs non hispanic whites | |
| Santini et al. (2014) | Helping Haiti: Addressing the burden of neurologic disease | Exclude | Couldn't find new text but potentially relevant from reading abstract, includes burden of dementia in haiti aswell as other neurological diseases. Received 19/05/17 - poster presentation, no mention of AC/dementia exclude. | |
| Santoso et al. (2016) | HIV-associated dementia in the Dominican Republic: A consequence of stigma, domestic abuse and limited health literacy | Exclude | Nothing specific to AC people in the paper but paper is about HIV related dementia in the caribbean and barriers to seeking help, DR not CARICOM counry | |
| Santoso, Erkkinen & Adon (2016) | The Montreal cognitive assessment may not be an effective screening tool in low income countries with education inequality | Exclude | Poster, study assessing use of MOCA at an infectious disease clinic in Santo Domingo, Dominican Republic. | |

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| Sayegh & Knight (2013) | Cross-cultural differences in dementia: the Sociocultural Health Belief Model | Exclude | Some discussion of AC people with dementia but model is broadly a conceptual framework for examining cross-cultural differences in dementia care-seeking among diverse groups.  Useful theory/background information | Dilworth et al. (2008); Dilworth-Anderson et al. (2008); Gray et al. (2009); Hinton et al. (2005) |
| Sepulveda et al. (2015) | Un Cafe Por El Alzheimer: An innovative awareness approach in Puerto Rico | Exclude | Cant access full article. Access to check for inclusion. Received from doc supply, exclude - poster presentation, service in caribbean but nothing about options re/its use by AC people.  Also Puerto Rico not CARICOM country | |
| Shah (2007) | Can the recognition of clinical features of mental illness at clinical presentation in ethnic elders be improved | Exclude | Not specific to AC with dementia. BME groups generally.  Might be useful for background/intro info | |
| Shah et al., (2009) | CR156. Psychiatric Services for Black and Minority Ethnic Older People | Exclude | Royal College of Psychiatrists report. Discusses AC people and dementia. Discusses papers that are already included (e.g. Lawrence) and is not focussed on dementia but has useful background information | Richards et al (1998) |
| Shah, Dalvi & Thompson (2005) | Is there a need to study behavioral and psychological signs and symptoms of dementia across cultures? | Exclude | Letter, not specific to AC people | |

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| Sharan et al. (2009) | Mental health research priorities in low- and middle-income countries of Africa, Asia, Latin America and the Caribbean | Exclude | Nothing specific to AC people with dementia | |
| Skills for care | Dementia and diversity : a guide for leaders and managers | Exclude | Guide, limited information about AC people and dementia services. | |
| Sleath et al. (2004) | Medication use among black and white caregivers of older male veterans with dementia | Exclude | cant access full text. Gain access to check for inclusion. Screened at meeting exclude. | |
| Sleath et al. (2005) | African-American and white caregivers of older adults with dementia: Differences in depressive symptomatology and psychotropic drug use | Exclude | Not AC/dementia experiences/services | |
| Sosa et al. (2012) | Prevalence, distribution, and impact of mild cognitive impairment in Latin America, China, and India: A 10/66 population-based study | Exclude | Not AC/dementia experiences/services | |
| Spencer et al., (2010) | The role of migrant care workers in ageing societies : report on research findings in the United Kingdom, Ireland, Canada and the United States (policy document - international organization for migration | Exclude | No specific information on African-Caribbean with dementia - useful background info | |
| Stella et al. (2015) | Caregiver report versus clinician impression: Disagreements in rating neuropsychiatric symptoms in Alzheimer's disease patients | Exclude | Not AC/dementia experiences/services | |

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| Stevens, Leavey & Livingston (2004) | Dementia and hypertension in African/Caribbean elders | Exclude | study examined the association between country of birth and type of dementia in a representative community sample of people aged 65 years and older in Britain. - AC people & dementia | |
| Stewart et al. (2001) | Apolipoprotein E genotype, vascular risk and early cognitive impairment in an African Caribbean population | Exclude | Genetic study. Reduced risk of AD associated with the apolipoprotein E (APOE) allele | |
| Stewart et al. (2001) | Cognitive function in UK community-dwelling African Caribbean elders: Normative data for a test battery | Exclude | Cognitive tests with African Caribbean sample and comparison with other ethnic groups. But differences in cognitive ability/symptomatic differences is not in eligibility criteria. (Subsequent study to Richards et al.) Also not focussed on dementia, focus on cognitive function and cultural differences. Possibly useful background information | |
| Stewart et al. (2001) | Depression, APOE genotype and subjective memory impairment: A cross-sectional study in an African-Caribbean population | Exclude | Genetic study. APOE genotype, depression and memory impairment in AC population | |

