

**Title:** Family caregivers' experiences of providing care for family members from minority ethnic groups living with dementia: A qualitative systematic review

## **Abstract**

**Aims and objectives:** To review the literature on family caregivers' experiences of providing care for a family member from an ethnic minority group living with dementia within the European context.

**Background:** Due to labour migration during the late 1960s and early 1970s, many European countries are now encountering an increasing number of older people from diverse ethnic minority groups who have been diagnosed with dementia. Although family care is predominantly used as a care pathway among families with immigrant backgrounds, little is known about family caregivers' experiences of providing care for a family member with dementia.

**Design:** A systematic review of qualitative literature.

**Methods:** Eight databases (CINAHL, EMBASE, MEDLINE, PsychINFO, SCOPUS, Social Care Online, SocIndex, and Epistemonikos) were searched for original, peer-reviewed papers, published in English between 2010 and 2021. The literature review was conducted and reported in accordance with PRISMA 2020 checklist for reporting systematic reviews.

**Results:** After identifying, screening, and assessing articles for eligibility, fourteen articles were critically appraised using the standardised assessment tool Mixed methods Appraisal Tool (MMAT, version 2018) and included in the review. The data synthesis process identified four themes across the qualitative studies: controversies and challenges; a lack of health literacy; barriers to seeking support from the healthcare or social services; and models of care.

**Conclusions:** Most of the family caregivers highlighted the value of being able to care for a family member living with dementia. However, the findings also reveal that they experience

controversies and challenges due to their lack of dementia health literacy and perceived barriers to seeking healthcare support.

**Relevance to clinical practice:** The findings from the current review can inform healthcare and social services in relation to implementing models of care that facilitate and complement family caregivers' role in caring for family members living with dementia from minority ethnic groups.

**Keywords:** Dementia care, Ethnicity, Family caregivers, Minority ethnic groups, Older immigrants, Literature review

### **Impact statement**

#### **What does this paper contribute to the wider global community?**

- The literature review raises awareness of the challenges family caregivers from minority ethnic groups face when providing care to a family member living with dementia.
- The findings highlight the importance of healthcare and social services adopting and implementing different models of care that are sensitive to issues related to migration-, culture-, and religion, thus meeting family caregivers' individual needs.

## 1 INTRODUCTION

European countries are making progress in implementing the Strategy and Action Plan for Refugee and Migrant Health adopted in 2016 by the World Health Organisation [WHO] - Regional Committee for Europe, aimed at guiding progress on the health aspects of population movement (WHO Europe, 2018). However, more knowledge is needed to successfully fulfil the strategy. While most recent research on minority ethnic groups has focused on the health problems of newly arrived immigrants and refugees in Europe (Pavli & Maltezos, 2017), less attention has been given to the health problems of older people from minority ethnic groups and their informal caregivers who are already settled and have lived in a European country for a number of decades.

In the context of the European Union [EU], ‘minority’ is defined as a non-dominant group which is usually numerically less than the majority population of a state or region as regards their ethnic, religious or linguistic characteristics, and who (if only implicitly) maintain solidarity with their own culture, traditions, religion or language (European Union, n.d.). An ‘immigrant’ is a person who establishes their usual residence in the territory of an EU Member State for a period that is, or is expected to be, of at least 12 months, having previously been usually resident in another EU Member State or a third country (European Union, n.d.). The Oxford Learner’s Dictionary defines ‘ethnic minority’ as “a group of people that share a cultural tradition, religion, etc., or a member of this group, living in a country where the main ethnic group is different”. For the purpose of the present study, the term ‘minority ethnic groups’ will be used to address first-generation immigrants who have settled in a European country.

Minority ethnic groups have different cultural, religious and socio-economic backgrounds to those of the host population and this may influence their overall health situation (Lanari et al., 2018). A limited or lack of information about the healthcare systems in

their host countries can also lead to families deciding to provide care for family members aging in place themselves. This decision can delay professional assessments of the healthcare needs of the older population from minority ethnic groups, and, in turn, have a detrimental effect on their health. Policy makers/stakeholders should therefore take account for this this vulnerability and develop policies that target specific immigrant groups thus, ensuring that their specific needs are met (Lanari et al., 2018).

As people age, they are more likely to experience multimorbidity. This results in significant public health concerns due to the negative impact on function, quality of life, and the use and costs of the healthcare services at the individual, familial and societal level (Northwood et al., 2018). These conditions therefore demand adaptive and innovative thinking when it comes to providing care to the older population from minority ethnic groups. However, it appears to be a general characteristic in the Nordic countries that relatively few older people from minority ethnic groups live in long-term care facilities such as nursing homes (Plejert et al., 2014). This indicates that older family members receive care from family members at home. The care provided to older people from minority ethnic groups often depends on their family's efforts, and it is therefore necessary to provide help to these caregivers. With appropriate support from the healthcare services, more persons from minority ethnic groups would be able to provide care to their family member with reduced risk of burn out.

The burden of care is a complex construct that is usually defined by its impact and consequences on caregivers, and it seems likely that the perceived burden of care is universal, independent of the type of chronic disease (Zarit et al., 1986). However, it is impossible to incorporate all aspects of caregiving for older people from minority ethnic groups living with chronic diseases in one literature review. We have therefore deliberately conducted a systematic literature review focusing on the breadth of the caregiving challenges that lie ahead

when providing care to a family member from a minority ethnic group living with dementia. Since the first symptoms of dementia often appear to be accepted and interpreted as a consequence of ageing (Bature et al., 2017), hence delaying the diagnosis and interventions, the condition can eventually require attention from different levels of the health services. However, the perception of the burden of care and its effects varies across illnesses, individuals, cultures and ages (Sales, 2003).

Family practices and expectations of family care vary between minority ethnic groups (Kavli & Nadim, 2009). A family orientation that emphasises family duties and obligations can increase the risk of negative health consequences for caregivers (Gallagher-Thompson, 2006). In addition, family members may feel a responsibility to provide care for their ill family member when they feel that healthcare personnel do not take account of their habits and traditions, a situation that may increase their perception of the caring obligation as a burden (Ingebretsen, 2020).

A number of studies have provided consistent evidence of the detrimental effects of caring for people with chronic illness, such as dementia, on caregivers' physical and psychological health (Bremer et al., 2017). Feelings of guilt, embarrassment, stress and anxiety, and the mere physical extent of the workload influence the perceived burden of care. Living with a chronic disease, regardless of the type, will also commonly impact the lives of family caregivers, as they can often become more emotionally affected by the illness than the patients themselves (Cherry et al., 2017).

The contribution of ethnicity and cultural issues on the subjective burden of care has also been the subject of research (Siegler et al., 2010). Although families have proved remarkably adaptable in the face of such changes, the ability of families from minority ethnic groups to provide professional care and support still poses a risk. Moreover, recognising the crucial role of informal caregiving (HOD, 2017), researchers need to move beyond

evaluations of single interventions and instead direct attention towards innovative thinking when it comes to caring for older people, particularly those belonging to minority and immigrant populations. As such, policymaking should be based on an understanding of different socio-economic and life situations and family structures (Ingebretsen, 2020). This may facilitate the adoption of migrant-sensitive, non-discriminatory and inclusive health policies, legal frameworks and programme interventions that provide better access to the healthcare services for the minority ethnic population.

## **2 AIMS**

To the best of our knowledge, international research is scarce on the topic of informal caregivers' experiences and needs when providing care to a home-dwelling family member with dementia from a minority group. To date, no systematic literature review has been conducted that aims to explore this topic and there is thus an identified need. In order to fulfil this objective, a review was conducted of international literature describing the experiences and needs of family caregivers in this situation. Specifically, the aim was to answer the following research question: What are the experiences of family caregivers who provide care to home-dwelling older people from minority ethnic groups living with dementia?

## **3 METHODS**

This systematic review has been reported using the guidelines for the Preferred Reporting Items for Systematic Review and Meta-Analyses checklist (PRISMA 2020; Page et al., 2021; (Supplementary File S1)).

### **3.1 Design**

The study was designed as a systematic review with a view to identify and summarise all empirical evidence that fits the pre-specified inclusion criteria within the scope of the research question (Snyder, 2019).

