Informal carer experiences of UK dementia services – a systematic review

First author: Dr Nick Francis, School of Psychology, University of Surrey. BA (hons), PsychD.

Corresponding Author: Dr Paul Hanna, University of Surrey, PhD, 13AC04, School of Psychology, Faculty of Health and Medical Science, University of Surrey, Guildford, Surrey, GU2 7XH, UK. +44 (0)1483 683637, p.hanna@surrey.ac.uk, BA (hons), MSc, PhD.

Please refer to the definitive version of this article when citing:

Francis, N. & Hanna, P. (2020). Informal carer experiences of UK dementia services—A systematic review.

Journal of Psychiatric and Mental Health Nursing, DOI: 10.1111/jpm.12698

Abstract

Aim: To understand the experiences of informal carers' of individuals with dementia in the UK when engaging with services for support in their caring role.

Methods: Following the PRISMA guidelines, a qualitative systematic literature review was carried out. Six internet databases were searched. Results were screened and eligible studies were appraised using Critical Appraisal Skills Programme (CASP, 2019) and data synthesised using Evan & Pearson (2001) and Evans (2002).

Results: The search returned 231 records, 11 were selected for critical appraisal and data synthesis. Four main themes (information for carers, process of diagnosing dementia, difficulties accessing support, and cultural differences of experiences of services) were extracted.

Discussion: Carers experience services as providing inadequate support for the Person with Dementia (PwD) and themselves for support relating to dementia. Difficulties in receiving information and support were experienced from before diagnosis to End of Life (EoL) care. Additionally, cultural differences were found in carers' experiences.

Implications for practice: The provision of and access to dementia support should be improved; more information for carers about dementia and dementia services is needed; cultural differences need to be appreciated in the support and information offered.

Relevance: Informal dementia care is essential to supporting an overstretched health service but the level of care an individual can offer is reliant on the support they receive. This paper reviews contemporary research exploring carers' experiences with services when seeking dementia support.

Accessible summary

What is known on the subject?

- Dementia affects an increasing number of people and a person with dementia requires significant levels of care.
- Dementia care is often delivered by family members.
- Caring for someone with dementia places significant demand on the carer and support for the carer is often needed.

What the paper adds to existing knowledge?

- Research has been conducted into caregivers' experiences of caring for someone with dementia but a synthesis of findings for studies from the UK is needed to collate the research evidence and provide an account of the common trends within the existing research.
- This paper adds to existing knowledge by highlighting the key difficulties experienced by carers of a person with dementia in their caring role and their experiences with support services across the existing research evidence.

What are the implications for practice?

- Improvements to the process of dementia assessment and the process of receiving a dementia diagnosis are needed.
- Information and support needs to be more accessible for the carer of a person with dementia
- Cultural differences need to be acknowledged in the support and information offered to carers of a person with dementia.

Keywords Dementia, Carers, Support Services, Review, Caregivers

Introduction

As of May 2019, the number of people with a dementia diagnosis in the UK is around 537,097 (Dementia Statistics Hub, 2019). Importantly, dementia care is often undertaken by the 670,000 unpaid/informal carers (from now on referred to as 'carers') for People with Dementia (PwD) (Carers Trust, 2019). The government recognised that carers are the "most important resource" regarding dementia care (Department of Health, 2009) with informal carers defined as "anyone who cares, unpaid, for a friend or family member who due to illness, disability, a mental health problem or an addiction cannot cope without their support" (Carers Trust, 2019). Given that the number of people living with dementia is expected to rise (Dementia UK, 2014), it is important to be aware of the experiences of carers in this process as they provide crucial support and alleviate some of the costs to, and strain on, formal healthcare services.

Andrén and Elmståhl (2005) found carers have both positive and negative experiences of caring for a PwD. Often negative experiences occur when the carer feels they do not have the resources to cope with the demands (Lazarus & Folkman, 1984). It is therefore argued that carers need support from services to cope with these demands. This includes education about dementia, knowledge of available services for the PwD (Corbett, et al., 2012) alongside the often-forgotten need for support for the carers of a PwD (Livingston, et al., 2017).