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| Stewart et al. (2001) | Vascular risk and cognitive impairment in an older, British, African-Caribbean population | Exclude | Exclude, looks at associations between hypertension etc and cognitive impairment -Participants interviewed and examined for cardiovascular risk factors, including a blood test for lipid profile and fibrinogen. A battery of 11 psychometric tests was administered blind to medical status. Cognitive impairment was defined on the basis of a composite measure derived from individual test scores. | |
| Stewart et al. (2002) | The distribution of Mini-Mental State Examination scores in an older UK African-Caribbean population compared to MRC CFA Study norms | Exclude | Description of normalities data for the mini-mental state examination (MMSE) in a UK African-Caribbean populationand comparison with norms for white UK born elders | |
| Stewart et al. (2004) | ACE genotype and cognitive decline in an African-Caribbean population | Exclude | Genetic study | |
| Stewart, Guerchet & Prince (2016) | Development of a brief assessment and algorithm for ascertaining dementia in low-income and middle-income countries: The 10/66 short dementia diagnostic schedule | Exclude | Study is developing and evaluating a short version of the 10/66 dementia diagnostic schedule for use in low-income and middle-income countries - not related to AC and dementia specifically | |

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| Stewart, Prince & Mann (2003) | Age, Vascular Risk, and Cognitive Decline in an Older, British, African-Caribbean Population | Exclude | Study investigates associations between baseline factors and subsequent cognitive decline in an older African-Caribbean population | |
| Stock & Lambert (2011) | Who cares wins? Carers' experiences of assessment since the introduction of the Carers (Equal Opportunities) Act 2004 | Exclude | No specific information on african-caribbeans with dementia | |
| Strech (2013) | The full spectrum of ethical issues in dementia care: Systematic qualitative review | Exclude | Not related to AC people with dementia | |
| Suh et al. (2009) | International price comparisons of Alzheimer's drugs: A way to close the affordability gap | Exclude | Study looks at costs of AD drugs in different countries. Inc caribbean (dominican republic) | |
| Tang et al. (2001) | Incidence of AD in African-Americans, Caribbean Hispanics, and Caucasians in northern Manhattan | Exclude | Exclude, incidence rates for AD among elderly African-American, Caribbean Hispanic, and white individuals and to determine whether coincident cerebrovascular disease contributes to the inconsistency in reported differences among ethnic groups | |
| Tappen, Gibson & Williams (2011) | Explanations of AD in Ethnic Minority Participants Undergoing Cognitive Screening | INCLUDE | Includes results AC people's understanding/explanatory models of AD. Sample includes African Americans, African Caribbeans and European Americans | |

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| Taylor et al. (2013) | Midlife Hypertensive Status and Cognitive Function 20 Years Later: The Southall and Brent Revisited Study | Exclude | Study investigates long term prospective associations between a range of measuresments of hypertensive status in midlife and cognitive impairment 20 years later - cohort study. Multiethnic population | |
| Taylor et al. (2015) | Treatment for dementia : learning from breakthroughs for other conditions - policy research | Exclude | No specific information on african-caribbeans with dementia | |
| Taylor, Albanese & Stewart (2012) | The association of dementia with upper arm and waist circumference in seven low- and middle-income countries: the 10/66 cross-sectional surveys | Exclude | Not related to AC people with dementia | |
| Taylor, Chatters & Jackson (2007) | Religious and spiritual involvement among older African Americans, Caribbean Blacks, and non-Hispanic Whites: Findings from the National Survey of American Life | Exclude | Black caribbeans included in sample. Religious and spiritual involement of older people in different ethnic groups - caribbean black, non-hispanic white and african americans. Exclude but may have some useful background info | |
| Teruel et al. (2011) | Interactions between genetic admixture, ethnic identity, APOE genotype and dementia prevalence in an admixed Cuban sample; a cross-sectional population survey and nested case-control study | Exclude | Genetic study - APOE-e4 allele | |