### **3.2 Protocol and registration**

Before starting the literature search, a search was conducted in PROSPERO (the international database of prospectively registered systematic reviews) to check whether others had performed a recent literature review on a similar topic. At the time, there were no early or ongoing reviews registered. This systematic review was prospectively registered with PROSPERO (reg. no CRD42020160924, 6 December 2019).

### **3.3 Search strategy**

Eight electronic databases were systematically searched from January 2020 to March 2020 and updated in May 2021 for relevant publications. In addition, the researchers received regular email alerts and the titles and abstracts were scrutinised by the first author. Key concepts were identified by consulting two research librarians (Elisabeth Karlsen & Camilla Thorvik). A combination of three groups of key concepts: ‘Dementia’, ‘Immigrants’, AND ‘Informal caregivers’ and their related terms were used to search the databases, i.e.

‘Dementia’ OR ‘Alzheimer Dementia’ OR ‘Cognitive Impairment’ OR ‘Dement\*’ OR ‘Senile’ OR ‘Presenile’; ‘Immigrants’ OR ‘Ethnic groups’ OR ‘Minority groups’ OR ‘Minority backgrounds’ OR ‘Refugees’ OR ‘Non-western’ OR ‘Cultural minorities’ OR ‘Multi-ethnic’, and ‘Informal caregivers’ OR ‘Family care’ OR ‘Unpaid care provider’ OR ‘Next of kin’ OR ‘Significant other’ OR ‘Spouses’ OR ‘Daughters’/’Sons’ OR ‘Relatives’.

These groups of key concepts consisted of search terms that are valid in the thesaurus of each database: mesh terms (MEDLINE), thesaurus (PsychINFO), subject headings (EMBASE) sociological thesaurus (SocIndex), subject terms (CINAHL, SCOPUS, Social Care Online) and search terms (Epistemonikos), and they informed the search strategy used for these databases. The search strategy was also peer reviewed by another specialist librarian (Malene Wøhlk Gundersen) after execution.

An example of the full electronic search strategy in the Cinahl database is presented in Table 1.

Table 1 should be included here: .....

### **3.4 Inclusion and exclusion criteria**

The following inclusion and exclusion criteria were developed by the research team to locate articles that addressed the aim of the systematic literature review.

#### *Inclusion criteria:*

- Original peer reviewed studies about family caregivers' experiences of caring for an older family member from a minority ethnic group living with dementia or cognitive impairment
- Research about family caregiving approaches
- Articles published in English or in a Scandinavian language (Danish, Norwegian or Swedish)
- Available in full text
- Research study conducted in a European context
- Published between 2010 and 2021

#### *Exclusion criteria:*

- Articles published before 2010
- Studies with no English translation available
- Not in the European context
- Review articles, meta-analyses, meta-syntheses
- Conference papers, posters, editorials, protocols
- Books, book chapters, theses

The citations were transferred into an EndNote library and duplicates were removed by the librarians, using Endnote's duplicate identification strategy.

### **3.5 Study selection and review process**



All qualitative empirical research that explored or examined data about family caregivers' experiences with providing care to home-dwelling older people from minority ethnic groups living with dementia was included. The review process was conducted in three steps:

- Step 1: Screening titles

After removing the duplicates, a total of 2,463 citations were initially identified for possible inclusion through the systematic search of databases. The first author screened the titles and citations that were books, book chapters, review articles, conference papers, posters, editorials, PhD theses or protocols. These were excluded. The first author then excluded a further 100 articles after they were assessed for eligibility.

- Step 2: Reading abstracts

The review consisted of 380 articles to be appraised by all four authors. Responsibility for screening the abstracts was shared by all four authors. Three authors screened the titles and abstracts of 100 articles each and one author screened 80 articles. The authors applied the inclusion and exclusion criteria by firstly reading the title followed by the abstract, and then excluding the articles that were not relevant to the research question. During this step, 3 articles were excluded for not meeting the inclusion criteria. This included not being original studies (N = 36), not conducted within a European context (N = 277), not at convenience sampling (N = 27), or after a full-text reading (N = 26). The authors entered the information into a charting form using an Excel file with columns for data variables to describe the articles identified for the present study. The data recorded from each article included the following characteristics: author(s), year of publication, country of origin, title, aim of the study, research design, data collection methods, sample, results, included/excluded.

- Step 3: Reading full-text articles and data extraction

All authors discussed the information included in their charting form and after reaching consensus, a final charting form was eventually corroborated. The full-text review resulted 14

articles. The first author read all of the full-text articles. Each article was read thoroughly, and all pertinent information was extracted. Articles reporting on the same study but describing different or new findings were included as separate sources (Berdai Chaouni & De Donder, 2019; Berdai Chaouni et al., 2020; Hossain, 2021; Hossain & Khan, 2019). In addition to study characteristics, data extraction was conducted by focusing on the aim of the present study, hence assessing similarities or/and differences between the studies included. A flow chart describing the selection of the studies is presented in Figure 1.

Figure 1 should be included here:

.....

### **3.6 Quality assessment of the articles**

To rate the quality of the articles, the authors used the standardised assessment tool Mixed Methods Appraisal Tool (MMAT, version 2018), as described by Hong et al. (2018).

The MMAT includes a total of 25 criteria and two screening questions. As in the previous version, the MMAT can appraise five different categories of study designs: (a) qualitative, (b) randomized controlled, (c) nonrandomized, (d) quantitative descriptive and (e) mixed methods. Each category has five core quality criteria rated as ‘yes’, ‘no’ or ‘can't tell’. All 14 reviewed and included articles were rated as high-quality studies, meeting all five quality criteria for qualitative studies.

## **4. RESULTS**

To address the research question, the characteristics of the included articles are presented in detail, including a synthesis of their findings.

### **4.1 Characteristics of the included studies**

Although all of the studies included are qualitative by research design, they vary in terms of the year of publication, country, aim, sample and data collection methods. An overview of the included studies' characteristics is presented in Table 2.

Table 2 should be included here: .....

*Year of publication:* The articles included in the current review were published between 2011 and 2021, and, due to relatively recent research interest in the topic, peak at eleven articles published in the last five years (Figure 2).

Figure 2 should be included here: .....

Two authors, one from Belgium (Berdai Chaouni & De Donder, 2019; Berdai Chaouni et al., 2020) and one from the UK (Hossain, 2021; Hossain & Khan, 2019) have published two articles originating from the same study.

*Country of origin:* The studies were conducted in a European country (Belgium, N = 2; Denmark, N = 1; Germany, N = 1; The Netherlands, N = 2; Norway, N = 1; UK, N = 6; Sweden, N = 1), as shown in Figure 3.

Figure 3 should be included here: .....

Most of the studies came from the UK. This country is well known for its increased level of migration, shaped by its past imperial history and colonisation of different parts of the world, resulting in large immigration movements from the mid-20<sup>th</sup> century onwards (Shankley et al., 2020).

*Aim and research design:* All of the articles included in the current review are qualitative studies with a qualitative explorative or descriptive design. They explore or describe the experiences, perspectives or views of family caregivers from minority groups who provide care to a family member living with dementia. One study (Parveen et al., 2018) also evaluates whether the Information Programme for South Asian families had an immediate and medium-term impact on the lives of carers/relatives. One of the two studies conducted by the same researchers additionally explores family carers' knowledge about dementia (Hossain & Khan, 2019), while the other identifies factors that may have an impact on caregiving and

categorises the effects of caregiving on the health and well-being of Bangladeshi family caregivers (Hossain, 2021).

*Sample:* In total, 314 family members who provide care to a family member with dementia from a minority ethnic group participated in the 14 studies. Five of the studies (Baghirathan et al., 2018; Berdai Chaouni & De Donder, 2019; Berdai Chaouni et al., 2020; Nielsen et al., 2020; Sagbakken et al., 2018) have a mixed sample consisting of both family caregivers and healthcare professionals (N = 65). Most family caregivers participating in the studies lived in the same house as the person with dementia, with only a few living separately. With the exception of two studies (Ahmad et al., 2019; van Wezel et al., 2016), where the sample only comprised women, the studies included both male and female participants. However, the number of female participants was predominant (Baghirathan et al., 2018; Berdai Chaouni & De Donder, 2019; Hossain, 2021; Nielsen et al., 2020; Parveen et al., 2018; Sagbakken et al., 2018).