Dementia is a progressive illness leading to a decline in many areas of functioning. Despite frameworks to help individuals who lose the ability to make decisions be involved in their own care, this responsibility often falls to carers (Lord, Livingston & Cooper, 2015). Many carers find making decisions on behalf of the PwD stressful (Samsi & Manthorpe, 2013) showing the need for carers to receive support in making these decisions. Evidence shows that having carers involved closely in the care of the PwD can have benefits for the quality of care the PwD receives (Ablitt, Jones & Muers, 2009).

In addition, caring for a PwD is known to lead to many negative outcomes for carers themselves (Schoenmakers, Buntinx & DeLepeliere, 2010). Although there are positive experiences for many, such as a sense of satisfaction in providing care (Shim, Barroso & Davis, 2012), there are significant and enduring

negative effects for many carers of a PwD (Brodaty & Donkin 2009). For example, a meta-analysis found that carers of the elderly are more likely to be depressed, have a lower sense of wellbeing, have worse physical health, lower self-efficacy and be more stressed than their non-carer counterparts (Pinquart & Sorenson, 2003). Further, many carers experience 'carer burden' which has been defined as "a multidimensional response to physical, psychological, emotional, social, and financial stressors associated with the caregiving experience" (Kasuya, Polgar-Bailey & Takeuchi, 2000, p. 119). Carer burden is likely to increase throughout the course of dementia as the amount of time required to care increases with severity of the dementia (Langa et al., 2001). As such, carer burden can have substantial negative effects on carers which can worsen over time. Therefore, there is a need for services to support carers in maintaining their own physical and mental wellbeing.

In summary, carers of PwD require support from services for their role of caring and decision making and also to maintain their own wellbeing which also affects their ability to care for the PwD. However, carers of those with dementia have struggled to access support having transitioned into the caring role (Ducharme, et al., 2011). Therefore, it is important that carers are able to access required support for their own wellbeing and the wellbeing of the PwD. As such, the experience of carers with services relating to dementia support needs to be investigated.

Rationale and aims of this review

It is clear that it is important to understand carers' experiences with services to determine if they are able to use services effectively. There has been some work in reviewing this area investigating the experiences of PwD and carers of the dementia diagnosis and treatment internationally (e.g. Bunn et al., 2012).

However, to our knowledge there are no previous reviews of qualitative literature solely on the carers' experiences of services for dementia support in the UK. Further, with services offered varying between countries, this review takes the UK as its focus due to increased political rhetoric specifically addressing the provision of services for carers of PwD in recent years. For example, in 2009, the UK government recognised the importance of improving the support provisions for carers and the PwD in the UK (Department of health, 2009). Further, in 2015, the UK government launched 'Dementia 2020 challenge'

(Department of Health, 2015). This initiative was introduced with a view to make dementia care in the UK the best in the world. However, in the latest progress review, it was recognised that improvements are still required in post-diagnostic care and support for carers (Department of Health, 2019). Therefore, this review seeks to synthesize existing research with the aim of understanding the experiences carers of a PwD have with services offering support in fulfilling their role as a carer for a PwD in the UK.

Methods

Drawing on the PRISMA checklist (Moher et al., 2009), a systematic literature review was carried out using six internet databases (PsychINFO, Psych Articles, Psychology and Behavioural Science Collection, MedLine; Web of Knowledge and SCOPUS). These six databases were selected to enable a search strategy that allowed for research published in a broad range of disciplinary traditions including psychology, nursing and the broader social sciences. We restricted our search strategy to papers published in English, however there was no date restriction. The search was conducted between 2nd June – 20th June 2019 to find peer reviewed articles with search terms, search results and quality appraisal undertaken by the lead author and reviewed by the co-author. A full example of our search strategy for PsychINFO is as follows:

carer OR caregiver* AND United Kingdom OR England OR Northern Ireland OR Wales OR Scotland
OR Britain AND dementia service* OR dementia support OR memory service* AND experience*
OR perspective* OR view* OR perception* OR attitude* ('in': Abstract (AB); 'Limit to': peer
reviewed; 'Publication date': All dates)

