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SPECIAL ISSUE REVIEW

Migrant informal caregiver perceptions and experiences of caring for a family member with dementia: A systematic review and thematic synthesis

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Abstract

Aims and objectives: To describe migrant family caregivers' experiences and perceptions of caring for a family member with dementia.

Background: There are demographic trends of aging populations and increased migration between countries. Age-associated diseases, such as dementia, are expected to increase, with migrants being at significantly increased risk. Knowledge of how dementia care is provided within migrant families is scarce.

Design: Systematic review and thematic synthesis of qualitative research were performed to inform the development of interventions that can acknowledge and respond to the needs, concerns and preferences of migrant family caregivers.

Methods: Searches were performed in PubMed, PsycINFO and CINAHL and reference lists in published articles were reviewed for the period 2000–October 2020. The CASP checklist for qualitative research was used to assess evidence quality, and the ENTREQ framework was used as a guide for study reporting.

Results: Twenty-six articles from 10 Western countries, including 360 informal migrant caregivers from more than 30 countries of origin, were eligible. Within four areas of construct—perceptions of dementia and initial help-seeking; barriers to accessing and using formal dementia care; caregiver burden and coping and resilience—12 descriptive themes were identified. Several concepts cut across the themes, such as language difficulties; the role of the family in relation to care and support; cultural perceptions of dementia and care; stigma, pride and shame; the importance of religion and the importance of trust.

Conclusions: The review revealed commonalities among migrant family caregivers that resulted in reduced understanding of dementia and the importance of diagnosis and treatment.

Relevance to clinical practice: To prevent a negative trajectory in caregiving, with perceived demands causing high levels of stress and strain, several barriers to migrants accessing and using formal care need to be assessed and addressed.

KEYWORDS
caregiver burden, dementia, experiences, informal caregiver, migrants, perceptions, qualitative research, social support, systematic review

1 | INTRODUCTION

In Europe, there is a demographic trend of aging populations, and the region has also experienced increased migration. Today, international migrants make up almost 10% of the total European population. Since the late 2000s, the region has experienced an influx of non-European refugees and immigrants, with a peak in 2015 (WHO Regional Office for Europe, 2018). Many refugees and migrants are young adults, but an increasing number are elderly and disabled people. Hence, age-associated diseases are expected to increase, with migrants (including immigrants, refugees and asylum seekers), from low- and middle-income countries in particular being at significantly increased risk of dementia (Selten et al., 2020).

Dementia is an umbrella term used to describe a syndrome caused by a disease of the brain, usually of a chronic or progressive nature, in which brain cells stop working properly or die. Cognitive function impairments are often accompanied or preceded by deterioration in emotional control, social behaviour or motivation (World Health Organization, 2019). Many risk factors for dementia cluster with inequalities which are common in Black, Asian and minority ethnic groups and vulnerable populations (Selten et al., 2020). Worldwide, around 50 million people live with dementia, and this number is projected to increase to 152 million by 2050 (Patterson, 2018).

Upon arrival in a host country, migrants tend to be healthier than both the average majority population citizen and the population in their country of birth, a phenomenon sometimes referred to as 'the healthy migrant effect'. However, due to disadvantaged socioeconomic positions, long-term effects of traumatic experiences and different exposures to risk factors (before migration, during transit and after arrival in the final destination country), refugee and migrant populations have a different trajectory in aging compared with majority populations. The healthy migrant effect is less common among non-European migrants, who are often refugees or family reunion migrants. For those migrating at a higher age, there is a tendency towards poorer overall health on arrival and a higher risk of developing health problems in the country of destination, with a steeper health decline in later life (WHO Regional Office for Europe, 2018).

Migrants born in countries outside Europe provide care to family members to a much higher extent than European-born people (Socialstyrelsen, 2012). Differences in caregiving patterns may reflect that people born outside Europe, compared with European-born people, have a different attitude towards caring for relatives. However, another explanation may be that many migrants find it difficult to access and use primary care (Cheng et al., 2015; Selten et al., 2020). Public care may not be able to adapt its efforts to needs based on ethnic background, for example, to provide care in a language that the care recipient understands (Shanley et al., 2012). In addition to language problems, there is often also lower knowledge about health and a lack of social support and other socioeconomic factors in migrant groups, making it difficult to seek care (O'Donnell et al., 2016).

What does this paper contribute to the wider global clinical community?

- Due to migration, the elderly population of Europe is becoming more ethnically diverse.
- This review provides a unique synthesis of migrant informal caregivers' perspectives of caring for a family member with dementia, with themes covering: conceptions of dementia and help-seeking behaviour; barriers to accessing and using dementia care; caregiver burden; coping and resilience.
- The review improves understanding of the needs, concerns and preferences of migrant family caregivers, which could be used to align future development of interventions with them.

Even if many migrants may feel culturally obliged to care for older relatives, this does not mean that all minority ethnic caregivers feel willing to provide care or are prepared for the various aspects of providing support to a person living with dementia (Parveen & Oyebode, 2018). Family caregivers of people with dementia have been found to be at high risk of depression and anxiety disorders (Livingston et al., 2017). Risk factors for caregiver burden include female gender, low educational attainment, residence with the care recipient, more hours spent caregiving, depression, social isolation, financial stress and lack of choice in being a caregiver (Adelman et al., 2014). Caregiver burden is associated with the demand-control model, a model explaining that when work with low decision latitude is combined with high demands on productivity, the work is experienced as stressful (Karasek & Theorell, 1990). The model was originally developed to examine health outcomes in paid work, but has also been used to shed light on the health effects of informal caregiving (Molloy et al., 2008). As control and support are assumed to interact in protecting against adverse health effects of stress (Karasek & Theorell, 1990), the stress imposed on the informal caregiver can potentially be buffered with social support.

The elderly population of Europe is aging and becoming more ethnically diverse. Population and health statistics show that dementia is a key concern affecting public health, and issues linked to cultural background will not disappear as the current migrant population ages and population movement continues (Parveen & Oyebode, 2018; Patterson, 2018; Selten et al., 2020; WHO Regional Office for Europe, 2018). Family members often struggle to care for relatives

with dementia, but when factoring in the triple jeopardy of cultural, social and often practical barriers, the task of caring may become overwhelming and the family caregiver's own mental and physical health may be affected (Parveen & Oyebode, 2018). The informal caregivers who provide comprehensive care to family members with dementia suffer consequences to health, employment and quality of life, thus making up a vulnerable group (Sand, 2014). Knowledge about how dementia care is provided within migrant families is scarce, and there is a lack of knowledge about the complex category of elderly foreign-born people and their access to healthcare and support (Gove et al., 2018). There is thus a need to identify what special needs migrant caregivers of relatives with dementia have, and how society can best meet the needs in order to support them in their care work.

1.1 | Aims

The aim of this review was to systematically search and synthesise the qualitative literature exploring migrant family caregivers' experiences and perceptions of caring for a relative with dementia.