Eight studies (Ahmad et al., 2019; Baghirathan et al., 2018; Berdai Chaouni & De Donder, 2019; Berdai Chaouni et al., 2020; Herat-Gunaratne et al., 2020; Monsees et al., 2020; Nielsen et al., 2020) provide complete demographic information about the family caregiver, for example, age, gender, ethnicity, education level, living arrangements, socioeconomic profile, and relation to the older person with dementia. Five studies only provide the family caregivers' ethnicity, age, gender, and relation to the older person with dementia (Botsford et al., 2012; Hossain, 2021; Hossain & Khan, 2019; Mazaheri et al., 2011; Parveen et al., 2018; Sagbakken et al., 2018). Four studies (Baghirathan et al., 2018; Hossain, 2021; Hossain & Khan, 2019; Parveen et al., 2018) do not report the age of the study participants. Only one study (Botsford et al., 2012) has a sample solely comprising spouses. The sample used in the other studies is comprised of spouses, adult children, children-in-law or siblings.

All of the studies provide the family caregivers' ethnicity, cultural group or nationality. Six studies focus on only one cultural group. These were reported by nationality, for example, Bangladeshi (Hossain, 2021; Hossain & Khan, 2019), Iranian (Mazaheri et al., 2011), Moroccan (Berdai Chaouni & De Donder, 2019; Berdai Chaouni et al., 2020) or Turkish (Monsees et al., 2020). Three studies only focus on one ethnic or cultural group, for example, BAME (Black, Asian, and other Minority Ethnic), which includes South Asian, African Caribbean and Chinese communities (Baghirathan et al., 2018) or just South Asian including people with Indian, Pakistani or Bangladesh heritage (Herat-Gunaratne et al., 2020; Parveen et al., 2018). Four studies include more than one ethnic or national group: Turkish, Moroccan and Surinamese Creole (van Wezel et al., 2016), Greek Cypriot and African Caribbean (Botsford et al., 2012), Chinese, Indian Surinamese, Moroccan-Berber, Moluccan and Turkish (Ahmad et al., 2019) or several countries of origin: Afghanistan, Pakistan, China, Vietnam, Turkey, Lebanon, Sri Lanka and Chile (Sagbakken et al., 2018).

*Data collection and analysis methods:* Although a purposeful sampling strategy is employed in all of the studies, some studies found it necessary to employ a combination of purposive and snowball sampling since the target population was hard to reach (Baghirathan et al., 2018; Hossain, 2021; Hossain & Khan, 2019; Monsees et al., 2020). Most studies employed face-to-face, semi-structured, in-depth interviews and/or focus group interviews/discussions. The data analysis process varied, but thematic or qualitative content analysis were commonly used. Two studies (Baghirathan et al., 2018; Botsford et al., 2012) generated grounded theories. One study (Ahmad et al., 2019) used Hochschild's interpretative framework of framing and feeling rules.

#### **4.2 Data synthesis**

The purpose of synthesising the data was to classify how the literature addresses the research question. Inspired by Sandelowski and Barroso (2003), the data synthesis process consisted of

collating and summarising similarities and/or differences between the studies' findings.

Although five of the studies present findings that were also generated from interviewing healthcare professionals or volunteers in addition to family caregivers, only data generated from family caregivers were extracted, analysed, and included in the synthesis. The extracted data were synthesised, and the findings were framed under the following four themes:

controversies and challenges; a lack of health literacy; barriers to seeking support from the healthcare or social services; and models of care (Table 3). The researchers considered the characteristics of the included studies and discussed the themes until consensus was reached.

Table 3 should be included here: .....

*Controversies and challenges:* The review of the findings revealed a number of controversies and challenges as regards how family members perceive their own role and their experience of providing care to an older person with dementia from a minority ethnic group. The controversies concerned family caregivers feeling a combination of reciprocal love, filial responsibility and religious duty (Ahmad et al., 2019; Herat-Gunaratne et al., 2020; van Wezel et al., 2016), devotion (Berdai Chaouni & De Donder, 2019) and fulfilling life experiences (Mazaheri et al., 2011). In most of the studies, family caregivers refer to the positive aspects of being the primary caregiver for their family member with dementia (Mazaheri et al., 2011), such as being 'satisfying even if it's a heavy burden' (van Wezel et al., 2016, p. 78) or as a continuation of their identity as a partner (Botsford et al., 2012).

However, some of the findings also reveal that caregiving was simply perceived as a duty that gradually became a hardship and unbearable, leading to feelings of disappointment (Ahmad et al., 2019), loneliness (van Wezel et al., 2016), a physical, psychological and socioeconomic burden, and eventually social isolation and dislocation from the community (Hossain, 2021; Nielsen et al., 2020).

*Lack of health literacy:* The findings also revealed challenges concerning families from minority ethnic groups' health literacy in relation to how they address dementia, and some demonstrated a lack of knowledge about the dementia condition. Although dementia was seen as a medical condition (Hossain & Khan, 2019) or a normal consequence of aging (Berdai Chaouni & De Donder, 2019; Botsford et al., 2012), findings from several studies show that the dementia condition could also be framed within the context of superstition (Baghirathan et al., 2018). This concerned perceiving the condition as 'madness', forgetfulness', or 'losing their memory' in old age (Hossain & Khan, 2019), and the people who had dementia as being 'crazy' or 'mad' (Botsford et al., 2012). This could lead to family caregivers hiding the condition and the older person with dementia from the outside world (Hossain, 2021). Mazaheri et al. (2011) revealed that the participants in their study considered dementia to be a transient condition and that if they provided appropriate care and support, the condition could be overcome.

*Barriers to seeking support from the healthcare or social services:* A lack of health literacy about dementia and its consequences (Hossain & Khan, 2019) among families from minority ethnic groups led to a reluctance among the family caregivers to ask for support due to the risk of being 'diminished' by the local community or encountering healthcare services that did not understand their needs (Baghirathan et al., 2018). Other reasons for not requesting support from the healthcare or social services included the family caregivers experiencing unsatisfactory service organisation (Herat-Gunaratne et al., 2020) or discriminatory and stereotyping attitudes from the healthcare services, as well as not receiving practical support when they needed it (Hossain, 2021). Another perceived barrier was linked to a fear of what other people might think (Monsees et al., 2020) and hence stigmatisation (Baghirathan et al., 2018; Berdai Chaouni & De Donder, 2019). This not only concerned the family member with dementia, but the whole family, thus posing a risk of the daughters in the family not being

married (Hossain & Khan, 2019). The caregivers' expectations of themselves could also entail a barrier (Herat-Gunaratne et al., 2020) in relation to them being able to take care of 'their own' or else feeling guilt or shame (Sagbakken et al., 2018), or a fear of not being perceived as 'good children' if they did not take care of their parents in old age (Nielsen et al., 2020). Seeking help from healthcare services could hence be considered a sign of failure (Ahmad et al., 2019). Having insufficient knowledge or not being aware of the existence of healthcare services was also a reason why family caregivers did not request support (Berdai Chaouni & De Donder, 2019). Although these findings describe several barriers to asking for support from the healthcare services, studies have also revealed that the healthcare services are nonetheless utilised by this group (Hossain, 2021; Monsees et al., 2020; Nielsen et al., 2020; Parveen et al., 2018; Sagbakken et al., 2018).

