

Experiences of older immigrants living with dementia and their carers: a systematic review and meta-synthesis

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BMJ Open Experiences of older immigrants living with dementia and their carers: a systematic review and meta-synthesis

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ABSTRACT

Objective To systematically review and synthesise evidence on the experiences of older immigrants living with dementia and their carers.

Design A systematic review and meta-synthesis of qualitative studies.

Methods Studies exploring the experiences of older immigrants living with dementia and their carers were eligible. Databases were searched including CINAHL, MEDLINE, PsycINFO, PubMed, Embase, Web of Science and Cochrane Library from January 2000 to April 2021. Quality assessment was undertaken using the Critical Appraisal Skills Programme checklist for qualitative studies. Data were then synthesised using the thematic synthesis approach.

Results The results of this meta-synthesis were reported according to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses statement and Enhancing transparency in reporting the synthesis of qualitative research statement. A total of 3857 studies were returned from the database search. Eighteen studies were included for meta-synthesis. Five synthesised findings were identified: living with dementia and caregiving; family relationships; barriers to dementia care services; stigma and discrimination; and legal and financial issues. The experiences of living with dementia and caregiving presented multiple challenges for older immigrants living with dementia and their families. However, there seems to be very little difference between the experiences of those who have migrated to a new country and those who were born and aged in the same country, but the ability to access and use the available services is different.

Conclusion A lack of culturally appropriate dementia services, language barriers and dementia stigma can impede access to dementia care for older immigrants. Strategies to mitigate these barriers are urgently needed to ensure people from culturally and linguistically diverse backgrounds with dementia and their families have the information, education and support to access dementia services, in addition to research that explores the experiences of culturally and linguistically diverse populations.

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INTRODUCTION

The demand for dementia services among immigrants is increasing globally due to issues identified across developed countries,

STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ This systematic review follows the Preferred Reporting Items for Systematic Reviews and Meta-Analyses statement and Enhancing transparency in reporting the synthesis of qualitative research statement.
- ⇒ Our search strategy was restricted to studies published in English and all the selected studies came from high-income countries.
- ⇒ The Critical Appraisal Skills Programme checklist was used to assess the quality of the included studies, but all the studies were included for meta-synthesis irrespective of their quality.
- ⇒ Meta-synthesis was conducted using the thematic synthesis approach and synthesised findings were interpreted using the socioecological model.

in relation to the increasing life span, health risks and age profiles of this population group.¹ However, older immigrants experience several barriers to accessing dementia care,²⁻⁴ including delay in seeking diagnosis and care.^{5,6} The number of migrants is increasing globally, with 34.3 million older immigrants (aged 65 years or above) worldwide.⁷ Immigrants are at higher risk of developing dementia due to lower education levels,⁸ social isolation caused by migration,⁹ cultural differences and language barriers,¹⁰ poor dietary habits, smoking and sedentary lifestyles.¹¹ Several studies have reported a higher prevalence of dementia in immigrants.¹²⁻¹⁴

Arora *et al*¹⁵ have reported that the older immigrants' healthcare experiences are affected by aspects of their health literacy, language barriers and differences in health beliefs. Immigrants are a culturally and socioeconomically diverse group, where their experiences of health service use, including dementia care, can vary considerably from the rest of the population.¹⁶ Hence, healthcare policies that are sensitive to diversity and practices are needed in order to tackle the health and social needs of these ageing

immigrants.¹⁷ This should include high-quality, person-centred dementia care, where the individual needs, preferences and values drive the care, rather than a standardised approach to treatment.¹⁸

Understanding immigrants' experiences of living with dementia can help tailor person-centred services for people living with dementia and their families and carers.¹⁹ However, research regarding ageing, illness and the dying needs of immigrants and refugees is sparse and fragmented, despite its recognition as an important public health issue.²⁰ A preliminary search of PROSPERO, MEDLINE, the Cochrane Database of Systematic Reviews and Joanna Briggs Institute of Evidence Synthesis at the time of the study revealed no systematic reviews on the experience of care for older immigrants with dementia. Therefore, this systematic review aimed to explore the experiences of older immigrants living with dementia, regardless of their country of origin or destination. The research question 'what are the experiences of older immigrants living with dementia and their carers?' guided this systematic review.