2 | METHODS

This is a systematic review and thematic synthesis of qualitative research (Thomas & Harden, 2008). The rationale for performing the review was to support the development of interventions that can acknowledge and respond to the needs, concerns and preferences of migrant family caregivers.

Before starting the literature search, a search was conducted in PROSPERO to check whether others had performed a recent literature review on a similar topic. At the time, except for a study which was planned to cover both quantitative, qualitative and mixed-methods studies (Lillekroken et al., 2020) there were no planned or ongoing reviews registered. When seeking a greater understanding of the experiences of people with dementia and of their informal and formal caregivers, especially when the aim is to include specific groups such as ethnic minorities, qualitative research is better suited—and even required—than quantitative research (Carmody et al., 2015).

Our goal was to stay close to the results of the primary studies and as outlined in Table S1, The Enhancing Transparency in Reporting the Synthesis of Qualitative Research (ENTREQ) framework (Tong et al., 2012) was used as a guide to report the stages of the synthesis and methods for synthesising qualitative findings in a transparent way.

2.1 | Selection criteria

Qualitative original or primary research studies written in the English language, in which family members of migrants with dementia expressed views on or experiences of informal care, were included. Dementia could be any subtype of the condition, but studies exclusively describing migrant caregivers' experiences through the perspective of others than the caregivers (e.g., healthcare professionals or community leaders) were excluded. Moreover, studies describing 'ethnic' populations which were not explicitly reported as being migrants were excluded due to ambiguity between ethnicity and migration. Reviews as well as commentaries and brief reports (including letters to the editor) were excluded, although their reference lists were reviewed for identification of primary research articles.

2.2 | Data sources and searches

Systematic comprehensive literature searches were conducted by a health sciences librarian, using PubMed, PsycINFO and the Cumulative Index to Nursing and Allied Health Literature (CINAHL), for the period 2000 to October 2020, and updated in April 2022 for relevant updates. The electronic search strategy is provided in Table S2 (available as online supplementary material). In addition, we studied the reference lists in published scientific articles. Titles and abstracts of retrieved citations were screened by the first author (JS), and full papers of potentially relevant abstracts were obtained. Then, the full texts of potentially relevant studies were assessed for eligibility. The second author (KH) cross-checked and agreed on the included and excluded articles.

2.3 | Data extraction and quality assessment

All included articles were appraised for quality by both authors using the Critical Appraisals Skills Programme (CASP) checklist for qualitative studies (Critical Appraisal Skills Programme, 2018). CASP consists of 10 questions for systematic appraisal of three broad issues: Are the results of the study valid? What are the results? Will the results help locally? Disagreements in scoring were resolved by reaching consensus. There was no a priori quality threshold, and no articles were excluded on grounds of quality; assessment was undertaken to ensure transparency in the process.

Quotations from all study participants and all text from the Results/Findings section of each study were imported verbatim into NVivo (version 1.3 [535] QSR International Pty Ltd, 1999–2020) software.

2.4 | Data analysis

For data analysis, Thomas and Harden's three stages of thematic synthesis of qualitative evidence were used: line-by-line coding of the findings of the primary studies; organisation of codes into related areas of construct and into *descriptive* themes and development of *analytic* themes. Thematic synthesis serves to stay 'close' to the results of the primary studies, synthesising them in a transparent way and facilitating the explicit production of new concepts and hypotheses (Thomas & Harden, 2008). The three stages of analysis overlapped to a certain degree.

The first author (JS) performed the line-by-line coding of the findings of the studies. Codes were created inductively to capture the meaning and content of each sentence. As each study was coded, content was added to the bank of codes and new codes were developed when necessary. This process created a total of 34 initial codes. In the next stage, both authors reviewed the codes, which were then grouped into a hierarchical tree structure based on similarities and differences, as illustrated in Table S3. New codes were created in order to capture the meaning of groups of initial codes. This process resulted in a tree structure with several layers, organising a total of 12 descriptive themes within four areas of construct. The authors discussed the addition or revision of themes until consensus was reached. In the final stage of analysis, three analytic themes cutting across the four areas of construct and relating to the study aim were generated. A selection of informal caregivers' quotations illustrating each theme is given in Table S4. Ethical approval and informed consent were not required for this systematic review, which was based on existing published qualitative research.

3 | RESULTS

3.1 | Literature search

The electronic search yielded 281 citations, of which 26 articles reporting on 22 separate studies, involving more than 600 respondents—of whom at least 360 are informal caregivers—were eligible. The selection process is presented in the Preferred reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) flowchart (Page et al., 2021) (Figure 1). The characteristics of the included studies are listed in Table 1. The studies were conducted in 10 Western countries: Australia ($n = 3$), Belgium ($n = 1$), Canada ($n = 1$), Denmark ($n = 1$), Germany ($n = 1$), the Netherlands ($n = 2$), Norway ($n = 3$), Sweden ($n = 1$), United Kingdom ($n = 3$), United States ($n = 6$) and included people of 30 different migrant backgrounds, with the vast majority being of African or Asian origin.

3.2 | Comprehensiveness of reporting

The comprehensiveness of study reporting varied. Although the vast majority of studies were of good quality, there were areas in which reporting was often limited, as shown in Table 2; 50 percent ($n = 13$) of the included studies did not clearly describe the relationship between researcher and participants.

3.3 | Synthesis

As presented in Table 3, 12 descriptive themes relating to family caregivers' experiences and perceptions of caring for a relative with dementia were identified in the reviewed studies and sorted into four areas of construct: perceptions of dementia and initial help-seeking, barriers to accessing and using dementia care, caregiver burden and coping and resilience in migrant caregivers. Several concepts were found to cut across the themes, such as language difficulties; the role of the family in relation to care and support; cultural perceptions of dementia and care; stigma, pride and shame; the importance of religion and the importance of trust.

Further considerations and discussions on the part of the authors led to the identifications of three theory-driven analytic themes, relating to the demand-control model (Karasek & Theorell, 1990). The analytic themes concerned issues that need to be addressed in the development of interventions, acknowledging and responding to the needs, concerns and preferences of migrant family caregivers. The results of the thematic synthesis are presented below, with the descriptive themes organised under their respective area of construct. The analytic themes are further considered in the discussion section.

3.3.1 | Perceptions of dementia and initial help-seeking

Caregivers' lack of understanding of the causes and symptoms of dementia

Fourteen studies contributed to this theme (Berdai Chaouni & De Donder, 2019; Czapka & Sagbakken, 2020; Hossain & Khan, 2019; Liu et al., 2020; McCleary et al., 2013; Morhardt et al., 2010; Naess & Moen, 2015; Nielsen et al., 2020; Ramsay et al., 2017; Sagbakken et al., 2020; Sun et al., 2014; van Wezel et al., 2018; Xiao et al., 2015; Yeo et al., 2002).