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| Thawani, Schupf & Louis (2009) | Essential tremor is associated with dementia Prospective population-based study in New York | Exclude | Not AC & dementia.  Study looks at whether essential tremor is associated with prevalent and incident dementia in an ethnically diverse sample of elders. | |
| The (2008) | In death's waiting room: living and dying with dementia in a multicultural society | Exclude | Exclude - Book | |
| The Campaign to End Loneliness policy document | Alone in the crowd: loneliness and diversity | Exclude | No specific information on african-caribbeans with dementia - some useful background information | |
| The Condition of Britain (report) | The generation strain : collective solutions to care in an ageing society | Exclude | No specific information on african-caribbeans with dementia | |
| Thiyagarajan, Prince & Webber (2014) | Social support network typologies and health outcomes of older people in low and middle income countries-A 10/66 Dementia Research Group population-based study | Exclude | Assessing construct validity of wenger social support network typology in low and middle income countries | |
| Tibbs (1996) | Amos: a self lost and found | Exclude | Personal accouunt discussing lack of culturally sensitive services for people from ethnic minority groups. Nothing specific to AC people and dementia | |
| Tolosa, Calandrella & Gallardo (2004) | Caribbean parkinsonism and other atypical Parkinsonian disorders | Exclude | Not AC people & dementia | |
| Tosto et al. (2015) | Admixture analysis of Alzheimer's disease in caribbean hispanics | Exclude | Podium presentation, genetic study (APOE-e4) not AC people & dementia | |

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| Townsend (2003) | Scoring trends on the rey-osterrieth Complex Figure Test within both normal and Dementia of the Alzheimer's type Caribbean-Hispanic populations | Exclude | Thesis, caribbean hispanics scoring trends on the 'CFT'. Not AC people & dementia | |
| Truswell (2013) | Black, Asian and minority ethnic communities and dementia : where are we now? (A Race Equality Foundation Briefing Paper) | Exclude | Includes infromation about services available to african caribbeans with dementia and useful background information | Truswell (2011) |
| Truswell (2016) | Communities can't be left to 'look after their own' | Exclude | Exclude but use for background. Paper describes how 'culture dementia UK' works to raise awareness about dementia in the African-Caribbean and other UK minority ethnic communities. Get access. Received 19/05/17 - include, discusses cultural issues related to AC people and their understanding of dementia and experiences of services | Not a research article |
| Tuerk & Sauer (2015) | Dementia in a Black and minority ethnic population: Characteristics of presentation to an inner London memory service | INCLUDE | Study examines data on referrals to a memory clinic in london to explore any differences in referral rates, cognitive assessments and stages of dementia between ethnic groups - AC people included/ experiences of services | Mukadam et al. (2011); La Fontaine et al. (2007); Moriarty, Sharif & Robinson (2011); Daker-White et al. (2002) |

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| Unverzagt et al. (1999) | Clinical utility of CERAD neuropsychological battery in elderly Jamaicans | Exclude | Study examines efficacy of the corsortium to establish a registry for alzheimer's disease (CERAD) neuropsychological battery in Jamaican men and women | |
| Vardarajan et al. (2014) | Age-specific incidence rates for dementia and Alzheimer disease in NIA-LOAD/NCRAD and EFIGA families: National Institute on Aging Genetics Initiative for Late-Onset Alzheimer Disease/National Cell Repository for Alzheimer Disease (NIA-LOAD/NCRAD) and Estudio Familiar de Influencia Genetica en Alzheimer (EFIGA) | Exclude | Not AC people & dementia | |
| Vardarajan et al. (2015) | Inbreeding among Caribbean Hispanics from the Dominican Republic and its effects on risk of Alzheimer disease | Exclude | Not AC people, only caribbean hispanics inlcuded | |
| Whitfield et al. (2008) | Blood pressure and memory in older African Americans | Exclude | Not AC people, and dementia. African americans and cognitive functioning | |
| WHO report (2012) | Dementia : a public health priority | Exclude | No specific information on african-caribbeans with dementia. Useful contextual/background information about dementia prevalence/incidence etc in caribbean | |
| WHO report (2015) | WHO World report on ageing and health - 2015 | Exclude | No specific information on african-caribbeans with dementia | |
| Wiley (2012) | Cuba's Integrated Health Care | Exclude | No informaion related to AC & dementia | |