Inclusion and Exclusion Criteria

The PICO tool was utilised as it has been argued to provide a useful framework for qualitative systematic reviews (Methley et al., 2014) and is also used in this paper to present the inclusion/exclusion criteria, alongside the search terms used (see Table 1). Due to vast difference in health service delivery cross culturally, this review focused on carers of a person with dementia in the UK (P) and thus excluded studies from outside of the UK. More specifically we were interested in the experiences, understandings and perspectives (O) of dementia care/support services (I), excluding studies exploring paid caregivers experiences, or experiences of non-dementia focused services, from a qualitative perspective (C)

excluding quantitative studies and mixed methods studies due to lack of depth in the qualitative component. The inclusion/exclusion criteria were used when screening results from the initial database search to ensure their relevance to the research question. They were first used when reading titles and abstracts of the articles and then again when reading the full article to ensure relevance and ability to answer question.

[INSERT TABLE 1 HERE)

Risk of Bias

The remaining papers were appraised using the Critical Appraisals Skills Programme (CASP) qualitative checklist (CASP, 2019). This was used as it provided a clear method to screen papers and evaluate their quality in a systematic way. It has three broad sections looking at whether the study is valid, what the results are and whether the study is valuable for clinical practice. With its categories of “yes”, “no” and “can’t tell”, it allowed a table to be drawn to determine if these elements were in the study. Criteria used in other systematic reviews using CASP (Kanavaki, et al., 2016; Carolan, et al., 2018) were used to determine if they should remain for the data synthesis. As suggested by Carroll, Booth & Lloyd-Jones (2012) low quality studies would be removed. With this method, studies were rated as ‘high quality’ if they met eight out of ten the criteria, ‘medium quality’ if the met 5-7 of the criteria and ‘low quality’ if they met four or less criteria.

Study selection

Returns from the search were screened by title and abstract, in addition, the reference lists of these papers were mined to uncover relevant articles not returned in the search, however no additional articles were uncovered through this process. This was followed by reading the full studies to ensure they were appropriate based on inclusion/exclusion criteria. Then the quality of studies was appraised to determine if any ‘low quality’ studies should be removed before data synthesis. Excluding these studies is known to have a positive effect on the quality of subsequent data synthesis (Carroll, Booth & Lloyd-Jones, 2012).

Data extraction and synthesis

As this review was interested in carers of PwD experiences or dementia services all qualitative data that was identified as being data of carers of PwD was extracted from the research papers and placed in a separate document for later synthesis. An interpretative strategy for data synthesis listed by Evans and Pearson (2001) and Evans (2002) was used. Such as data synthesis strategy has featured in other dementia research (Evans & Lee, 2014) and was deemed appropriate for this review. This method involved reading and rereading the text while noting key ideas/statements. After reading each article multiple times, key ideas/statements from across the data that had been noted were coded in a table format to help see across which studies the themes were reported. Quotes and other text in the results sections were all analysed and synthesised as suggested by Thomas and Hardman (2008). The codes were keywords that represented the text and a list was created from each study. These were then compared against the other studies and categorised based on similarities into themes and sub-themes. These were reviewed against the original study data to ensure it represented the data. As our synthesis was specifically focused on the aims of this review, an interpretative approach was adopted in order for the authors to hold the aims in mind when synthesizing the data and draw on existent theory and research to develop our analytic themes that go beyond re-description and offer an interpretation which generates new understandings of the phenomena (Thomas & Hardman, 2008).