Several studies ($n = 11$) reported that migrant caregivers for people with dementia felt that they did not have the necessary information about dementia—its causes, its symptoms and prognosis. Usually, family members started the process of searching for an explanation after witnessing alarming symptoms such as markedly 'unfamiliar' and/or dangerous behaviours, for example burning something at home. Comments and recommendations from relatives outside the immediate family played an important role in the family caregivers' recognition of a problem ($n = 7$). A tendency for 'accidental diagnosis' through late contact with medical help was described in a few studies ($n = 3$), meaning that dementia was a secondary finding when a person was treated for another medical problem. It was emphasised that identifying the potential dementia symptoms and the process of diagnosis were crucial for a good beginning to the caring journey, as opposed to living with uncertainty. However, many studies ($n = 13$) reported that caregivers' lack of knowledge of the disease and its causes and symptoms in many cases led to perceiving dementia as a normal part of aging. It was therefore considered untreatable, meaning that there was no perceived need to seek medical evaluation.

Lack of cultural and linguistic ability to achieve diagnosis

Ten studies contributed to this theme (Berdai Chaouni et al., 2020; Berdai Chaouni & De Donder, 2019; Czapka & Sagbakken, 2020; Hossain & Khan, 2019; Jutlla, 2015; Morhardt et al., 2010; Naess & Moen, 2015; Ramsay et al., 2017; Sun et al., 2014; Xiao et al., 2015).

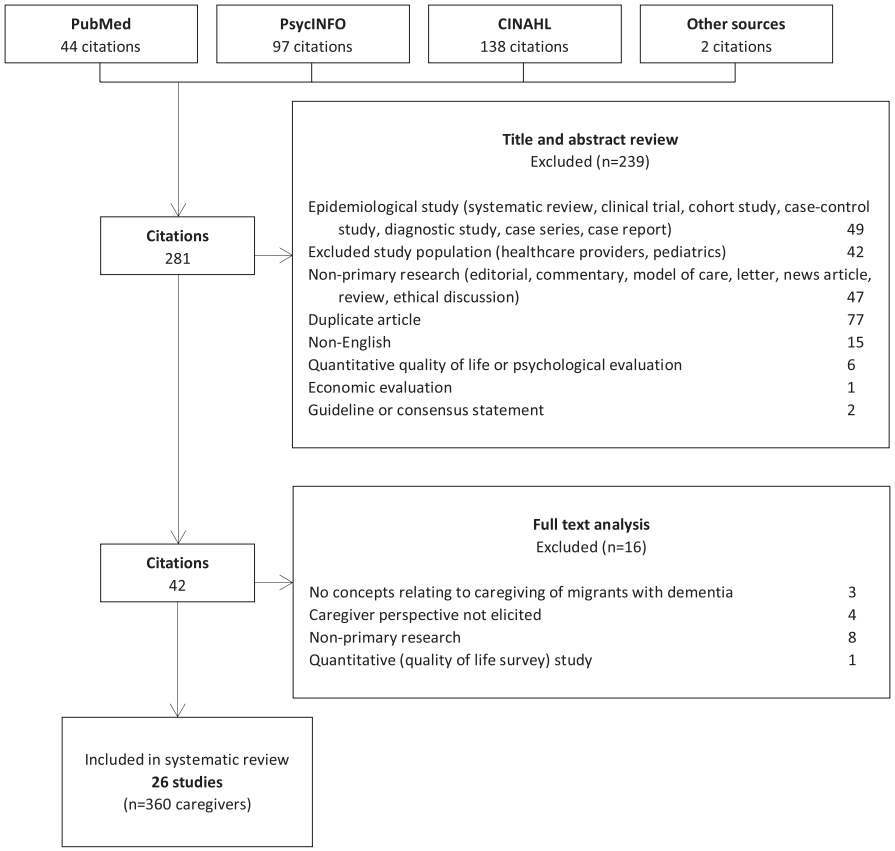

FIGURE 1 Outcome of study selection: PRISMA flow diagram

A number of studies (n = 5) reported on the lack of specialist dementia knowledge, particularly among general practitioners (GPs). The family caregivers talked about difficulties in convincing their GP that their relative had memory problems and was behaving differently, and some participants felt ignored. In many cases, the attitudes of GPs were seen to reinforce normalisation of memory loss as part of aging, resulting in minimisation of caregiver concerns and failure to reach diagnosis. A few studies (n = 3) reported that informal caregivers experienced discrimination and racism in their encounters with healthcare professionals.

Healthcare professionals, for their part, reported the absence of adequate assessment tools alongside the presence of a language barrier as the most challenging aspects in diagnosing migrant elderly (n = 5). Furthermore, due to language barriers and/or the advanced stage of the dementia, physicians generally communicated the diagnosis to the informal caregivers, and not always in the presence of the older person. The informal caregivers were left with the task of conveying the diagnosis to the older person, which did not always happen. Caregivers reported that in several languages the terms 'dementia' and 'Alzheimer' did not even exist.

Stigmatising beliefs and distrust in Western medicine

Fourteen studies contributed to this theme (Berdai Chaouni & De Donder, 2019; Czapka & Sagbakken, 2020; Hinton et al., 2008; Hossain & Khan, 2019; Liu et al., 2020; Mackenzie, 2006; McCleary et al., 2013; Morhardt et al., 2010; Nielsen et al., 2020; Sagbakken et al., 2020; Sun et al., 2014; van Wezel et al., 2018; Xiao et al., 2015; Yeo et al., 2002).

Stigmatising beliefs about dementia was a commonly reported issue (n = 12) that prevented or delayed dementia care-seeking. Some respondents believed that dementia is a condition that comes from God or saw dementia as a form of insanity. It was reported that beliefs in spirit possession and the evil eye were not uncommon. However, some caregivers, for example Bangladeshi family caregivers in a study from the UK and Moroccan caregivers in a Belgian study, claimed that the community harboured no stigmas in relation to dementia or people with dementia.

A number of studies (n = 10) reported that migrant caregivers felt ashamed by public displays of dementia-related behaviour and sought to avoid such situations; studies revealed examples of families trying to hide the dementia and 'keep it in the family'. The person with dementia would be hidden away from the public in order to protect his/her reputation and also not to bring shame, embarrassment and disrespect on the family. Some studies (n = 5) reported that families did not want others to know that the care recipient had dementia because of concerns that no one would marry their children due to fear that the disease might be inherited.

Distrust in Western medicine was reported as a barrier to seeking medical evaluation (n = 5), and even after a diagnosis, some studies (n = 6) reported caregivers or other family members did not always believe the physician but were in denial.