Socioecological model

The socioecological model (SEM) was used in this study to provide a multilevel perspective in understanding the experiences of older immigrants living with dementia. According to the SEM, individual health behaviours are influenced by intrapersonal, interpersonal, organisational, community and policy factors that are inter-related.²¹ The intrapersonal level includes individual characteristics like knowledge, attitudes, skills, behaviours and self-concepts, followed by interpersonal factors referred to via social networks, relationships with family and friends and support systems. The organisational level involves institutions with operational rules whereas the community level involves relationships among institutions. The policy level refers to legal systems and government policies.²¹

METHODS

Design

A meta-synthesis was deemed appropriate for this systematic review, as it allows for in-depth exploration of the findings of multiple studies²² in developing an understanding of the experiences of older immigrants living with dementia and their carers. The results of this meta-synthesis have been reported using the Preferred Reporting Items for Systematic Reviews and Meta-Analyses²³ statement and Enhancing transparency in reporting the synthesis of qualitative research statement.²⁴ A few amendments from the study registered with PROSPERO are discussed in the methods sections.

Eligibility criteria

The inclusion criteria of this systematic review included (1) older immigrants living with dementia or described as having dementia or receiving care for dementia-related

conditions. Immigrants were defined as people who moved from their country of nationality to live in a foreign country as their new place of residence²⁵ whereas older people were determined as those aged 55 years or older. The age of 55 years was chosen to include people from low and middle-income countries, who are known to have shorter life expectancies.²⁶ Studies focusing on the experiences of carers of older immigrants living with dementia were included in the review. 'Carers' for this review included family caregivers (FCG) who have taken up a caring role; and healthcare workers consisting of personal care aides, nurses, psychiatric nurses, nurse assistants, care managers, physicians, general practitioners, doctors, psychologists, neurologists, voluntary sectors, consultants, representatives of immigrants and health professionals, as well as intercultural mediators. Further to this, the inclusion criteria included (2) the phenomena of interest focused on the experiences of dementia; (3) primary studies with qualitative or mixed methods research design that had qualitative data; (4) English-only studies, considering the risk of data being misunderstood or lost during the translation²⁷ as well as for the reason of feasibility. This systematic review excluded asylum seekers and refugees as their experiences involve challenges that are different when compared with immigrants.

Search strategy

A systematic search using an a priori search strategy was conducted in CINAHL, MEDLINE, PsycINFO, PubMed, Embase, Web of Science and Cochrane Library, with the publication dates from January 2000 to April 2021 to improve the relevance of studies included, and to align with the changing healthcare systems and recent migration patterns. Manual searching of reference lists of included studies was conducted to identify any relevant studies. The search strings and the titles extracted from each database are shown in [table 1](#).

Study selection

All identified studies were imported into EndNote V.X9.3.3 (Clarivate Analytics, Philadelphia, USA) and duplicates were removed. PC screened references by titles and abstracts, where full eligible texts were assessed independently by PC and DP, recording the reasons for excluded articles. Discrepancies were resolved through discussion with other reviewers.

Critical appraisal

This systematic review used the Critical Appraisal Skills Programme²⁸ tool to assess the methodological quality of included studies. This is the most frequently used tool²⁹ that addresses the principles and assumptions underpinning qualitative research.²⁴ PC independently appraised all 18 articles, where two reviewers (LW and BL) peer-reviewed 10 articles each. Discrepancies were resolved through discussion.

Table 1 Titles extracted from each database using search query

Search query	Database							
	CINAHL	MEDLINE	PsycINFO	Embase	WOS	PubMed	CL	
S1 older OR elder* OR senior* OR geriatric OR adult* OR aged	2 569 203	8 676 527	2 369 350	11 301 861	6 361 200	8 929 504	954 140	
S2 immigrant* OR emigrant* OR migrant* OR foreign-born OR overseas-born OR non-English-speaking	52 194	60 299	41 150	680 067	153 622	60 018	1588	
S3 dementia OR Alzheimer's OR 'cognitive impairment' OR 'cognitive disorders' OR 'memory loss' OR 'memory disorders'	165 349	362 851	157 024	455 278	377 185	356 477	32 456	
S4 #1 AND #2 AND #3	2417	530	284	432	402	367	46	
S5 S4 narrowed by language (English), peer-reviewed and publication dates (January 2000 to April 2021)	2144	452	217	398	333	271	42	

Search date: 5 April 2021.
CL, Cochrane Library; WOS, Web of Science.