Results

PRISMA Flow Diagram

The searches produced 231 records that were screened by title and abstract with 184 removed due to irrelevance or duplication (see Figure 1). Sixteen papers were read fully, two studies were removed as they did not focus on carer experience and a further three were removed as it was not possible to separate out the findings from the carers alone as many of the themes were reported as both carer and patients together. Therefore, eleven papers in total were included in the final review, a number similar to other systematic reviews that have been published in related areas (e.g. Johl, Patterson & Pearson, 2016; Hudson, Remedios & Thomas, 2010; Lloyd, Patterson & Muers, 2016).

[INSERT FIGURE 1 HERE]

Study characteristics

[INSERT TABLE 2 HERE]

The characteristics of the studies included in this review have been collated in table 2. Only five of the studies included looked at the experiences of carers alone. The other six either included patients' and professionals' experiences in addition however it was possible to separate the findings from the carers. Across all studies, the majority of carers were female (n=236, 69%) with fewer male carers (n=74, 31%). Eight of the studies reported the carers' relationship with the PwD. The carers in these studies were mostly spouses (n=76, 51%). The majority of other carers were adult children carers (n=64, 43%). The remaining participants were either other relatives (n= 8, 5%) or friends (n=2, 1%). Nine of the eleven studies used semi structured interviews, one focus groups and one a combination of focus groups and semi structured interviews. Five of the studies used Thematic Analysis, four used Grounded Theory and two used Content Analysis.

Quality Appraisal of studies

Table 3 shows the results from the quality appraisal for each study. All included studies were deemed to be of "high quality" according to the criteria used in previous reviews (e.g. Kanavaki et al., 2016; Carolan et al., 2018).

[INSERT TABLE 3 HERE]

Summary of themes

The emergent themes were: Information for carers; Diagnosis of dementia; Access to support; Cultural differences of experiences of services. Table 4 shows the themes, which papers contributed to the theme and some example extracts.

[INSERT TABLE 4 HERE]

Information for carers

Nine studies (Laparidou, et al., 2018; Sutcliffe, et al., 2015; Gorska et al., 2013; Lawrence, et al., 2008; Baghirathan, et al., 2018; Abley et al., 2013; Moore et al., 2017; Greenwood, et al., 2017 and Willis, et al., 2009) in this review reported information was important to carers in their experiences of services. Seven studies (Laparidou et al., 2018; Sutcliffe, et al., 2015; Gorska, et al., 2013; Moore et al., 2017; Lawrence et al., 2008; Baghirathan et al., 2018 and Abley et al., 2013) reported that there was a lack of information for carers provided by services. For example, one study investigated the experiences of carers when interacting with the healthcare system finding there was “little or almost no information or education about dementia offered” to carers (Laparidou et al., 2018, p.8). Similarly, other studies also found carers experienced a lack of information from services (Sutcliffe, et al., 2015; Gorska, et al., 2013). Moore et al., (2017) investigated the experiences of family carers of End of Life (EoL) care finding carers were not often informed about the potential progression of dementia which made it difficult to prepare for EoL. However, carers were unsure when a good time would be to provide information about EoL. Additionally, Lawrence et al., (2008) found carers thought that information should have been provided earlier, while Baghirathan et al., (2018) found that information was inaccessible as information was not translated for non-English speakers.

Abley, et al., (2013) studied carers’ and patients’ views on communication when undergoing memory assessments. Carers expressed being informed throughout assessment of what to expect and of the results was helpful. Carers also found voluntary organisations beneficial in order to gather relevant information. Further, the study found carers found it helpful when information was tailored to the needs of the PwD and for this to be staggered over time and found it beneficial when written information was provided following a face-to-face meeting. This study similarly found that information was not always given or took a very long time throughout assessment.

In addition to the delivery of formal information, Greenwood et al., (2017) found carers valued discussing challenges faced when caring for a PwD with other carers as they could provide information that helped them cope with their own challenges. One other study found information from other carers beneficial with Willis et al., (2009) highlighting that carers who attended a carer group found they gathered useful information from these groups.