*Models of care:* Overall, the findings revealed a traditional family-oriented model of care provision for the family member with dementia. The majority of the caregivers lived with the family member and provided care for them in the person's own home (Ahmad et al., 2019; Herat-Gunaratne et al., 2020; Hossain, 2021; van Wezel et al., 2016), hence demonstrating a strong family-centred orientation to the relationship between the family members (Botsford et al., 2012). Sagbakken et al. (2018) also describe a similar model of care where extended family members lived together and shared the responsibility for providing extensive care to the person with dementia. In other cases, the family member with dementia was moved between their relatives' homes, a caring model Nielsen et al. (2020) refer to as 'rotational 24-hour care', which is also presented in the study conducted by Herat-Gunaratne et al. (2020). While the aforementioned family caring models were most commonly employed, Berdai Chaouni et al. (2020) also revealed other alternative care options for the older family member with dementia, such as employing undocumented domestic helpers from their native country



to care for the older family member with dementia, sending the person with dementia to their native country for a short stay or even entering into a care marriage.

## **5 DISCUSSION**

The literature review provides an overview of current knowledge about the experiences of family caregivers providing care to home-dwelling older people from minority ethnic groups living with dementia within the European context. The review also presents the characteristics and findings of a heterogeneous sample of studies, drawing a complex picture of expectations and practices rooted in cultural values and traditions, communication, and language barriers. The synthesis of the findings shows that caring for older people with dementia from minority ethnic groups reflects a dual reality.

On the one hand, the current review highlights the value of being able to care for a family member living with dementia (Ahmad et al., 2019; Berdai Chaouni & De Donder, 2019; Herat-Gunaratne et al., 2020; Hossain, 2021). This was often grounded in cultural and religious norms. By employing different models of family care, the family caregivers, when they were adult children, could reciprocate parental supporting during their childhood (Ahmad et al., 2019; Nielsen et al., 2020), while when the caregivers were spouses, they perceived it as a natural and expected role in the course of married life (Botsford et al., 2012; Mazaheri et al., 2011).

On the other hand, several studies also reveal the physical, emotional, and socioeconomic burden experienced by caregivers in this situation (Ahmad et al., 2019; Berdai Chaouni & De Donder, 2019; Berdai Chaouni et al., 2020; Hossain, 2021; Hossain & Khan, 2019). These findings are also supported by the findings from a systematic review conducted by de Souza Alves et al. (2019) that aimed to identify the consequences of Burnout Syndrome among the informal caregivers of older adults living with dementia. The findings demonstrate that family caregivers suffer from burnout due to social isolation, poor health, and negative

future perspectives. One explanation may be that, among the sample of caregivers themselves, there are notable gender disparities in the distribution of caregiving duties and intensity, where women predominantly took on the role of the caregivers. In line with findings from de Souza Alves et al. (2019), the studies in the present review showed a higher prevalence of female caregivers, most of whom were daughters, daughters-in-law or wives. This may be related to cultural norms and an expectation that female family members should care for family members with dementia. Similar findings are presented in a study conducted by Sanjana et al. (2020) exploring female Pakistani carers' views of future care and healthcare accessibility for their older relatives living in Norway, which found that they felt responsible for their older family members' care, even though formal care options were available.

Most of the caregivers participating in the studies included in the present review were adult daughters, and this may be explained as a matter of family hierarchy. According to de Souza Alves et al. (2019), if the older person with dementia's wife was unable to provide care, their older daughters assumed this role, especially if they were not married, if they had caregiving experience or if they lived close by.

Gender norms in caregiving among immigrant communities, and the fact that women often ending up caring for both male and female relatives, particularly affects daughters and daughters-in-law who are often expected to provide such care, despite potentially coming into conflict with their childrearing responsibilities. Similar findings have also been presented in previous empirical studies (De Tavernier & Draulans, 2019). A review conducted by Johl et al. (2016) also shows that caregiving was seen as an extension of an existing responsibility, especially among female family members, thus delaying professional help-seeking and finding appropriate and effective support. The reasons behind this barrier to early help-seeking may be that the diagnosis did not change the family members' feelings of familial obligations and duties. This finding is similar to those presented in an empirical study by

Mukadam et al. (2011) exploring the link between attitudes to help-seeking for dementia and the help-seeking pathway in the minority ethnic and indigenous population in the UK.

However, according to Hossain et al. (2019), socioeconomic transformations in South Asian women's migration to Western countries may contribute to deterring them from providing family care. There is therefore a shift in women's attitudes towards caregiving in the UK. This proves that, although these changes are minor and do not include family caregivers from all minority ethnic groups, there are constant developments as regards attitudes towards family caregiving among these groups.

The review also revealed that the motivation to provide care to a family member living with dementia, despite facing controversies and challenges, was also determined by a fear of encountering stigma among relatives and in the community for failing to provide such care. This may be another explanation for why caregivers feel a physical and emotional burden, as they perceive placing their family member in a nursing home or receiving help from the home care services to be a failure. The fear of being stigmatised or diminished by other family members or the healthcare service staff delayed the process diagnosing the dementia, thus leading to isolation, not only for the family member with dementia but also for the family caregivers. In a recent study, Ryan (2021) presents several emotional barriers to utilising healthcare services among family caregivers in the Republic of Ireland. These include a fear of stigmatisation, feelings of embarrassment and a sense of obligation to provide care regardless of the family's ethnicity. However, similar to the findings of Johl et al. (2016), the current literature review reveals that family caregivers do not perceive the healthcare and social services to be culturally sensitive and sufficiently adapted to their needs. In addition, negative experiences such as discrimination, language barriers or a lack of clarity about where or how to access help, have been barriers to family caregivers seeking support from the healthcare and social services.

Another such barrier was also caused by a lack of health literacy among families from minority ethnic groups about dementia and failure to understand it as a medical condition. According to Lo (2019), there is little consensus on the definition of dementia literacy. However, Low and Anstey (2009) propose that dementia literacy is the 'knowledge and beliefs regarding dementia that aid recognition, management, or prevention' (p. 43). A lack of health literacy among family caregivers from minority ethnic groups in relation to dementia could be explained by their culturally based perceptions of the dementia condition as something that, for example, is part of the normal ageing process or a condition potentially caused by evil spirits. Understanding dementia science may thus influence how healthcare services can effectively translate state-of-the-art diagnostics and therapeutics into patient care, thereby preventing the physical, emotional, and socioeconomic burden experienced by family caregivers.

In their reluctance to receive help from the healthcare services, family caregivers risk exposing the family member with dementia to a gap between inaccessible provision of adequate care and the fragmentation of traditional family caregiving. In their continuous search for care solutions, new forms of culturally and religiously acceptable models of care have evolved. To accommodate their individual, social and working lives, family members have developed innovative rotating care patterns regardless of whether this responsibility originated from a sense of shared filial obligation or the wider family's gendered expectations that older daughters or daughters-in-law would provide care. Family caregivers who do not have a shared care arrangement between the family members must provide the care themselves, with help from undocumented domestic helpers, or in extreme situations, by sending the person to their country of origin for a short stay or organising a care marriage. It is important to note that, regardless of ethnicity or immigrant status, similar family caregiving models that prioritise obtaining help from private-pay home carers or helpers, rather than

from the public healthcare and social services, is also a preferred caregiving option in several South European countries including Malta, Italy, Spain and Greece (Innes et al., 2011). As Nielsen et al. (2020) asserted, such care arrangements are extremely rare in Denmark, one of the Scandinavian countries that adheres to the Nordic welfare state model (Pedersen & Kuhnle, 2017), with free access to medical and social care for all legal residents. These differences in care arrangements among family caregivers from different parts of Europe are also supported by findings in Chiatti et al.'s (2018) study, revealing that Swedish participants more frequently utilised healthcare and social services than Italian participants, who thus spent more time on caregiving.

### **5.1 Strengths and limitations of the study**

This review has several strengths. Firstly, it employs systematic methods and multiple sources to identify relevant studies. The reference lists of the relevant empirical studies were also examined in order to identify other studies not captured by the database search. Secondly, the MMAT was used to assess the quality of the studies to allow different study designs to be included in the review. However, given the aim of the review – to explore the family caregivers' experiences – only qualitative studies were included. This could be perceived as both a strength and a limitation. Including studies with a quantitative research design could have generated other types of knowledge that, together with the synthesis from qualitative studies, could enrich the knowledge about family members' experiences of providing care to home-dwelling older people with dementia from minority ethnic groups.