TABLE 1 Characteristics of the included studies

Study and country	Sample Role (*n*) and age	Migration background	Data collection and conceptual/ methodological framework	Data analysis	Topic
Ahmad et al. (2020)	Family caregivers *n* = 12 42–67 years	Chinese, Indian-Surinamese, Moroccan-Berber, Moluccan, Turkish	Semi-structured interviews, Hochschild's interpretive framework	Qualitative content analysis	Reasons for caring, challenges in shared care
Berdai Chaouni and De Donder, (2019) Belgium	Family caregivers *n* = 12 36–63 years HCP *n* = 13	Moroccan, Belgian	Semi-structured interviews, Cross-sectional qualitative	Inductive conceptualisation process	Influence of culture and religion on experience and how to manage
Berdai Chaouni et al. (2020) Belgium	”	”	”	Inductive, grounded theory	How care is provided, and challenges faced
Caldwell et al. (2014) Australia	Family caregivers *n* = 27 33–86 years	Chinese background or English-speaking background	Semi-structured interviews, Qualitative approach	Thematic analysis	Decision-making process for placing a person with dementia in a nursing home
Czapka and Sagbakken (2020) Norway	Family caregivers *n* = 8 PwD *n* = 3 Community *n* = 5 HCP *n* = 6	Somali, Polish, Croatian, Pakistani, Indian, Turkish, Atlantic Ocean islanders	Semi-structured interviews, Qualitative approach	Thematic analysis	Barriers and facilitators in accessing and using dementia care
Hinton et al. (2008) USA	Family caregivers *n* = 9 29–78 years	Vietnamese	In-depth interviews, Ethno-gerontology	Thematic analysis	Religious and spiritual dimensions of caregiving
Hossain and Khan (2019) United Kingdom	Family caregivers *n* = 6 23–64 years	Bangladeshi	Semi-structured interviews	Thematic analysis	Knowledge and day-to-day experiences, myths, and stigmas
Hossain et al. (2020) United Kingdom	Community *n* = 21 Family caregivers *n* = 6 23–64 years	Bangladeshi	Focus groups, semi-structured interviews	Thematic analysis	Traditional gender roles and effects of dementia caregiving
Jutlla (2015) United Kingdom	Family caregivers *n* = 12 44–83 years	Sikh	Narrative interviews, Biographical approach	Constructivist grounded theory	Sikhs' experiences of caregiving
Kiwi et al. (2018) Sweden	Family caregivers *n* = 20 30–63 years	Iranian	Semi-structured interviews	Content analysis	How the decision to cease caregiving at home is made
Kong et al. (2010) USA	Family caregivers *n* = 10 40–70 years	Korean	Semi-structured interviews, Symbolic interactionism	Content analysis	Experiences regarding American nursing home placement
Liu et al. (2020) USA	Family caregivers *n* = 27 50–89 years	Chinese	Semi-structured interviews, Developmental life course perspective	3-step hybrid grounded theory model	Challenges and resilience of caregivers
Mackenzie (2006) United Kingdom	Family caregivers *n* = 21	Pakistani, Indian, Polish, Ukrainian	Semi-structured interviews, Social theory ‘microsociology’	Content analysis	Stigma and dementia
McCleary et al. (2013) Canada	Family caregivers *n* = 8 PwD *n* = 6	Indian, Sri Lankan	Semi-structured interviews, Attribution theory (applied retrospectively)	Content analysis	Help-seeking and diagnosis, and affective responses

TABLE 1 (Continued)

Study and country	Sample Role (*n*) and age	Migration background	Data collection and conceptual/ methodological framework	Data analysis	Topic
Monsees et al. (2020) Germany	Family caregivers *n* = 8 31–57 years	Turkish	Semi-structured interviews, Practice-oriented approach	Qualitative content analysis	Experiences and utilisation of healthcare services
Morhardt et al. (2010) USA	Family caregivers *n* = 48	Arabic, Assyrian, Bosnian, Hindi, Urdu	Semi-structured interviews	Grounded theory	Barriers to seeking diagnostic evaluation
Naess and Moen (2015) Norway	Family caregivers *n* = 8 Community, HCP *n* = 14	Pakistani	Observations, individual interviews, focus groups	Thematic narrative analysis approach	How dementia is 'negotiated' in a different culture
Nielsen et al. (2020) Denmark	Family caregivers *n* = 12 30–70 years HCP *n* = 12, Cultural-link workers *n* = 11	Turkish, Pakistani, Arabic Turkish, Pakistani, Arabic	Semi-structured interviews, Hermeneutic phenomenology	Thematic analysis	Barriers in access to dementia care
Ramsay et al. (2017) Australia	Family caregivers *n* = 10 > 18 years	Turkish	Semi-structured interviews, Ethnography	Thematic analysis with inductive approach	Cultural needs, beliefs and health-seeking behaviours
Sagbakken et al. (2017) Norway	Family caregivers *n* = 12 25–78 years HCP *n* = 45, 35–62 years	Afghanistan, Pakistani, Chinese, Vietnamese, Turkish, Lebanese, Sri Lankan, and Chilean	Individual and dyad in-depth interviews and focus groups, Phenomenology	Kvale and Brinkmann's contexts of interpretation	Views and experiences of family members and professional caregivers regarding the care provided to immigrants with dementia
Sagbakken et al. (2020) Norway	Older immigrants *n* = 51 50–80 years Family caregivers *n* = 12 25–78 years HCP *n* = 45, 35–62 years	Pakistani, Indian, Afghanistan, Iranian, Turkish, Algerian, Mexican, Chilean, Polish and Bosnian Afghanistan, Pakistani, Chinese, Vietnamese, Turkish, Lebanese, Sri Lankan and Chilean	Individual and dyad in-depth interviews and focus groups	"	Perceptions of dementia in ethnically diverse groups
Sun et al. (2014) USA	Family caregivers *n* = 6 HCP *n* = 6	Chinese	Focus groups, A practice-oriented model	Content analysis	Perceptions of service barriers
van Wezel et al. (2016) The Netherlands	Family caregivers *n* = 69 20–84 years	Turkish, Moroccan, Surinamese Creole	Semi-structured interviews, focus groups Generic qualitative approach	Inductive qualitative	The perspectives of female family caregivers
van Wezel et al. (2018) The Netherlands	"	"	"	"	Explanatory models and openness about dementia
Xiao et al. (2015) Australia	Family caregivers *n* = 6 18–58 years HCP *n* = 7 30–45 years	Vietnamese	Semi-structured interviews, focus groups, Gadamer's philosophical hermeneutics	Thematic analysis	Perceived challenges in dementia care
Yeo et al. (2002) USA	Family caregivers *n* = 10 28–72 years	Vietnamese	Structured interviews	Content analysis	Conceptions of dementia

HCP: healthcare professionals, PwD: people with dementia.

TABLE 2 Quality appraisal of the included studies based on the Critical Appraisals Skills Programme (CASP) checklist for qualitative studies

Question	Yes	No	Unclear
Was there a clear statement of the aims of the research?	25	0	1
Is a qualitative methodology appropriate?	26	0	0
Was the research design appropriate to address the aims of the research?	23	0	3
Was the recruitment strategy appropriate to the aims of the research?	23	3	0
Was the data collected in a way that addressed the research issue?	21	4	1
Has the relationship between researcher and participants been adequately considered?	13	13	0
Have ethical issues been taken into consideration?	19	7	0
Was the data analysis sufficiently rigorous?	19	7	0
Is there a clear statement of findings?	19	7	0
How valuable is the research?	26	0	0

3.3.2 | Barriers to accessing and using dementia care

Difficulties in navigating the healthcare system

Fifteen studies contributed to this theme (Berdai Chaouni et al., 2020; Berdai Chaouni & De Donder, 2019; Caldwell et al., 2014; Czapka & Sagbakken, 2020; Jutlla, 2015; Kiwi et al., 2018; Kong et al., 2010; Liu et al., 2020; Monsees et al., 2020; Naess & Moen, 2015; Nielsen et al., 2020; Ramsay et al., 2017; Sagbakken et al., 2020; Sun et al., 2014; Xiao et al., 2015).