These studies demonstrate that carers valued being informed throughout the process of dementia about available support. Most carers wanted to be informed of the likely progression of dementia to help them prepare but also found that being given information face-to-face was best when supplemented by written information. Therefore, the context of information provision is important. This is also shown in the studies showing the usefulness of information gathered from peer support from other carers. Unfortunately, these studies show that this is not the experience of many carers with most reporting not being given enough information from services.

Diagnosis of dementia

Receiving a diagnosis

Five studies (Laparidou et al., 2018; Baghirathan et al., 2018; Sutcliffe et al., 2015; Gorska et al., 2013; Abley et al., 2013) reported carers experienced difficulties with the diagnostic process. These studies all showed carers struggled with the length of time to receive a diagnosis with two studies reporting the process taking “several years” (Baghirathan et al., 2018 & Sutcliffe et al., 2015). For example, Gorska et al., (2013) highlights how carers describe early diagnosis as crucial to help them access appropriate services with obstacles to receiving a timely diagnosis (time unreported in study) including the dismissal of their concerns by the primary care doctors. Laparidou et al., (2018) similarly found carers felt their concerns about the PwD were not believed by healthcare professionals again increasing the time to diagnosis. Carers believed other causes for delay came from poor communication between services (Gorska et al., 2013). This study also found carers did not believe the assessment tools were sensitive enough to detect functional difficulties the cared for person was presenting.

In a study of the experiences of BAME carers’ experiences, one PwD and carer travelled to Hong Kong to receive a diagnosis as it had been too difficult (due to cultural differences the carer thought was affecting the diagnosis and previous experiences of poor care) to receive one in the UK (Baghirathan et al., 2018). Other carers reported paying privately for someone to receive a diagnosis (Sutcliffe et al., 2015). Abley et al., (2013) found some carers and PwD did not find out the results from the assessment for a long time. This shows the significance of receiving a timely diagnosis to carers and how in the UK, many experience

this process as difficult as they struggle to receive a diagnosis for the person suspected of having dementia. The importance of this is highlighted by Lapidou et al., (2018) who discovered the challenge of the PwD receiving a diagnosis was experienced as a primary stressor for carers.

One study reported carers wanting to know the information about the assessment process to help with their expectations of the process (Abley et al., 2013). Carers valued being given the outcome of the assessment whether it was positive or negative. Receiving the diagnosis was seen as helpful as it allowed the PwD to access support (Gorska, et al., 2013). Willis et al., (2009) found the experiences of assessment made the PwD feel anxious, agitated, uncomfortable and stressed causing concern for some carers about the validity of assessment. These studies show that often carers have difficulty in pursuing a diagnosis for the suspected PwD and found there is often a delay in receiving the diagnosis once the assessment is complete. This can raise anxiety for the carer and does not allow for the carer to prepare for the future. Carers generally wanted to find out the diagnosis regardless of the outcome (positive or negative) as it facilitated an understanding of what was happening for the PwD and allowed for future planning. Crucially, the process of assessment was often anxiety-provoking for carers. Therefore, carers reported valuing some information on the process of assessment (in order to receive the diagnosis) to better manage their expectations.

Access to support

Support for the PwD

Seven studies (Gorska et al., 2013; Lapidou et al., 2018; Sutcliffe et al., 2015; Davies, et al., 2017; Lawrence et al., 2008; Baghirathan et al., 2018 and Jutlla, 2015) reported carers found accessing support for the PwD difficult. Lapidou et al., (2018) found that carers were not able to access appropriate support easily and had to fund these services themselves. Sutcliffe et al., (2015) reported similar experiences from carers finding carers in the focus groups struggled to find access for appropriate support for the PwD. Gorska et al., (2013) revealed that carers were also unable to access support post-diagnostically. This was primarily thought to be due to poor co-ordination between services. Carers also recognised they struggled to access non-pharmacological support for the PwD to help with engagement

with previously valued activities. This was echoed by Davies et al., (2017) who found themes from carers about their preference for psycho-social support which was not always accessible for the PwD.