One potential limitation of the review concerns the inclusion of articles in which the primary study was solely conducted in the European context. However, while the phenomenon of migration in other parts of the world, such as Canada, Australia or the USA, is seen as an important part of the country's history that contributed to the formation of the nation (Fukuyama & Gocek, 2019), migration in Europe is a new phenomenon that started in

the period after the Second World War (Van Mol & de Valk, 2016). Consequently, an abundance of the empirical research studies on similar topics are from the USA (Liu et al., 2020), Canada (Koehn et al., 2019) or Australia (Benedetti et al., 2013), while few research studies from Europe were registered during the literature search. Given the political and socio-economic impacts of migration, regardless of the reasons, on European countries (Guzi et al., 2021), it was a deliberate choice to only include studies conducted in the European context in order to reveal current knowledge on the experiences of family caregivers within the setting of this study. However, it is a limitation that all of the studies included in the review target countries in Northern and Central Europe, with countries in Southern Europe remaining unexplored. This means that knowledge about family caregivers' experiences with providing care to a family member from a minority ethnic group living with dementia remains fragmented.

Another potential limitation is that the search strategy only included studies that reflect family caregivers' experiences. Although five of the studies have samples comprising healthcare personnel and volunteers, in addition to family members, only the findings generated from family members were assessed and synthesised. Consequently, the findings presented in the current review do not offer insight into formal carers' experiences of providing care to home-dwelling older people with dementia from minority ethnic groups.

Finally, the inclusion of grey literature could also be deemed a limitation. Grey literature was not examined and there was therefore a risk of overlooking relevant findings. However, all of the alerts the researchers received by e-mail were thoroughly reviewed by the first author and, if relevant, included in the study (e.g., Sagbakken et al., 2018).

## **6 CONCLUSION**

The current review shows that family caregivers who provide care to home-dwelling older people with dementia from minority ethnic groups experience a dual reality as regards their

caregiver role. Although providing care to a family member with dementia generates positive feelings, there proved to be many controversies and challenges that led to the family caregivers, who were mostly women, experiencing the role as a physical, emotional, and socioeconomic burden.

The review also revealed that family caregivers often choose not to seek support from the public healthcare and social services, despite the services being readily available and easy to obtain. This was due to a lack of dementia health literacy, a fear of stigmatisation and being diminished by other family members and the community, as well as not perceiving the healthcare services as culturally sensitive and sufficiently adapted to their needs. Although family caregivers were aware of the consequences of living with a family member with dementia, they wished to take care of 'their own'. This generated several models of caregiving, including extended family members living together, rotational 24-hour care, bringing in undocumented domestic helpers, care marriages or sending the person with dementia to their country of origin for a short stay.

## **7 RELEVANCE TO CLINICAL PRACTICE**

The current review can inform institutional policies in relation to identifying models of care that comprise an appropriate balance between what the healthcare and social services can offer and what family caregivers need help with. This would in turn provide services that meet the caregivers' needs for appropriate support when providing care to a family member with dementia from a minority ethnic background. Moreover, the findings can help healthcare and social services to adopt care strategies that are sensitive to issues related to migration-, culture-, and religion, thus showing family caregivers possibilities and examples of how care responsibilities can be shared to complement their caregiving role and reduce the burden of care.

## **Acknowledgments**

The authors sincerely thank the research librarians (E.K., C.T., & M.W.G.) at Oslo Metropolitan University for their help with the search process.

### **Conflict of interest**

The authors declare no conflict of interest.

### **Funding sources**

No external funding.

### **References**

- Ahmad, M., van den Broeke, J., Saharso, S., & Tonkens, E. (2019). Persons With a Migration Background Caring for a Family Member With Dementia: Challenges to Shared Care. *The Gerontologist*, *60*(2), 340-349. <https://doi.org/10.1093/geront/gnz161>.
- Baghirathan, S., Cheston, R., Hui, R., Chacon, A., Shears, P., & Currie, K. (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. *Dementia*, *19*(5), 1672-1691. <https://doi.org/10.1177/1471301218804714>.
- Bature, F., Guinn, B.-A., Pang, D., & Pappas, Y. (2017). Signs and symptoms preceding the diagnosis of Alzheimer's disease: a systematic scoping review of literature from 1937 to 2016. *BMJ open*, *7*(8), e015746-e015746. <https://doi.org/10.1136/bmjopen-2016-015746>.
- Benedetti, R., Cohen, L., & Taylor, M. (2013). "There's really no other option": Italian Australians' experiences of caring for a family member with dementia. *Journal of Women & Aging*, *25*(2), 138-164. <https://doi.org/10.1080/08952841.2013.760330>.



- Berdai Chaouni, S., & De Donder, L. (2019). Invisible realities: Caring for older Moroccan migrants with dementia in Belgium. *Dementia (London)*, 18(7-8), 3113-3129.  
<https://doi.org/10.1177/1471301218768923>.
- Berdai Chaouni, S., Smetcoren, A.-S., & De Donder, L. (2020). Caring for migrant older Moroccans with dementia in Belgium as a complex and dynamic transnational network of informal and professional care: A qualitative study. *International Journal of Nursing Studies*, 101, 103413.  
<https://doi.org/https://doi.org/10.1016/j.ijnurstu.2019.103413>.
- Botsford, J., Clarke, C. L., & Gibb, C. E. (2012). Dementia and relationships: experiences of partners in minority ethnic communities. *Journal of Advanced Nursing*, 68(10), 2207-2217. <https://doi.org/https://doi.org/10.1111/j.1365-2648.2011.05905.x>.
- Bremer, P., Challis, D., Hallberg, I. R., Leino-Kilpi, H., Saks, K., Vellas, B., Zwakhalen, S. M. G., & Sauerland, D. (2017). Informal and formal care: Substitutes or complements in care for people with dementia? Empirical evidence for 8 European countries. *Health Policy*, 121(6), 613-622. <https://doi.org/10.1016/j.healthpol.2017.03.013>.
- Cherry, M. G., Taylor, P. J., Brown, S. L., Rigby, J. W., & Sellwood, W. (2017). Guilt, shame and expressed emotion in carers of people with long-term mental health difficulties: A systematic review. *Psychiatry Research*, 249, 139-151.  
<https://doi.org/10.1016/j.psychres.2016.12.056>.
- Chiatti, C., Rodríguez Gatta, D., Malmgren Fänge, A., Scandali, V. M., Masera, F., Lethin, C., On behalf of the, Up-Tech Tech Home research groups (2018). Utilization of Formal and Informal Care by Community-Living People with Dementia: A Comparative Study between Sweden and Italy. *International Journal of Environmental Research and Public Health*, 15(12).  
<https://doi.org/10.3390/ijerph15122679>.

de Souza Alves, L. C., Monteiro, D. Q., Bento, S. R., Hayashi, V. D., Pelegrini, L. N. C., &

Vale, F. A. C. (2019). Burnout syndrome in informal caregivers of older adults with dementia: A systematic review. *Dementia & Neuropsychologia*, 13(4), 415-421.

<https://doi.org/10.1590/1980-57642018dn13-040008>.

De Tavernier, W., & Draulans, V. (2019). Negotiating informal elder care, migration and

exclusion: the case of a Turkish immigrant community in Belgium. *International Journal of Ageing and Later Life*, 12(2), 89-117.

<https://doi.org/https://doi.org/10.3384/ijal.1652-8670.18404>.

European Union (n.d.). *immigrant*. Retrieved 15.09.2021 from: [immigrant \(europa.eu\)](http://immigrant.europa.eu)

European Union (n.d.). *minority*. Retrieved 15.09.2021 from: [minority \(europa.eu\)](http://minority.europa.eu).

Fukuyama, F., & Gocek, N. (2019). *Immigration and populism in Canada, Australia, and the*

*United States*. Center on Democracy, Development and the Rule of Law. Freeman

Spogli Institute for International Studies. [https://fsi-live.s3.us-west-](https://fsi-live.s3.us-west-1.amazonaws.com/s3fs-public/immigration_and_populism_in_canada1_3.pdf)

[1.amazonaws.com/s3fs-public/immigration\\_and\\_populism\\_in\\_canada1\\_3.pdf](https://fsi-live.s3.us-west-1.amazonaws.com/s3fs-public/immigration_and_populism_in_canada1_3.pdf).