Several studies (n = 12) reported on caregivers' lack of knowledge, familiarity and awareness of services available for dementia. Participants challenged the widespread assumption that migrant caregivers do not ask for formal support from services, highlighting the complexity of the issue: 'If you don't know what's available, how are you going to ask [for support]?' (Jutlla, 2015). Healthcare professionals, for their part, expressed examples of unrealistic expectations of cure from dementia among patients and relatives, and challenges related to migrant families' lack of understanding of how the care services and institutions are organised.

Language barriers were cited as a major obstacle to accessing relevant information about available services (n = 9), and there were examples of healthcare professionals not using interpreters in order to lower costs. However, a number of studies (n = 6) reported socioeconomic factors, and status—defined by the combination of education, income and occupation—was highlighted as a more important factor for inequities in access to dementia care than minority ethnic background.

Services' lack of cultural awareness

Sixteen studies contributed to this theme (Ahmad et al., 2020; Berdai Chaouni et al., 2020; Berdai Chaouni & De Donder, 2019; Caldwell et al., 2014; Czapka & Sagbakken, 2020; Jutlla, 2015; Kong et al., 2010; Monsees et al., 2020; Morhardt et al., 2010; Naess & Moen, 2015; Nielsen et al., 2020; Ramsay et al., 2017; Sagbakken et al., 2017, 2020; Sun et al., 2014; van Wezel et al., 2016).

Several studies (n = 10) reported that migrant caregivers of people with dementia identified the public healthcare system and nursing homes as a second option or as a last resort. This was for a number of reasons, such as negative experiences with healthcare professionals, distrust based on experiences of nursing homes in the home country or rumours about care institutions in the host country. Caregivers' experiences of professional caregivers who did not respect religious rituals (such as prayer), halal dietary practices or gender matching was another issue, reported in several studies), enhancing anxieties about entrusting a relative with dementia to professional caregivers (n = 11).

The impact of cultfilial ure and familial expectations of care decisions

Twenty studies contributed to this theme (Ahmad et al., 2020; Berdai Chaouni et al., 2020; Berdai Chaouni & De Donder, 2019; Caldwell et al., 2014; Czapka & Sagbakken, 2020; Hinton et al., 2008; Hossain et al., 2020; Jutlla, 2015; Kong et al., 2010; Mackenzie, 2006; Monsees et al., 2020; Naess & Moen, 2015; Nielsen et al., 2020; Ramsay et al., 2017; Sagbakken et al., 2017, 2020; Sun et al., 2014; van Wezel et al., 2016; Xiao et al., 2015; Yeo et al., 2002).

A large number of studies (n = 16) reported that for many migrant caregivers, limited acceptance of nursing homes and home-based services were associated with willingness to fulfil family obligations. There was a strong norm associated with 'taking care of our own', and a number of studies reported that the people with dementia themselves objected to being moved to a nursing home. Migrant caregivers who consider themselves as belonging to a religious denomination, regardless of the religion practised, were found to emphasise the importance of filial piety more strongly than caregivers who did not.

A majority of the studies (n = 20) reported that seeking formal support was considered to be a sign of failure in relation to the framing rule of reciprocal love or filial piety. Participants talked about this in terms of shame or taboo. Children and other family members feared gossip, disapproval and condemnation from the community or feared that parents with dementia would think they were being abandoned. Some caregivers described conflicts between siblings or parents about whether it was the right decision to apply for or accept a place at a nursing home.

3.3.3 | Caregiver burden

Stress and strain associated with caring for a person with dementia

Seventeen studies contributed to this theme (Ahmad et al., 2020; Berdai Chaouni et al., 2020; Caldwell et al., 2014; Czapka & Sagbakken, 2020; Hossain & Khan, 2019; Jutlla, 2015; Kiwi et al., 2018; Liu et al., 2020; McCleary et al., 2013; Monsees et al., 2020; Morhardt

TABLE 3 Three analytic themes found to recur within the four areas of construct and 12 descriptive themes, related to migrant family caregivers' experiences and perceptions of caring for a relative with dementia, were identified across the articles

	Analytic themes		
	A need to: educate and inform migrant communities about dementia and available care services	**A need to: adapt care services to be more culturally sensitive**	**A need to: identify and address cultural issues in order to empowering the informal migrant caregiver**
Areas of construct	**Descriptive themes**		
(1) Perceptions of dementia and initial help-seeking	(a) Caregivers' lack of understanding of the causes and symptoms of dementia	(b) Lack of cultural and linguistic ability to achieve diagnosis	(c) Stigmatising beliefs and distrust in Western medicine
(2) Barriers to accessing and using dementia care	(a) Difficulties in navigating the healthcare system	(b) Services' lack of cultural awareness	(c) The impact of culture and familial expectations on care decisions
(3) Caregiver burden	(a) Stress and strain associated with caring for a person with dementia	(b) Caregiver stress associated with acculturation	(c) Cultural traditions limiting the caregivers' freedom of choice
(4) Coping and resilience in migrant caregivers	(a) Coping strategies	(b) Reciprocal love—meaning and satisfaction in caregiving	(c) Caregivers challenging cultural traditions

et al., 2010; Nielsen et al., 2020; Ramsay et al., 2017; Sagbakken et al., 2017; van Wezel et al., 2016, 2018; Xiao et al., 2015).

In several studies (n = 12), the informal caregivers reported on imbalance between demands and perceived capabilities. Most families reported having no previous experiences of dementia care. Caregivers talked of struggling to communicate with care recipients and manage problems related to behaviour, mood and psychological aspects, because of their own limited knowledge and skills. A number of studies (n = 9) reported that caring for an immediate family member with dementia, especially someone whose former personality and coping skills had changed, led to feelings of loss and grief. The person with dementia was sometimes perceived as a stranger. Narratives revealed many sources of suffering for family caregivers, including difficult behavioural problems such as violent or aggressive behaviours, incontinence, paranoia, dangerous situations and intense time demands, and in several studies, caregivers (n = 13) admitted to feeling overwhelmed.

In addition, having no time for themselves between working and caring for their family contributed to caregivers' high level of stress. Caregivers with younger families reported considerable stress, whereas several older caregivers reported needing to manage health problems of their own. Feelings of isolation and of being misunderstood by other family members often exacerbated the exhaustion; caregivers had experiences of relatives and friends deliberately distancing themselves on hearing of an older person's diagnosis. Disappointment over non-caregiving family members led to tensions and sometimes conflicts, usually left unspoken.