Data extraction and synthesis

PC independently extracted the following data from the included studies: study (year), country, study objectives, participants and setting, design and main findings. Two reviewers (DP and BL) examined the extracted data with discrepancies resolved through discussion.

The five levels of the SEM framework were used to frame the data. PC conducted meta-synthesis using the thematic synthesis method, specifically designed for qualitative systematic reviews.³⁰ It was an inductive approach as the themes were generated based on the data. First, PC carefully read and re-read the included studies to get familiarised with the studies. Second, all the included studies were coded line by line. All the coded texts were checked to ensure consistency of interpretations and when necessary new codes were created. Third, similar codes were grouped and categorised as subthemes. Subthemes across articles were compared and matching subthemes from different articles were grouped. PC reassessed and reorganised subthemes and themes throughout the process. Findings, subthemes and themes were examined by all other reviewers to ensure rigour. Finally, similar subthemes were then grouped into a larger theme and interpreted using the SEM framework.

Patient and public involvement

Patients and the public were not involved in the design, conception or conduct of this study.

RESULTS

Literature search

A total of 3857 studies were identified and, whereby after deduplication, 2681 titles and abstracts were screened. After a full-text assessment of 263 articles, 18 studies were included in the meta-synthesis. The overall literature search and selection process is outlined in figure 1.²³

Quality assessment

The quality assessment of the included studies is summarised in table 2. Only five studies reported the researcher-participant relationship.^{16 31-34} Six studies insufficiently reported the ethical approval process.³⁵⁻⁴⁰ Studies were not excluded based on their quality as there is currently no accepted method for the synthesis of qualitative research,⁴¹ where individual studies may well generate new insights.⁴²

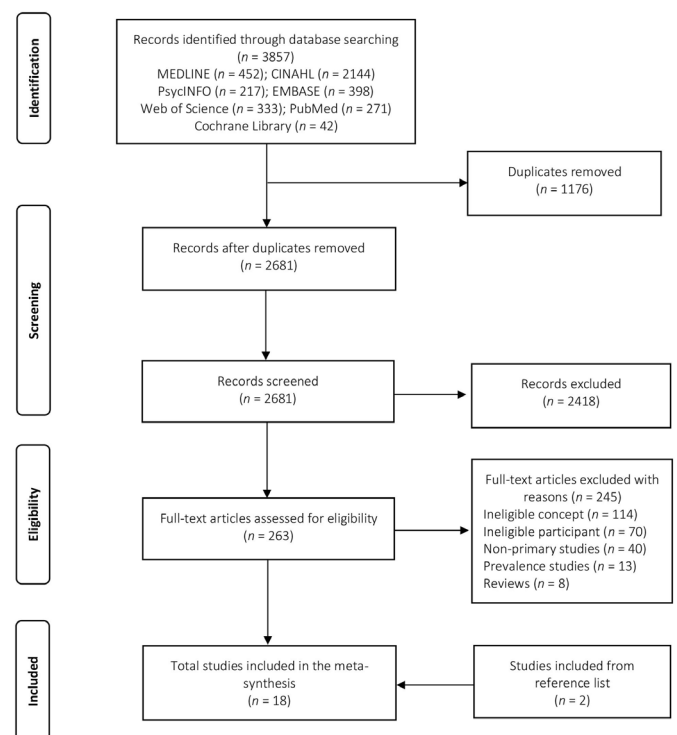


Figure 1 Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) flow chart.