The three studies that investigated BAME carers' experiences also found there were difficulties in accessing services for carers from BAME backgrounds (Lawrence et al., 2008; Baghirathan et al., 2018; Jutlla, 2015) as a result of their cultural background. Concerns over diminishment (losing the PwD's culture) were reported (Baghirathan et al., 2018) as it was felt that services in the UK were not equipped to deal with the individual's culture therefore reducing access. Jutlla (2015) also found carers reporting social inequality and previous racial abuse were key aspects as to why they did not access services for the PwD. In the third study of BAME experiences, carers likened accessing services to a "battle" (Lawrence et al., 2008). This study also reported different beliefs about the caring role (traditional vs. non-traditional) affected use of services as explained in the 'Cultural differences in the experiences of services' section.

Carer specific support

Two papers described support carers had received for themselves from groups involving other carers (Willis et al., 2009; Greenwood et al., 2017). Greenwood et al., (2017) was the only study exploring the experiences of carers attending dementia cafes finding that carers experienced the cafes as a useful form of support for themselves (not solely for the PwD). The cafes provided carers an opportunity to gain peer support from other carers, to enjoy themselves and "switch off" from being carers, they normalised the experiences and reduced social isolation. However, Laparidou et al., (2018) highlighted a current lack of services specifically for carers. This was also found in another study (Sutcliffe et al., 2015) with their being a perceived lack of support specifically for carers. Moore et al., (2017) found carers of a PwD at the advance stage of the illness and approaching End of Life care would have liked some emotional support around this time to cope with the range of feelings that arise in this context. Similarly, Laparidou et al., (2018) and Sutcliffe et al., (2017) found this type of support was not often provided. Additionally, most of these studies focused on the support received for the PwD, not on interventions/support specifically to help the carer.

Cultural differences in the experiences of services

Three studies explicitly investigated the experiences of carers from BAME backgrounds (Baghirathan et al., 2018; Lawrence et al., 2008; Jutlla, 2015) all revealing perceptions based on carers' cultural backgrounds (either of services or their role) affected their experiences of services. The most recent paper found carers from South Asian, African Caribbean and Chinese backgrounds had concerns around the PwD being diminished as a person by services (Baghirathan et al., 2018). Crucially the carers recognised they needed support but thought that statutory services would risk diminishing the identity of the PwD. In order to protect the PwD from diminishment, they used BAME-led voluntary services instead. Similarly, Jutlla (2015) also reported perceptions of services, affected by the carers' cultural background and history, organised their experience of services. The study looked at the migration histories of Sikh carers and their experience of caring in the UK. It found there were difficulties engaging with services due to social inequalities and previous negative experiences when arriving in the UK including hostility and racism. This had an impact on their likelihood to access services. Both studies indicate how experiences of services were affected by cultural background and perceptions of services. The third study investigated the attitudes and support needs of Black Caribbean, South Asian and White British carers of PwD. They found experiences of services varied depending on whether the carer held traditional or non-traditional views of caring. Traditional ideology of caring was described as being "expected, natural and virtuous". Non-traditional ideology was described as beliefs that caring is "unnatural", "lacking virtue" and causing "conflicts with expectations". Carers who held traditional views had less difficulties with services however those with non-traditional, had more as they thought services should take on more responsibility for caring for the PwD (Lawrence et al., 2008). The majority of South Asian, and half of the Black Caribbean carers possessed the traditional ideology compared to a minority of White British carers. This highlights the difference in the cultural beliefs around caring and the impact this has on the experience of services regarding their effectiveness for carers. These all reveal how carers' perceptions affected experience and use of services (for themselves and the PwD) as a result of their cultural background.

Discussion

The aim of this review was to understand the experiences of carers of a PwD with services in the UK by critically evaluating current empirical evidence. There were no themes reported that were consistent across all eleven studies. The theme most consistently reported across studies (nine studies) was concerned with information provision. This shows the importance for carers of being informed throughout the dementia process. Crucially, most carers were not informed to the degree they would have liked however, when they were, it was deemed helpful. Therefore, carers, across cultures and different stages of dementia (including EoL), found services had not provided them with enough appropriate information. The importance of information in dementia care has been noted previously in the literature (Robinson, Tang and Taylor, 2015).