Caregiver stress associated with acculturation

Twenty-one studies contributed to this theme (Ahmad et al., 2020; Berdai Chaouni et al., 2020; Berdai Chaouni & De Donder, 2019; Caldwell et al., 2014; Czapka & Sagbakken, 2020; Hinton et al., 2008; Jutlla, 2015; Kiwi et al., 2018; Kong et al., 2010; Liu et al., 2020; Mackenzie, 2006; Monsees et al., 2020; Morhardt et al., 2010; Naess & Moen, 2015; Nielsen et al., 2020; Ramsay et al., 2017; Sagbakken et al., 2017; Sun et al., 2014; van Wezel et al., 2016, 2018; Yeo et al., 2002).

Some studies including first generation migrants reported caregivers having internalised cultures and norms in their pre-migration lives and maintained those fully or to a certain extent in their post-migration lives. However, several studies (n = 11) reported that values held by the older generation were changing among younger caregivers. After immigration, there had been changes in living conditions, such as women's participation in the workforce and lack of extended family support. Second-generation migrants, who were born in the host country or had moved there at a young age, were more acculturated or assimilated to the dominant Western culture, which emphasises individualism, independence and privacy. However, informants still felt pressured to fulfil traditional filial piety, and hence felt caught between the traditional thinking and the reality of migrant life. Women in particular seemed to end up in situations with conflicting needs in a context with conflicting values and new and demanding roles.

Cultural traditions limiting the caregivers' freedom of choice

Sixteen studies contributed to this theme (Ahmad et al., 2020; Berdai Chaouni & De Donder, 2019; Caldwell et al., 2014; Czapka & Sagbakken, 2020; Hinton et al., 2008; Hossain et al., 2020; Jutlla, 2015; Kiwi et al., 2018; Kong et al., 2010; Naess & Moen, 2015; Nielsen et al., 2020; Ramsay et al., 2017; Sagbakken et al., 2017, 2020; van Wezel et al., 2016; Yeo et al., 2002).

Several studies (n = 14) reported that family caregivers perceived care to be a burden because they missed having freedom of choice, freedom to provide care in the way they felt was right or freedom to share the burden of care with professionals. Hierarchical and gendered family roles and positions sometimes meant that decisions

about dementia care rested with other family members than those providing the actual care. Although men did sometimes play a part in care tasks, such as shopping or organising care and social support, the physical, personal care (showering, washing and dressing) was in most cases done entirely by women.

Family care was reported to be seen as a duty, above all for women, and it was reported that women could be blamed if they failed to manage the needs of a care recipient ($n = 10$). The freedom of choice was limited because deviating from the expectations of the family or the broader community would have consequences, such as disrupted relationships and less respect within the family or the community.

3.3.4 | Coping and resilience in migrant caregivers

Coping strategies

Twenty studies contributed to this theme (Ahmad et al., 2020; Berdai Chaouni et al., 2020; Berdai Chaouni & De Donder, 2019; Caldwell et al., 2014; Czapka & Sagbakken, 2020; Hinton et al., 2008; Hossain et al., 2020; Hossain & Khan, 2019; Jutlla, 2015; Kiwi et al., 2018; Liu et al., 2020; Mackenzie, 2006; Monsees et al., 2020; Morhardt et al., 2010; Naess & Moen, 2015; Nielsen et al., 2020; Ramsay et al., 2017; Sagbakken et al., 2017; van Wezel et al., 2018; Xiao et al., 2015).

In several studies ($n = 15$), caregivers reported having a problem-solving approach. Examples mentioned were as follows: moving in with the relative with dementia, changing jobs, treating the relative as a child and taking over or assisting in maintaining the social roles of the person in question. Using the internet, reading books and consulting healthcare professionals or other people in the same situation, in order to gain more knowledge about the factors associated with dementia, were other coping strategies. Some caregivers reported having developed a capability to solve problems and a sense of mastery in pre- and post-migration life. Acculturation, education and host country language ability were factors reported as contributing to higher levels of self-efficacy. Some caregivers felt a sense of mastering the situation after applying to be on a waiting list for a nursing home. In that way, they would still have the choice to accept or reject a nursing home placement. Social support and care networks provided by friends and family, caregiver support groups were reported as contributing to shared care and decreasing feelings of isolation and loneliness ($n = 15$).

The consideration of alternatives to formal care, such as employing a full-time maid or undocumented domestic helper, moving the person with dementia between relatives' houses, or temporary relocation to the home country, were mentioned in a number of studies ($n = 4$). For example, in a Belgian study (Berdai Chaouni et al., 2020), half of the study participants were assisted by an undocumented helper; usually an adult Moroccan woman of recent migration history, who was often in a precarious situation and did not speak the local language. Moreover, care marriages were mentioned as a solution if a man with dementia was widowed.

Reciprocal love—meaning and satisfaction in caregiving

Sixteen studies contributed to this theme (Ahmad et al., 2020; Berdai Chaouni et al., 2020; Berdai Chaouni & De Donder, 2019; Caldwell et al., 2014; Czapka & Sagbakken, 2020; Hinton et al., 2008; Jutlla, 2015; Liu et al., 2020; Mackenzie, 2006; Monsees et al., 2020; Morhardt et al., 2010; Naess & Moen, 2015; Ramsay et al., 2017; Sagbakken et al., 2017; van Wezel et al., 2016; Yeo et al., 2002).

A prominent reason for family members to engage in caregiving was the conviction that it was morally appropriate; participants caring for a parent considered providing care a matter of reciprocating the love that parents give to children during their upbringing ($n = 12$). In addition, the impact of religion was mentioned in several studies ($n = 7$). Caregivers often expressed how religion and spirituality, irrespective of religious denomination, helped give meaning to suffering. The caregivers' views of illness helped them cope with their caregiving tasks, to accept that there was an unequal division of care tasks in some cases and to put the enormity of the job in perspective. Some caregivers considered their behaviour as morally superior to that of non-caregiving family members or saw themselves as being 'a better believer' than non-caregiving family members. Turkish and Moroccan family caregivers, in studies conducted in Germany and the Netherlands, reported that the caregiver role gave them more respect and appreciation within the family and the community. A number ($n = 6$) of studies reported that caregiving was associated with feelings of satisfaction.

Caregivers challenging cultural traditions

Twenty-two studies contributed to this theme (Ahmad et al., 2020; Berdai Chaouni et al., 2020; Caldwell et al., 2014; Czapka & Sagbakken, 2020; Hinton et al., 2008; Hossain et al., 2020; Jutlla, 2015; Kiwi et al., 2018; Kong et al., 2010; Liu et al., 2020; Mackenzie, 2006; Monsees et al., 2020; Morhardt et al., 2010; Naess & Moen, 2015; Nielsen et al., 2020; Ramsay et al., 2017; Sagbakken et al., 2017, 2020; Sun et al., 2014; van Wezel et al., 2016, 2018; Xiao et al., 2015).

With the increasing care needs of the person with dementia, several studies ($n = 16$) reported that finding ways to meet these needs became more important to the caregivers than adhering to culturally inspired ideas of care. Second-generation migrants seemed more open to institutional care and solutions combining family care with institutional care. Traditional family care practices and attitudes were reported to be gradually changing due to changing family structures, with more women taking up paid employment outside the home.