Gallagher-Thompson, D. (2006). The family as the unit of assessment and treatment in work

with ethnically diverse older adults with dementia. In G. Yeo & D. Gallagher-

Thompson (Eds.). *Ethnicity and the Dementias*. London: Routledge.

Guzi, M., Kahanek, M., & Ulceluse, M. M. (2021). Europe's Migration Experience and its

Effects on Economic Inequality. In G. Fisher & R. Strauss (Eds.). *Europe's Income,*

*Wealth, Consumption, and Inequality* (pp. 1-37). Oxford University Press.

<https://doi.org/10.1093/oso/9780197545706.003.0014>.

Hamer, K., McFarland, S., Czarnecka, B., Golińska, A., Cadena, L. M., Łuzniak-Piecha, M.,

& Jułkowski, T. (2020). What Is an "Ethnic Group" in Ordinary People's Eyes?

Different Ways of Understanding It Among American, British, Mexican, and Polish

Respondents. *Cross-Cultural Research*, 54(1), 28-72.

<https://doi.org/10.1177/1069397118816939>.

Herat-Gunaratne, R., Cooper, C., Mukadam, N., Rapaport, P., Leverton, M., Higgs, P., Samus, Q., & Burton, A. (2020). "In the Bengali Vocabulary, There Is No Such Word as Care Home": Caring Experiences of UK Bangladeshi and Indian Family Carers of People Living With Dementia at Home. *Gerontologist*, 60(2), 331-339.

<https://doi.org/10.1093/geront/gnz120>.

HOD (2017). "Living the entire life" - a quality reform for older people. Norwegian Ministry of Health and Care Services [In Norwegian]. Retrieved 10.02.2021 from:

<https://www.regjeringen.no/no/aktuelt/dep/hod/nett-tv/nett-tv-leve-hele-livet---kvalitetsreform-for-eldre/id2540935/>.

Hong, Q. N., Fàbregues, S., Bartlett, G., Boardman, F., Cargo, M., Dagenais, P., Gagnon, M.-P., Griffiths, F., Nicolau, B., O' Cathain, A., Rousseau, M.-C., Vedel, I., & Pluye, P. (2018). The Mixed Methods Appraisal Tool (MMAT) version 2018 for information professionals and researchers. *Education for information*, 34(4), 285-291.

<https://doi.org/10.3233/EFI-180221>.

Hossain, M. Z. (2021). The Costs of Caregiving: Exploring the Perceived Burden of Dementia among Bangladeshi Caregivers in Britain. *The American Journal of Family Therapy*, 49(1), 91-108. <https://doi.org/10.1080/01926187.2020.1777911>.

Hossain, M. Z., & Khan, H. T. A. (2019). Dementia in the Bangladeshi diaspora in England: A qualitative study of the myths and stigmas about dementia. *Journal of Evaluation in Clinical Practice*, 25(5), 769-778. <https://doi.org/10.1111/jep.13117>.

Ingebretsen, R. (2020). Dementia in older immigrants and families' role and needs [In Norwegian]. Demens hos eldre innvandrere, og familiens rolle og behov. In A. O. Berg & K. Holt (Eds.). *Culture and context in practical psychological work* [In

- Norwegian]. *Kultur og kontekst i praktisk psykologarbeid*. Oslo: Gyldendal Norsk Forlag.
- Innes, A., Abela, S., & Scerri, C. (2011). The organisation of dementia care by families in Malta: The experiences of family caregivers. *Dementia*, *10*(2), 165-184. <https://doi.org/10.1177/1471301211398988>.
- Johl, N., Patterson, T., & Pearson, L. (2016). What do we know about the attitudes, experiences and needs of black and minority ethnic carers of people with dementia in the United Kingdom? A systematic review of empirical research findings. *Dementia (London)*, *15*(4), 721-742. <https://doi.org/10.1177/1471301214534424>.
- Kavli, H. C., & Nadim, M. (2009). *Family practices and gender equality in immigrant families* [In Norwegian]. *Familiepraksis og likestilling i innvandrede familier*. FAFO-report 2009: 39. Institute for Labour and Social Research (FAFO).
- Koehn, S. D., Donahue, M., Feldman, F., & Drummond, N. (2019). Fostering trust and sharing responsibility to increase access to dementia care for immigrant older adults. *Ethnicity & Health*, 1-17. <https://doi.org/10.1080/13557858.2019.1655529>.
- Lanari, D., Bussini, O., & Minelli, L. (2018). The Effects of Immigrant Status and Age at Migration on Changes in Older Europeans' Health. *International Migration Review*, *52*(4), 1218-1249. <https://doi.org/10.1177/0197918318766359>.
- Liu, J., Lou, Y., Wu, B., & Mui, A. C. Y.-S. (2020). "I've been always strong to conquer any suffering:" challenges and resilience of Chinese American dementia caregivers in a life course perspective. *Aging & Mental Health*, 1-9. <https://doi.org/10.1080/13607863.2020.1793900>.
- Lo, R. Y. (2019). Uncertainty and health literacy in dementia care. *Ci ji yi xue za zhi = Tzu-chi medical journal*, *32*(1), 14-18. [https://doi.org/10.4103/tcmj.tcmj\\_116\\_19](https://doi.org/10.4103/tcmj.tcmj_116_19).

- Low, L. F., & Anstey, K. J. (2009). Dementia literacy: recognition and beliefs on dementia of the Australian public. *Alzheimers Dement*, 5(1), 43-49.  
<https://doi.org/10.1016/j.jalz.2008.03.011>.
- Mazaheri, M., Sunvisson, H., Nasrabadi Nikbakht, A., Sadat Madah, M., & Emami, A. (2011). Bearing witness to life narratives: Iranian immigrant experiences of taking care of a family member with dementia. *Diversity & Equality in Health and Care*, 8, 19-28. <https://diversityhealthcare.imedpub.com/bearing-witness-to-life-narratives-iranian-immigrant-experiences-of-taking-care-of-a-family-member-with-dementia.php?aid=1907>.
- Monsees, J., Schmachtenberg, T., Hoffmann, W., Kind, A., Gilmore-Bykovskyi, A., Kim, A. J., & Thyrian, J. R. (2020). Dementia in People with a Turkish Migration Background: Experiences and Utilization of Healthcare Services. *Journal of Alzheimer's Disease*, 77(2), 865-875. <https://doi.org/10.3233/jad-200184>.
- Mukadam, N., Cooper, C., Basit, B., & Livingston, G. (2011). Why do ethnic elders present later to UK dementia services? A qualitative study. *International Psychogeriatrics*, 23(7), 1070-1077. <https://doi.org/10.1017/s1041610211000214>.
- Nielsen, T. R., Waldemar, G., & Nielsen, D. S. (2020). Rotational care practices in minority ethnic families managing dementia: A qualitative study. *Dementia*, 20(3), 884-898. <https://doi.org/10.1177/1471301220914751>.
- Northwood, M., Ploeg, J., Markle-Reid, M., & Sherifali, D. (2018). Integrative review of the social determinants of health in older adults with multimorbidity. *Journal of Advanced Nursing*, 74(1), 45-60. <https://doi.org/doi:10.1111/jan.13408>.
- Oxford Learner's Dictionaries (n.d.). *Ethnic group*. Retrieved 15.09.2021 from: <https://www.oxfordlearnersdictionaries.com/definition/english/ethnic-minority?q=ethnic+minority>.