Table 2 Quality assessment of included studies

Study	1. Was there a clear statement of the aims of the research?	2. Is a qualitative methodology appropriate?	3. Was the research design appropriate to address the aims of the research?	4. Was the recruitment strategy appropriate to the aims of the research?	5. Were the data collected in a way that addressed the research issue?	6. Has the relationship between researcher and participants been adequately considered?	7. Have ethical issues been taken into considerations?	8. Was the data analysis sufficiently rigorous?	9. Is there a clear statement of findings?	10. How valuable is the research?
Sagbakken <i>et al</i> ¹⁶	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Lawrence <i>et al</i> ³¹	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Czapka and Sagbakken ³²	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
van Wezel <i>et al</i> ^{33 34}	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Ahmad <i>et al</i> ³⁵	Y	Y	Y	Y	Y	N	?	Y	Y	Y
Antelius and Kiwi ³⁶	Y	Y	?	?	?	N	?	?	N	N
Chaouni <i>et al</i> ⁴³	Y	Y	Y	Y	Y	N	Y	Y	Y	Y
Chaouni and De Donder ⁴⁴	Y	Y	?	?	?	N	?	?	?	?
Lee <i>et al</i> ³⁸	Y	Y	?	Y	Y	N	?	Y	Y	Y
Lee Casado <i>et al</i> ³⁷	Y	Y	?	Y	Y	N	?	Y	Y	Y
Mazaheri <i>et al</i> ¹⁹	Y	Y	Y	Y	Y	?	Y	Y	Y	Y
Monsees <i>et al</i> ³⁹	Y	Y	Y	Y	Y	?	Y	Y	Y	Y
Söderman and Rosendahl ⁴⁵	Y	Y	N	Y	Y	?	Y	Y	Y	Y
Sun <i>et al</i> ⁴⁶	Y	Y	N	Y	Y	N	Y	Y	Y	Y
Kong <i>et al</i> ⁴⁷	Y	Y	Y	Y	Y	N	Y	Y	Y	Y
Neary and Mahoney ⁴⁸	Y	Y	Y	Y	Y	N	Y	Y	Y	Y
Yeo <i>et al</i> ⁴⁰	Y	Y	?	Y	Y	N	?	?	Y	Y
Boughtwood <i>et al</i> ⁴⁹	Y	Y	Y	Y	Y	N	Y	Y	Y	Y
Bowes and Wilkinson ⁵⁰	Y	Y	?	Y	Y	N	?	?	?	?

?, Can't tell; N, No; Y, Yes.

Study description

Most of the included studies were published from 2014 to 2020 (n=14).^{16 19 32–39 43–46} The studies were conducted in nine different countries: USA (n=6),^{37 38 40 46–48} The Netherlands (n = 3),^{33–35} Sweden (n=3),^{19 36 45} Belgium (n=2),^{43 44} Norway (n=2),^{16 32} Australia (n=1),⁴⁹ Germany (n=1),³⁹ Scotland (n=1)⁵⁰ and the UK (n=1).³¹ Study participants were older immigrants living with dementia (n=2),^{19 31} FCGs (n=9),^{33–35 37 39 40 47–49} person care aides (n=1),³⁸ nursing staff (n=2)^{36 45} and a mixture of FCGs and healthcare workers (n=6) consisting of general practitioners, nurses, and nurse assistants,¹⁶ general practitioners, psychologist, neurologist, nurses and intercultural mediators^{43 44}; representatives of immigrants and health professionals³²; physicians, nurse, social workers, programme administrators⁴⁶; general practitioners, community psychiatric nurses, consultants and voluntary sector providers.⁵⁰

Participants were from Poland, Croatia, Finland, China, Korea, Vietnam, Pakistan, India, Bangladesh, Sri Lanka, Iran, Morocco, Turkey, Lebanon, Africa and South America. Most of the participants in the included studies were females. Participants were recruited via community organisations (dementia centres, mental health teams, nursing homes, memory clinics, religious centres) and key figures in the community,^{31–34 39 43 44 48–50} followed by community organisations alone.^{16 19 37 38 40 46 47} Purposive sampling^{16 31 35 37 38 47 48 50} was commonly used to recruit participants, with snowball^{39 43 44} and convenience⁴⁰ sampling in a few studies.