A number of studies ($n = 7$) reported on caregivers' positive experiences of accepting support or care. Caregivers who took their family member to get a medical evaluation and for whom it was a positive experience, felt that it had helped them modify their communication with the person with dementia. Caregivers with positive experiences of referring their relative to a nursing home mentioned relief from their concerns about the person with dementia, the ability

to escape any accusations from relatives in the event that something bad happened, and the possibility to come back to their normal life.

4 | Discussion

This review identified 22 qualitative studies in 26 articles from 10 Western countries with migrants from 30 different migrant backgrounds, mainly Asian and African. It provides a unique synthesis of migrant informal caregivers' perceptions and experiences of caring for a family member with dementia, with 12 descriptive themes covering four areas of construct: perceptions of dementia and initial help-seeking; barriers to accessing and using dementia care; caregiver burden and coping and resilience.

The analytic themes, which cut across the four areas of construct, improve the understanding of the needs, concerns and preferences of migrant family caregivers that need to be addressed in development of interventions. These include a need to educate and inform migrant communities about dementia and available care services, a need to adapt care services to be more culturally sensitive and a need to identify and address cultural issues in order to empower migrant informal caregivers.

The need to educate and inform migrant communities about dementia and available care services. A diagnosis of dementia opens the door to care services and also serves to identify who the patient's informal caregivers are and what support they need (Patterson, 2018). However, a diagnosis of dementia in migrant populations remains problematic due in part to the limited access to culturally and linguistically sensitive diagnostic tools and skills among primary healthcare staff, and in part to caregivers' cultural beliefs. Family members are often relied on for interpretation and also for conveying the dementia diagnosis to the person with dementia; their limited knowledge and understanding of dementia may thus be a barrier to diagnosis. As primary healthcare is often the initial point for recognition and diagnosis of dementia, this is a key area for further research. However, interventions working to improve knowledge of dementia in the population and improving GP recognition of the problem and adapting services to give patients more choice will not work if cultural beliefs/expectations and issues of communication and trust are not taken into consideration.

The results of this review showed that three elements seem to motivate migrants' inclination for familial care; a concern for the wellbeing of the person with dementia, a wish to comply with imported cultural norms and the care recipient's wishes, and awareness that inability or unwillingness to comply with the expectations of the relative and other would cause permanent feelings of guilt and shame. In reality, the latter leaves the caregiver with little personal choice and control. As previously highlighted, feelings of cultural obligation to provide care do not necessarily equate to willingness to care (Parveen & Oyebode, 2018). Rather, a lack of knowledge of the disease and of available services, as well as preconceived ideas about the inappropriateness of support and public healthcare, may prevent caregivers from seeking or accepting formal support. This may contribute to migrant caregivers' vulnerability (Sand, 2014).

According to the demand-control-support model (Karasek & Theorell, 1990), a combination of high demands, low control and limited support in caregiving is associated with high strain and poorer physical and psychological health outcomes (Molloy et al., 2008). The reviewed studies showed that the burden placed on migrant caregivers, women in particular, was great and there would often come a point where it was no longer possible to give a family member with dementia the care they need without professional and formal care arrangements. In situations with limited control or freedom of choice, and where changing values due to acculturation challenged cultural traditions, the level of demands perceived by migrant family

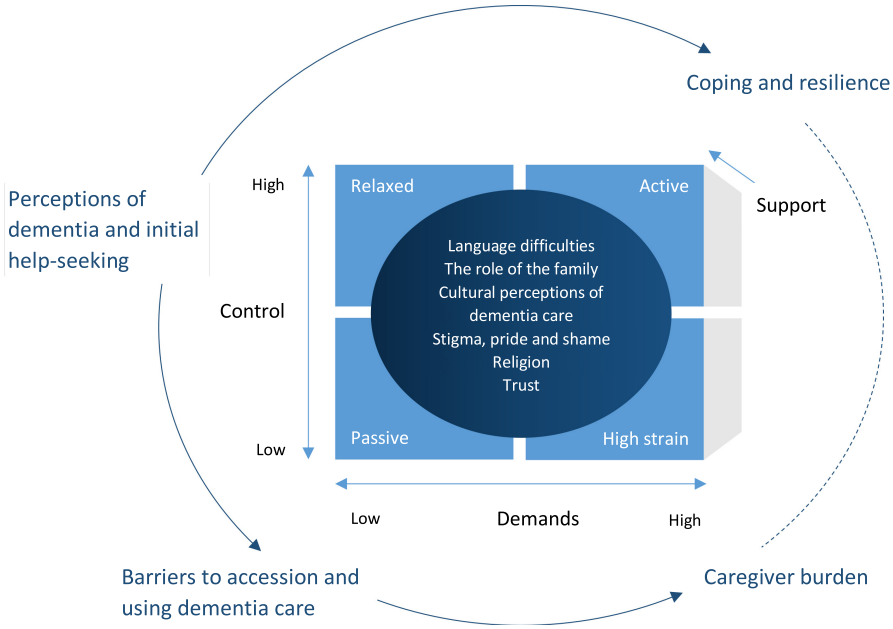

FIGURE 2 Four areas of construct in relation to the theoretical framework of the Karasek and Theorell (1990) demand-control-support model. For migrant informal caregivers, the issues listed in the inner circle will have an impact on the four concepts in the outer circle. Perceptions of dementia and help-seeking behaviour as well as access to and acceptance of formal care and support will affect the caregivers' ability to cope with the situation and their perceived level of caregiver burden. Efficient support may counteract the negative effects of high demands and thus prevent overwhelming strain [Colour figure can be viewed at wileyonlinelibrary.com]

caregivers was high, often overwhelming. As illustrated in Figure 2, an imbalance between demands and a caregiver's ability to cope with the demands contributes to high strain; informal caregivers who report a heavy caregiver burden are at higher risk of negative health sequelae such as depression (Adelman et al., 2014; Hunt, 2003).