- Page, M. J., McKenzie, J. E., Bossuyt, P. M., Boutron, I., Hoffmann, T. C., Mulrow, C. D., Shamseer, L., Tetzlaff, J. M., Akl, E. A., Brennan, S. E., Chou, R., Glanville, J., Grimshaw, J. M., Hróbjartsson, A., Lalu, M. M., Li, T., Loder, E. W., Mayo-Wilson, E., McDonald, S., McGuinness, L. A., Stewart, L. A., Thomas, J., Tricco, A. C., Welch, V. A., Whiting, P., & Moher, D. (2021). The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. *BMJ*, *372*, n71. <https://doi.org/10.1136/bmj.n71>.
- Parveen, S., Blakey, H., & Oyeboode, J. R. (2018). Evaluation of a carers' information programme culturally adapted for South Asian families. *International Journal of Geriatric Psychiatry*, *33*(2), e199-e204. <https://doi.org/10.1002/gps.4768>.
- Pavli, A., & Maltezou, H. (2017). Health problems of newly arrived migrants and refugees in Europe. *Journal of travel medicine*, *24*(4). <https://doi.org/10.1093/jtm/tax016>.
- Pedersen, A. W., & Kuhnle, S. (2017). The Nordic welfare state model In: O. P. Knutsen (Ed.). *The Nordic Models in Political Science: Challenged, but Still Viable?* (pp. 249-272). Oslo: Fagbokforlaget.
- Plejert, C., Jansson, G., & Yazdanpanah, M. (2014). Response practices in multilingual interaction with an older Persian woman in a Swedish residential home. *Journal of cross-cultural gerontology*, *29*(1), 1-23. <https://doi.org/10.1007/s10823-013-9217-2>.
- Ryan, L. (2021). Accessing community dementia care services in Ireland: Emotional barriers for caregivers. *Health & Social Care in the Community*, *00*, 1-10. <https://doi.org/https://doi.org/10.1111/hsc.13342>.
- Sagbakken, M., Spilker, R. S., & Ingebretsen, R. (2018). Dementia and Migration: Family Care Patterns Merging With Public Care Services. *Qualitative Health Research*, *28*(1), 16-29. <https://doi.org/10.1177/1049732317730818>.

- Sales, E. (2003). Family burden and quality of life. *Quality of Life Researchs*, 12 Suppl 1, 33-41. <https://doi.org/10.1023/A:1023513218433>.
- Sandelowski, M., & Barroso, J. (2003). Classifying the Findings in Qualitative Studies. *Qualitative Health Research*, 13(7), 905-923. <https://doi.org/10.1177/1049732303253488>.
- Sanjana, A., Bernd, R., Bergland, A., Straiton, M., & Debesay, J. (2020). Female Pakistani carers' views on future formal and informal care for their older relatives in Norway. *BMC Health Services Research*, 20(1), 603. <https://doi.org/10.1186/s12913-020-05468-z>.
- Shankley, W., Hannemann, T., & Simpson, L. (2020). The demography of ethnic minorities in Britain. In B. Byrne, C. Alexander, O. Khan, J. Nazroo, & W. Shankley (Eds.), *Ethnicity, Race and Inequality in the UK. State of the Nation*. (pp. 15-33). Policy Press. <https://library.oapen.org/bitstream/handle/20.500.12657/22310/9781447351269.pdf?seq#page=32>.
- Siegler, I. C., Brummett, B. H., Williams, R. B., Haney, T. L., & Dilworth-Anderson, P. (2010). Caregiving, residence, race, and depressive symptoms. *Aging & Mental Health*, 14(7), 771-778. <https://doi.org/10.1080/13607861003713257>.
- Snyder, H. (2019). Literature review as a research methodology: An overview and guidelines. *Journal of Business Research*, 104, 333-339. <https://doi.org/https://doi.org/10.1016/j.jbusres.2019.07.039>.
- Van Mol, C., & de Valk, H. (2016). Migration and Immigrants in Europe: A Historical and Demographic Perspective. In: B. Garcés-Mascareñas & R. Penninx (Eds.), *Integration Processes and Policies in Europe: Contexts, Levels and Actors* (pp. 31-55). Springer International Publishing. [https://doi.org/10.1007/978-3-319-21674-4\\_3](https://doi.org/10.1007/978-3-319-21674-4_3).

van Wezel, N., Francke, A. L., Kayan-Acun, E., Ljm Devillé, W., van Grondelle, N. J., & Blom, M. M. (2016). Family care for immigrants with dementia: The perspectives of female family carers living in The Netherlands. *Dementia (London)*, *15*(1), 69-84.

<https://doi.org/10.1177/1471301213517703>.

WHO Europe (2018). *Report on the health of refugees and migrants in the WHO European Region: no public health without refugee and migrant health (2018)*. WHO Regional Office for Europe. Retrieved 02.12.20 from:

<http://www.euro.who.int/en/publications/abstracts/report-on-the-health-of-refugees-and-migrants-in-the-who-european-region-no-public-health-without-refugee-and-migrant-health-2018>.

Zarit, S. H., Todd, P. A., & Zarit, J. M. (1986). Subjective burden of husbands and wives as caregivers: a longitudinal study. *Gerontologist*, *26*(3), 260-266.

<https://doi.org/10.1093/geront/26.3.260>



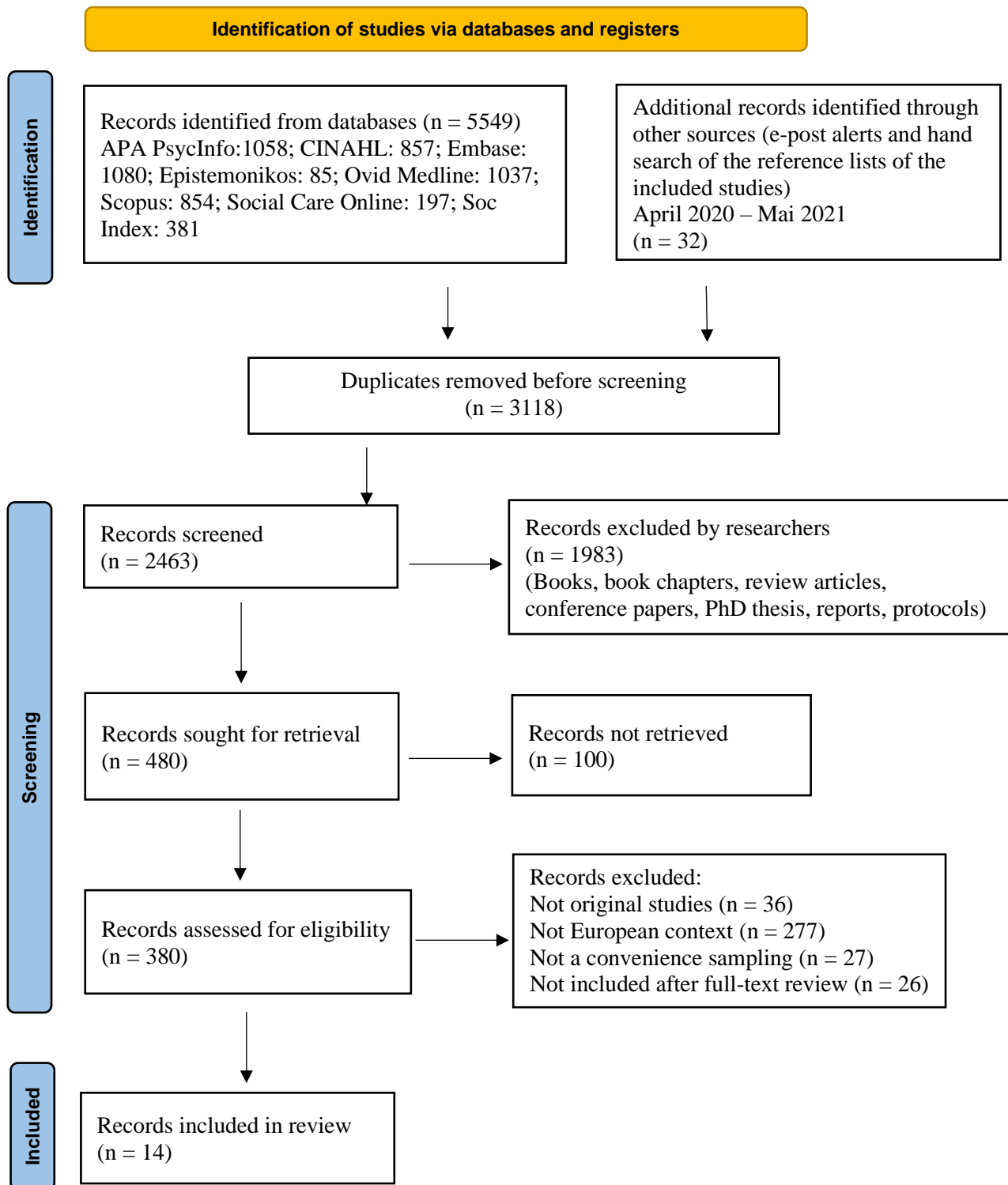


Figure 1 PRISMA 2020 flow diagram for identifying and selection of the studies included in review