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| Williams et al. (2001) | Obtaining family consent for participation in Alzheimer's research in a Cuban-American population: Strategies to overcome the barriers | Exclude | Not AC people & dementia, Cuban Americans | |
| Williams et al. (2001) | Willingness to be Screened and Tested for Cognitive Impairment: Cross-Cultural Comparison | Exclude | Includes AC people; comparison of different ethnic groups in willingness to be tested for cognitive impairment - not about dementia though. Use for background information | |
| Williamson (2012) | Ripple on the pond. DEEP : the engagement, involvement and empowerment of people with dementia in collective influencing. Appendix to main report : a stronger collective voice for people with dementia | Exclude | Appendix and no specific information on african-caribbeans with dementia | |
| Wilmo & Prince (2010) | World Alzheimer report 2010 : the global economic impact of dementia | Exclude | Exclude as not specific information on african-caribbeans with dementia but does include useful for background information e.g. prevelance in different caribbean countries | |
| Wilmo, Winblad & Jonsson (2010) | The worldwide societal costs of dementia: Estimates for 2009 | Exclude | Not AC people & dementia. Useful background/contextual information | |
| Wong et al. (2016) | Food insecurity is associated with subsequent cognitive decline in the Boston Puerto Rican health study | Exclude | Not AC people & dementia - puerto rican sample | |

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| Woodall et al., (2010) | Barriers to participation in mental health research : are there specific gender, ethnicity and age related barriers? | Exclude | No specific information on african-caribbeans with dementia | |
| Woods et al. (2009) | Reminiscence therapy for dementia | Exclude | Not AC people & dementia. Systematic review of reminiscence therapy for dementia | |
| Wortmann (2016) | Global dementia policy overview | Exclude | Poster presentation - useful background/contextual information | |
| Ye et al. (2013) | Mediterranean Diet, Healthy Eating Index 2005, and Cognitive Function in Middle-Aged and Older Puerto Rican Adults | Exclude | Not AC people & dementia - puerto rican sample | |
| Yenkamala et al. (2013) | A pilot study: ayurvedic approach on memory stimulation in the french west indies | Exclude | Not AC people & dementia | |
| Zahodne et al. (2015) | Is residual memory variance a valid method for quantifying cognitive reserve? A longitudinal application | Exclude | Not AC people & dementia | |
| Bridges et al (2018) | Implementing the Creating Learning Environments for Compassionate Care (CLECC) programme in acute hospital settings : a pilot RCT and feasibility study | Exclude | Not focused on dementia in AC population | |
| Manthorpe J. et.al (2019) | Service provision for older homeless people with memory problems : a mixed-methods study | Exclude | No details of ethnicity for participating homeless | |
| Livingston G et.al (2017) | Dementia prevention, intervention, and care | Exclude | No reference to AC community | |

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| NIHR (2017) | Getting help for forgetfulness. | Exclude | Leaflet not a research study | |
| Foreman K et.al (2018) | Forecasting life expectancy, years of life lost, and all-cause and cause-specific mortality for 250 causes of death: references and alternative scenarios for 2016–40 for 195 countries and territories. The Lancet. | Exclude | Not AC people & dementia | |
| Hill-Dixon A et.al (2018) | Being well together: the creation of the Co-op Community Wellbeing Index. | Exclude | Dementia isn't the focus nor discussed in detail per AC community | |
| Parveen & Oyebode (2018) | Dementia and minority ethnic carers. | Exclude | Briefing paper-no primary research or consultation findings | |
| The Brtish Psychological Society (2018) | Dementia, accessibility and minority groups | Exclude | Briefing paper-no primary research or consultation findings | |
| LGA (2018) | Dementia support guide for councils. | Exclude | No details of AC participation in the community action project | |
| Graham et al (2018) | An evaluation of a near real-time survey for improving patients' experiences of the relational aspects of care : a mixed-methods evaluation. | Exclude | Not AC people & dementia | |
| The mental health foundation and Housing & care (2018) | An evaluation of the Standing Together project | Exclude | No details of how many AC participants were with dementia or carers, no reference to dementia | |

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| Koffman J (2018) | Dementia and end of life care for black, Asian and minority ethnic communities. | Exclude | Briefing paper, no primary research or consultation findings | |
| Gridley et al (2019) | Specialist nursing support for unpaid carers of people with dementia : a mixed-methods feasibility study | Exclude | Results don't discuss AC specific data. Author's response: The proportion of carers in the survey carried out who reported themselves as from any BAME population was too small (2.5% of those who answered the question, n= 11) to allow separate analysis. Further sub-division into an African Caribbean category would be even less meaningful (0.7%, n=3) and sharing the data would compromise confidentiality. | |
| Fischer et al (2019) | Evaluation of technology-enabled collaborative learning and capacity building models | Exclude | Not AC people & dementia | |
| NIHR(2019) | How can we improve dementia care in UK black elders? | Exclude | Flyer, part of IDEMcare study which is included | |
| Ashby-Mitchell, K. & Anstey (2017) | The proportion of dementia in Barbados explained by common modifiable lifestyle factors. | Exclude | discusses risk factors based on data obtained from other studies (reviewed for inclusion in the search conducted in 2017) and not primary study. | |