The need to adapt care services to be more culturally sensitive. There is an assumption that ethnic minority populations prefer to 'care for their own' (Gove et al., 2018; Shanley et al., 2012), and while our findings supported this assumption to some degree, such care should not be relied on as an alternative to formal support and intervention. In situations where accepting formal care was perceived to be culturally inappropriate, there were examples of neglect and abuse, due to caregivers' limited understanding of dementia, managing dementia-related behaviours and coping with caregiver burden. Healthcare professionals were aware of the families' non-use of formal services. Sometimes, this may result in stereotypical thinking and behaviour, such as assuming that these families would not consider professional care options and consequently not even proposing such measures to them. Among older migrants, social networks, including intergenerational and diaspora networks, may be important sources of emotional, financial and practical support (WHO Regional Office for Europe, 2018). However, due to migration, family caregivers may experience fragmentation of families and geographic dislocation, leading to disrupted social networks. Thus, if the informal caregivers' cultural preference is to care for a family member with dementia themselves, services need to be adapted to take this into consideration, but not to rely upon it. In order to prevent caregiver strain caused by high demands in combination with low control, it is of great importance to identify the patients' informal caregivers and their needs and provide ongoing monitoring and support of these caregivers. A large proportion of participants considered available services to be inadequate in terms of both the dementia care options available and the way in which services were provided. Instead, many preferred options that would support them in providing dementia care at home. In some cases, caregivers accepted help from home-based services or moved their relative to a nursing home, but still held on to some of the caring tasks. By supplementing the services provided, a compromise was struck between keeping face and utilising available support. If considering a nursing home, migrant family caregivers reported that a major consideration was finding a culturally appropriate facility, mainly because of language, food and religious practices. Insufficient language proficiency is a frequently identified barrier to migrants accessing and using dementia care. Caregivers in a number of studies expressed a desire for—and in some cases, gratitude towards—bilingual healthcare professionals. Bilingual healthcare professionals are sometimes used as interpreters (Gove et al., 2018), but in the reviewed studies, it was reported that they are not always confident in this role. Rather, because interpreting should be planned carefully and in accordance with the individuals' desires, in order to deliver high-quality healthcare (Hadziabdic & Hjelm, 2013) professional interpreters should be made more readily available and budgeted into the cost of providing intercultural care and support (Cheng et al., 2015).

The need to identify and address cultural issues to empower migrant informal caregivers. Although caregiving is multidimensional, many researchers examine only the multiple negative dimensions and barriers to diagnosis and care (Hunt, 2003; Kenning et al., 2017; Parveen & Oyebode, 2018). Hence, there is a paucity of studies examining the positive aspects of caregiving and factors facilitating the use of support and formal care. Like a recent study, reviewing the literature on family caregivers' experiences of providing care for a family member from an ethnic minority group living with dementia, in Europe (Lillekroken et al., 2021), this review found that despite high demands, several migrant caregivers report a deep sense of pride in caring for a family member with dementia and find the reciprocal love in caregiving contributing to feelings of meaning and satisfaction. Intercultural care and support promotes awareness of and respect for cultural differences, and it has been suggested that intercultural care and support should be developed in cooperation with people from the specific communities who currently or may eventually use it (Gove et al., 2018; Hadziabdic & Hjelm, 2020). Migrant family caregivers suggested that providing education and skills training for family members and establishing connections between service professionals and clients are very important factors in overcoming barriers. Information interventions to prevent stigmatising beliefs and overcome taboos were warranted, as other family members' positive attitudes towards nursing homes and recommendations for help-seeking from persons outside the immediate family made it easier to make the decision to move a family member with dementia into a nursing home. Given the value of religious coping shown in the reviewed studies, health and social care professionals may find it beneficial to consult with religious leaders about what they need to know to support families in their communities who are affected by dementia.

In the included studies, there were examples of caregivers challenging framing and feeling rules by accepting support in the form of formal care. For example, second-generation migrant caregivers may feel trapped between their changing values due to acculturation and the traditional expectations held by older members of the community. These caregivers may rather need support in their acculturation process.

4.1 | Limitations

There are some limitations to this review. The decision was made to focus on peer-reviewed published qualitative studies, and a systematic review of the literature was performed, but the 'grey literature' was not searched. Moreover, it is possible that there are studies that were not identified, in part due to the lack of standardisation in the terminology used in this area. However, 26 articles fulfilling our inclusion criteria were identified, giving a large body of work for

conducting a thematic synthesis analysis. Furthermore, in contrast to a recently published review by Lillekroken et al. (2021), in this review studies conducted in non-European countries were included too, further adding to the body of knowledge about migrant (and minority ethnic groups) family caregivers' experiences and perceptions of caring for a relative with dementia. Thomas and Harden (2008, p. 3) suggest that it may not be necessary to locate every available study when conducting a systematic review and thematic synthesis of qualitative research. Because 'results of a conceptual synthesis will not change if ten rather than five studies contain the same concept but will depend on the range of concepts found in the studies, their context, and whether they are in agreement or not'.

Some may argue against the synthesis of qualitative research on the grounds that the findings of individual studies are decontextualised and that concepts identified in one setting are not applicable to others. For example, in the study selection of this review, there was wide variety in sample size, context and theoretical conceptual framework. However, we attempted to preserve context by providing structured summaries of each study (topic, setting, sample, method for data collection and analysis and conceptual/methodological framework, as detailed in Table 1), giving the readers the possibility to judge for themselves whether the contexts of the studies that the review contained are similar to their own, and if the concepts are thus applicable and transferable to their context. Lastly, some of the themes raised are not necessarily specific to migrant caregivers, for example perceiving dementia as a normal part of aging, due to insufficient knowledge, which can be seen in the general population. However, the fact that some themes are represented in general populations does not detract from their relevance in migrant caregivers. Comparison of themes between ethnic minority populations or in relation to general populations or analysis on gender aspects on family caregiving were not made since this was beyond the aim and scope of this review.

5 | CONCLUSIONS

While migrants should not be considered a single homogeneous group, this review revealed commonalities that resulted in reduced understanding of dementia and the importance of diagnosis and treatment among migrant family caregivers. Language difficulties, the role of the family in care and support, cultural perceptions of dementia and care, stigma, pride and shame, religion and trust will affect migrant informal caregivers' access to and acceptance of formal care and support. These concepts will thus have an impact on a caregiver's perceived level of demand and stress, and on their resilience and sense of control, and hence on their ability to cope with the situation. Future research regarding the implementation of interventions needs to ensure respect for cultural traditions and customs, and it may be appropriate to distinguish between different migrant groups. Nevertheless, although culture needs to be recognised, it should not overshadow recognition of people's individuality.

6 | RELEVANCE TO CLINICAL PRACTICE

To prevent a negative trajectory in caregiving, with perceived demands causing high levels of stress and strain, several barriers to migrants accessing and using formal care need to be assessed and addressed. The assumption that migrant family caregivers prefer to 'care for their own' should be challenged. Although this may be true, due to migration, family caregivers may experience fragmentation of families and geographic dislocation, leading to disrupted social networks. To balance the demands placed on migrants taking care of a family member with dementia, factors strengthening the caregivers' sense of control need to be recognised and supported by health care professionals. In case of language difficulties, offering support from a professional interpreter is a key issue. Although convenient, it may be inappropriate to rely on family members for interpretation; if the relatives' knowledge and understanding of dementia is limited, it may be a barrier to diagnosis. In several languages the terms 'dementia' and 'Alzheimer' may not even exist.

Since a multitude of studies reported on migrant caregivers' difficulties in navigating the health care system, it is equally important to educate migrant communities about how health professionals and health services work and to educate health professionals about migrant communities. Care services need to be more culturally sensitive. Because it is of equal importance that issues of communication and trust are taken into consideration, intercultural care and support should be developed in cooperation with people from the specific communities who currently or may eventually use it.

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CONFLICT OF INTEREST

The authors have no conflict of interest to declare.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.

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SUPPORTING INFORMATION

Additional supporting information may be found in the online version of the article at the publisher's website.

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