From: (Page et al., 2021)





# PRISMA 2020 Checklist

| Section and Topic             | Item # | Checklist item   | Location where item is reported |
|-------------------------------|--------|--|---------------------------------|
| <b>TITLE</b>                  |        |  |                                 |
| Title                         | 1      | Identify the report as a systematic review.  | Title, p. 1                     |
| <b>ABSTRACT</b>               |        |  |                                 |
| Abstract                      | 2      | See the PRISMA 2020 for Abstracts checklist.   | p.1                             |
| <b>INTRODUCTION</b>           |        |  |                                 |
| Rationale                     | 3      | Describe the rationale for the review in the context of existing knowledge.  | pp. 3 – 6                       |
| Objectives                    | 4      | Provide an explicit statement of the objective(s) or question(s) the review addresses.   | p. 6                            |
| <b>METHODS</b>                |        |  |                                 |
| Eligibility criteria          | 5      | Specify the inclusion and exclusion criteria for the review and how studies were grouped for the syntheses.  | p. 7                            |
| Information sources           | 6      | Specify all databases, registers, websites, organisations, reference lists and other sources searched or consulted to identify studies. Specify the date when each source was last searched or consulted.  | p. 7                            |
| Search strategy               | 7      | Present the full search strategies for all databases, registers and websites, including any filters and limits used.   | pp. 7 – 8                       |
| Selection process             | 8      | Specify the methods used to decide whether a study met the inclusion criteria of the review, including how many reviewers screened each record and each report retrieved, whether they worked independently, and if applicable, details of automation tools used in the process.                     | pp. 8 – 10                      |
| Data collection process       | 9      | Specify the methods used to collect data from reports, including how many reviewers collected data from each report, whether they worked independently, any processes for obtaining or confirming data from study investigators, and if applicable, details of automation tools used in the process. | p. 9 – 10                       |
| Data items                    | 10a    | List and define all outcomes for which data were sought. Specify whether all results that were compatible with each outcome domain in each study were sought (e.g. for all measures, time points, analyses), and if not, the methods used to decide which results to collect.                        | pp. 10 – 14                     |
|                               | 10b    | List and define all other variables for which data were sought (e.g. participant and intervention characteristics, funding sources). Describe any assumptions made about any missing or unclear information.   | pp. 11 – 14                     |
| Study risk of bias assessment | 11     | Specify the methods used to assess risk of bias in the included studies, including details of the tool(s) used, how many reviewers assessed each study and whether they worked independently, and if applicable, details of automation tools used in the process.                                    | pp. 9 – 10                      |
| Effect measures               | 12     | Specify for each outcome the effect measure(s) (e.g. risk ratio, mean difference) used in the synthesis or presentation of results.  | N/A                             |
| Synthesis methods             | 13a    | Describe the processes used to decide which studies were eligible for each synthesis (e.g. tabulating the study intervention characteristics and comparing against the planned groups for each synthesis (item #5)).   | pp. 9 – 11                      |
|                               | 13b    | Describe any methods required to prepare the data for presentation or synthesis, such as handling of missing summary statistics, or data conversions.  | N/A                             |
|                               | 13c    | Describe any methods used to tabulate or visually display results of individual studies and syntheses.   | Figures 1, 2, 3 (pp. 10-11)     |
|                               | 13d    | Describe any methods used to synthesize results and provide a rationale for the choice(s). If meta-analysis was performed, describe the model(s), method(s) to identify the presence and extent of statistical heterogeneity, and software package(s) used.  | pp. 13 – 14                     |
|                               | 13e    | Describe any methods used to explore possible causes of heterogeneity among study results (e.g. subgroup analysis, meta-regression).   | N/A                             |
|                               | 13f    | Describe any sensitivity analyses conducted to assess robustness of the synthesized results.   | N/A                             |
| Reporting bias assessment     | 14     | Describe any methods used to assess risk of bias due to missing results in a synthesis (arising from reporting biases).  | N/A                             |



# PRISMA 2020 Checklist

| Section and Topic             | Item # | Checklist item   | Location where item is reported                   |
|-------------------------------|--------|--|---|
| Certainty assessment          | 15     | Describe any methods used to assess certainty (or confidence) in the body of evidence for an outcome.  | N/A   |
| <b>RESULTS</b>                |        |  |   |
| Study selection               | 16a    | Describe the results of the search and selection process, from the number of records identified in the search to the number of studies included in the review, ideally using a flow diagram.   | Figure 1 - Flow diagram (p. 10) & Table 2 (p. 10) |
|                               | 16b    | Cite studies that might appear to meet the inclusion criteria, but which were excluded, and explain why they were excluded.  | p. 9 – 10, Figure 1 Flow diagram                  |
| Study characteristics         | 17     | Cite each included study and present its characteristics.  | Table 2, p. 10                                    |
| Risk of bias in studies       | 18     | Present assessments of risk of bias for each included study.   | p. 10   |
| Results of individual studies | 19     | For all outcomes, present, for each study: (a) summary statistics for each group (where appropriate) and (b) an effect estimate and its precision (e.g. confidence/credible interval), ideally using structured tables or plots.   | p. 14   |
| Results of syntheses          | 20a    | For each synthesis, briefly summarise the characteristics and risk of bias among contributing studies.   | N/A   |
|                               | 20b    | Present results of all statistical syntheses conducted. If meta-analysis was done, present for each the summary estimate and its precision (e.g. confidence/credible interval) and measures of statistical heterogeneity. If comparing groups, describe the direction of the effect. | N/A   |
|                               | 20c    | Present results of all investigations of possible causes of heterogeneity among study results.   | N/A   |
|                               | 20d    | Present results of all sensitivity analyses conducted to assess the robustness of the synthesized results.   | N/A   |
| Reporting biases              | 21     | Present assessments of risk of bias due to missing results (arising from reporting biases) for each synthesis assessed.  | N/A   |
| Certainty of evidence         | 22     | Present assessments of certainty (or confidence) in the body of evidence for each outcome assessed.  | N/A   |
| <b>DISCUSSION</b>             |        |  |   |
| Discussion                    | 23a    | Provide a general interpretation of the results in the context of other evidence.  | pp. 17 - 21                                       |
|                               | 23b    | Discuss any limitations of the evidence included in the review.  | pp. 21 - 22                                       |
|                               | 23c    | Discuss any limitations of the review processes used.  | pp. 21 - 22                                       |
|                               | 23d    | Discuss implications of the results for practice, policy, and future research.   | pp. 1; 23   |
| <b>OTHER INFORMATION</b>      |        |  |   |
| Registration and protocol     | 24a    | Provide registration information for the review, including register name and registration number, or state that the review was not registered.   | p. 7  |
|                               | 24b    | Indicate where the review protocol can be accessed, or state that a protocol was not prepared.   | p. 7  |
|                               | 24c    | Describe and explain any amendments to information provided at registration or in the protocol.  | N/A   |
| Support                       | 25     | Describe sources of financial or non-financial support for the review, and the role of the funders or sponsors in the review.  | p. 7  |
| Competing                     | 26     | Declare any competing interests of review authors.   | p. 24   |



## PRISMA 2020 Checklist

| Section and Topic                              | Item # | Checklist item   | Location where item is reported |
|--|--------|--|---------------------------------|
| interests                                      |        |  |                                 |
| Availability of data, code and other materials | 27     | Report which of the following are publicly available and where they can be found: template data collection forms; data extracted from included studies; data used for all analyses; analytic code; any other materials used in the review. | pp. 1 – 24<br>Table 3, p. 14    |

From: Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. *BMJ* 2021;372:n71. doi: 10.1136/bmj.n71  
For more information, visit: <http://www.prisma-statement.org/>