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| Azhar M et.al (2017) | Increased reporting accuracy of Alzheimer disease symptoms in Caribbean Hispanic informants. | Exclude | Caribbean Hispanic data combines Dominica, peurto rico and Cuba. Doesn’t discuss the Dominica data independently. Peurto Rico and Cuba not a part of Caricom countries. | |
| Boboolal et al (2018) | Comparisons between different elements of reported burden and common mental disorder in caregivers of ethnically diverse people with dementia in Trinidad | INCLUDE | | |
| Bhagirathan et al (2018) | A grounded theory analysis of the experiences of carers for people living with dementia from three BAME communities: Balancing the need for support against fears of being diminished | INCLUDE | | |
| Brown & Murphy (2018) | Barriers to informal caregiving of persons living with dementia in Barbados: A phenomenological inquiry | INCLUDE | | |

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| Burholt et al (2018) | Social support networks of older migrants in England and Wales: the role of collectivist culture | Exclude | Doesn’t discuss dementia. It’s a generic paper discussing support networks for older people from ethnic backgrounds | |
| Charles et al (2017) | Knowledge barriers to identifying Alzheimer's disease incidence in Grenada, West Indies. | Requested full text | No response | |
| Davis et al (2017) | Dementia prevalence in a population at high vascular risk: the Trinidad national survey of ageing and cognition | Exclude | Prevalence study | |
| Dooley et al (2017) | Involving patients with dementia in decisions to initiate treatment: effect on patient acceptance, satisfaction and medication prescription | Exclude | AC specific results not discussed | |
| Eldemire-shearer et al (2018) | Dementia among older persons in Jamaica: Prevalence and policy implications | Exclude | prevalence study | |
| Epps et al (2019) | Who's Your Family?: African American Caregivers of Older Adults With Dementia | Exclude | Doesn’t discuss AC population | |
| Godaert et al (2017) | Adapting the mini mental status to the context of the West-Indies | Exclude | Full paper in French, English version not available and abstract doesn’t clarify if it has made any difference in detection of dementia | |
| James et al (2019) | `Challenges in Defining Inappropriate Medication Use in Parkinson Disease Dementia | Exclude | Tests the validity of MMSE in Jamaican context, doesn’t address study objectives | |

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| Mantovani et al (2017) | Engaging communities to improve mental health in African and African Caribbean groups: a qualitative study evaluating the role of community well-being champions. | Exclude | Doesn’t have any reference to dementia | |
| Mawaka et al (2017) | Exploring the lived experience of the individual of black ethnicity living with dementia: A phenomenological study | Requested full text | No response | |
| Mukadam et al (2019) | Ethnic differences in cognition and age in people diagnosed with dementia: A study of electronic health records in two large mental healthcare providers | Exclude | Results don’t discuss AC specific data, combines all black ethnicity | |
| Parra et al (2018) | Dementia in Latin America Assessing the present and envisioning the future | Exclude | Review | |
| Patterson et al (2017) | Dominica dementia foundation report | Exclude | Full text not available, Report not a research. Abstract doesn’t describe process and methods of public involvement in dementia awareness which was the core objective of the project. | |
| Roche et al (2017) | The IDEMCare Study -Improving Dementia Care in Black African and Caribbean Groups: A feasibility cluster randomised controlled trial. | INCLUDE | | |
| Taylor et al (2017) | Extended Family Support Networks of Caribbean Black Adults in the United States. | Exclude | No reference to dementia | |

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| Victor et al (2019) | Exploring intergenerational, intra-generational and transnational patterns of family caring in minority ethnic communities: the example of England and Wales | Exclude | Not dementia specific. Study doesn’t discuss how many of AC people caring responsibilities towards PwD or explore care giving in dementia. | |
| Zuniga et al (2017) | The Respect for Autonomy in The Management of the Elderly with Dementia | Exclude | Conference abstract Full article not available | |