Individual interviews were used in 13 studies,^{19 31 32 35 36 39 40 43–45 47 48 50} with four studies using focus group interviews,^{37 38 46 49} two studies using both individual interviews and focus groups^{33 34} and one study using a mixture of individual, dyad and focus group interviews.¹⁶ A full description of the study characteristics is summarised in online supplemental table 1.

Review finding

Five themes emerged from the meta-synthesis, arranged under each level of the SEM as shown in figure 2. Studies contributing to each of these themes and subthemes are listed in table 3. An overview of themes and illustrative quotes is provided in online supplemental table 2.

Intrapersonal: living with dementia and caregiving

The intrapersonal level included the lived experiences of older immigrants living with dementia and those engaged in providing care, listed under four subthemes: living with dementia; caregiving challenges; caregiving obligation and benefits; and lack of dementia knowledge.

Living with dementia: being forgetful and becoming dependent

Living with dementia was described as living with forgetfulness.^{19 31 48 50} Older immigrants described living with dementia as sad and embarrassing, as their forgetfulness caused problems for their family members.¹⁹ Some described being incompetent and dependent as they failed

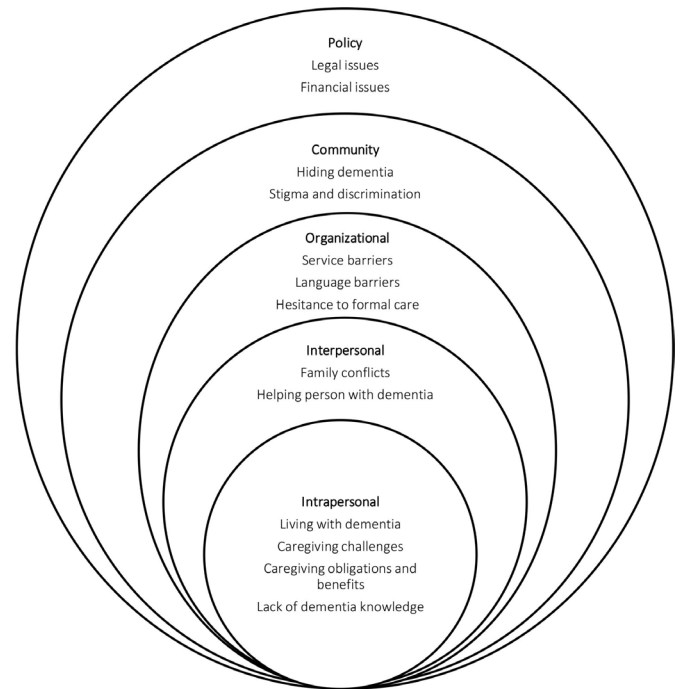


Figure 2 Socioecological model.

to do things on their own due to their forgetfulness.^{19 31} Older immigrants living with dementia felt worried about their future and concerned about the problems caused by their conditions,³¹ although they noted that they felt respected and loved within their families.¹⁹

Some older immigrants living with dementia expressed being comfortable going out whenever they liked, while others experienced difficulties integrating into a new society due to language barriers.¹⁹ Some described their efforts to keep things as normal as possible, not telling that they had forgotten anything when they experienced forgetfulness.¹⁹ Living with dementia was described as having a profound impact on the daily lives of older immigrants as the condition intensified.⁵⁰

Caregiving: emotionally and physically challenging

Caregiving was described as physically and emotionally challenging.^{43 44 49} Managing behavioural and psychological symptoms of dementia,^{35 37–40 43 45 48 50} including changes in behaviours like wandering, night activity and getting lost in familiar situations,^{37–39 50} was noted as challenging and increasing the caregiving burden. FCGs described the impact of caregiving on their health but experienced limited time to care for themselves since they had to be with older immigrants living with dementia all the time.^{37 49} One healthcare worker attributed her poor health to the demanding and stressful impact of the caregiving role.³⁸

FCGs explained how their marriage had been impacted and some described marital breakdowns as a result of the caregiving burden.⁴⁹ They also admitted their lack of preparedness to handle the pressure from the demands of providing care in addition to the impact of migration on their livelihood.¹⁶ Other challenges included