This review noted that carers often found the diagnostic process, from initial symptoms to assessment to receiving a diagnosis, difficult (five studies). This was also reported across different cultures. Difficulties often arose for carers when they were not believed by primary care professionals about the symptoms being reported but also with the amount of time it took in getting a diagnosis. They experienced significant delays which impacted the support the PwD could receive as the lack of a diagnosis was the barrier to support. However, the process was also experienced as anxiety-inducing for carers. Again, the importance of a timely diagnosis has been reported previously in this country (Robinson et al., 2015). Across Europe, similar experiences of carers have been shown with carers experiencing a delay in receipt of a diagnosis (Woods et al., 2018). Similarly, this study showed the importance of a timely diagnosis for carers but also how these experiences of delayed diagnosis is a significant issue. As such, it must be recognised that the process of receiving a diagnosis is important for carers and not solely for the individual receiving it.

This review has highlighted carers often experienced a lack of appropriate support from services in the UK. From these studies, there were two sub-themes in relation to this support. One related to support for the PwD which would assist the carer in their role of caring for the PwD. This included barriers to diagnostic services and post-diagnostic services. Again, this was common across cultures although it is important to note that the reasons for poor access were more culturally based for the BAME population. This highlights that although there are services that potentially might be helpful for carers in their role,

these are often not being accessed or are difficult to access. This has been found to be a similar difficulty experienced by carers in Australia (Bruce & Paterson, 2000). The second sub-theme was concerned with support for the carers themselves. Most studies did not report on this. This may indicate a lack of access to this support but may also indicate that carers are not aware that this support is available.

The three main themes discussed so far are similar in that they demonstrate how service provision has been less than is required by carers in these studies. This suggests carers experience of services in the UK was largely negative as it did not provide adequate information, support or diagnostic procedures. Crucially, many experienced services as helpful when these aspects were received. This element was largely absent from the studies investigating BAME experiences. This may be due to BAME carers resorting to other sources of support (Baghirathan et al., 2018). The BAME population has been shown in other studies in the UK to mobilise other forms of support when coping with dementia (Parveen, Peltier & Oyeboode, 2017). However, Lawrence et al., (2008) found that the experience of services was influenced by carers' beliefs about the caring role in BAME populations. Therefore, it is unclear whether those from BAME backgrounds who do manage to access support find the support helpful.

As discussed earlier, access to support was experienced as difficult for BAME carers in the three studies that investigated this group (Baghirathan et al., 2018; Lawrence et al., 2008; Jutlla, 2015). The review revealed that BAME carers experienced difficulties in accessing support but also indicated that their experiences more generally (socially) affected their willingness to engage with services. Therefore, in addition to having difficulties when wanting support, as most carers describe across many studies regardless of ethnicity, there were additional concerns from BAME carers about how the service will respond to the PwD and how they would be cared for as a result of their ethnicity. There were concerns about previous racism, social inequalities and a fear that services were not equipped to deal with the cultural variations which risked individuals' cultures being diminished. As such, the experiences of BAME carers, as seen in this review, is highly dependent on cultural aspects including their beliefs about the caring role. Therefore, when considering the experience of carers from BAME backgrounds, it is important that the culture of origin is taken into consideration.

Limitations

Lack of diversity

Across the eleven studies included, the majority of the carers who took part were female (69%). Whilst this appears to be a reflection of the estimated gender balance of carers with 60%-70% of carers being female (Alzheimer's Research UK, 2015), it does limit the findings in terms of capturing the experiences of male carers in the UK. Similarly, there was cultural homogeneity across many of the studies reviewed with the majority of studies only including carers from White British backgrounds. Three studies did explicitly investigate experiences of individuals from BAME backgrounds however as this number is small in our sample of studies this would likely have had implications on the research findings. Due to this lack of diversity it is difficult to conclude much about the experiences of these minority groups with services in the UK. In addition, due to healthcare systems being different in different countries this article only reviewed studies from the UK however that does have implications for the international relevancy of this review.

Unclear information in studies

In many studies included, the authors do not report exactly what type service the carer is reporting on. Only two studies explicitly focussed on the carers' experiences of specific services (dementia cafes and a memory service) whereas the other studies are unclear throughout what services the carer is expressing their opinions about. This limits what can be concluded from this review as there are many types of services that could be discussed who may provide vastly different services. However, we made the decision not to contact the authors for further information as the redaction of information on the service type might be due to the risk of anonymity breaches (e.g. the identification of a particular service), this of course can be seen as a limitation to our approach.

Five of the eleven included studies investigated more than just the experiences of carers and as such in their results sections, the themes were grouped across participants (carers and staff/patients). This makes an assumption that these groups (patients, carers and staff) are more homogenous than they are.

Indeed, in three studies that met the inclusion criteria, the results from carers or other groups could not be distinguished, this therefore limited the amount of studies that could be included in this review.

Implications

For clinical practice

This review reveals how carers experience difficulties in accessing the support they require whether in the form of information, support for the PwD or themselves, or for a diagnosis. This was shown across different cultures. Therefore, services would benefit from aiming to provide more timely information and developing strategies to help carers access the support or information they require. Additionally, services would benefit being more culturally sensitive when trying to engage with carers from BAME populations as many are actively avoiding statutory services for support due to concerns the care will not adjust to the cultural needs of the individual.

Implications for research

Research would benefit from investigating more into the specific areas of dementia care for carers. Therefore, we feel more research into the experience of carers with specific services is needed to help clarify what the experiences of specific services in the UK are. In addition, future research should further explore the experiences of carers regarding the different stages of caring for a PwD. Furthermore, research into the experiences of BAME carers of those with dementia with services is under-researched. Most studies in this review, unless specifically investigating BAME experiences, do not include many participants from BAME backgrounds. This may represent a difficulty in the recruitment process for studies which has been recognised generally with research in the UK (Smart & Harrison, 2017). Further, in general, the BAME population access dementia services later in the course of their illness (Tuerk & Suer, 2015). Therefore, it can be expected that carers of these individuals will be required to be involved with more care for the PwD as the individual will likely be more impaired and therefore the engagement with services will be more likely to be the responsibility of the carer. As such, BAME carers involvement with services will be very important and thus we call for future research in this area.

Conclusion

To conclude, the overarching experience reported across these studies is that of a lack of appropriate support from services including information (about EoL care included), access to specific support, difficulties with diagnostic procedures and a lack of cultural flexibility from services affecting the experiences of BAME carers. When such aspects of service provision have been provided, carers from these studies reported finding them useful however, the pursuit of these is often seen as a significant challenge for the carer in the UK before a diagnosis, post-diagnostically and at the stage of EoL care.

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Table 1: Study inclusion and Exclusion Criteria

Inclusion Criteria	Exclusion criteria:
Participants	
Participants were carers of someone with dementia	Care staff/formal care providers
Participants recruited in the UK	Studies from outside of the UK
Participants must be informal carers	Person with dementia
Intervention	
Dementia services, medical services relating to dementia support (e.g. GP for a diagnosis) or dementia support services	Non-dementia focused services
Comparison	
Qualitative studies	Quantitative and mixed methods studies
Outcome	
Studies exploring carers experiences/perspectives/perceptions	Studies quantifying barriers/factors/behaviours
Search terms: Population: carer OR caregiver* AND United Kingdom OR England OR Northern Ireland OR Wales OR Scotland OR Britain Intervention: dementia service* OR dementia support OR memory service* Comparison: Qualitative data collection and analysis	

Outcome: experience* OR perspective* OR view* OR perception* OR attitude*