Table 3 Themes, subthemes and studies contributing

Themes	Living with dementia and caregiving			Family relationship		Barriers to dementia care			Stigma and discrimination			Legal and financial issues	
	Living with dementia	Caregiving challenges	Obligation/benefits	Dementia knowledge	Family conflict	Helping the OIWD	Service barriers	Language barriers	Hesitance towards formal care	Hiding dementia	Shame/discrimination	Legal issues	Financial issues
Subthemes → Studies													
Sagbakken <i>et al</i> ¹⁶	FCG	FCG	FCG	FCG/HCW	FCG HCW		FCG HCW	FCG	FCG				
Lawrence <i>et al</i> ³¹	OIWD												
Czapka and Sagbakken ³²	FCG	FCG	FCG	FCG/HCW			FCG HCW	FCG	FCG	FCG	FCG	HCW	HCW
van Wezel <i>et al</i> ³³									FCG	FCG			
van Wezel <i>et al</i> ³⁴	FCG	FCG	FCG		FCG			FCG					
Ahmad <i>et al</i> ³⁵	FCG	FCG	FCG		FCG			FCG					
Antelius and Kiwi ³⁶										FCG	FCG		
Chaouni <i>et al</i> ⁴³	FCG	FCG	FCG				FCG	FCG	FCG	FCG	FCG	HCW	FCG
Chaouni and De Donder ⁴⁴	FCG	FCG	FCG			FCG	FCG HCW	FCG	FCG	FCG	FCG	FCG	FCG
Lee <i>et al</i> ³⁸	FCG	FCG	FCG				FCG	FCG					
Lee Casado <i>et al</i> ³⁷	FCG	FCG	FCG				FCG	FCG					
Mazaheri <i>et al</i> ¹⁹	OIWD												
Monsees <i>et al</i> ³⁹	FCG	FCG	FCG				FCG	FCG					
Söderman and Rosendahl ⁴⁵	FCG	FCG	FCG				FCG	FCG					
Sun <i>et al</i> ⁴⁶	FCG	FCG	FCG				FCG	FCG					
Kong <i>et al</i> ⁴⁷	FCG	FCG	FCG				FCG	FCG	FCG	FCG	FCG		
Neary and Mahoney ⁴⁸	FCG	FCG	FCG				FCG	FCG	FCG	FCG	FCG		
Yeo <i>et al</i> ⁴⁰	FCG	FCG	FCG				FCG	FCG	FCG	FCG	FCG		
Bowes and Wilkinson ⁵⁰	FCG	FCG	FCG				FCG	FCG	FCG	FCG	FCG		
Boughtwood <i>et al</i> ⁴⁹	FCG	FCG	FCG				FCG	FCG	FCG	FCG	FCG		

FCG, family caregiver; HCW, healthcare worker; OIWD, older immigrant living with dementia.

difficulties in understanding the needs of older immigrants living with dementia¹⁶ and the stigma associated with dementia⁴⁰ that augmented their caregiving challenges. FCGs described a lack of support from family members in providing care for older immigrants living with dementia,^{35 37 43 50} with struggles to work full time and provide care as other family members abandoned them.³⁵

Several FCGs reported that they felt disappointed with the lack of support from family members and sought help only if it was required.³⁷ There were instances when FCGs often directed their frustrations to older immigrants living with dementia when they were too tired to provide care.³⁵ They had limited time for themselves as they were the only ones providing care for older immigrants living with dementia,^{16 33 39 49 50} where some even sacrificed their jobs to provide care.^{35 39}

Caregiving: obligation and benefits

Caregiving was described as a family obligation, a religious or cultural responsibility, a symbol of respect or a means of reciprocating love that they have received from their parents when they were young.^{16 32 34 35 37–40 44 48 50} FCGs described sending their loved ones to a nursing home as disheartening, disrespectful and unfilial.⁴⁷ FCGs expressed caregiving as a payback for the love and care they received from their parents when they were young.^{16 39 44} For some, providing care to a family member meant transferring the legacy of caregiving to their children so that the younger generations learnt to provide care to their elders in the future.⁴⁸

FCGs believed caregiving to be a means of earning respect within the family and community.⁴⁰ However, family caregiving practices limited their choice of caregiving or seeking formal care.³⁴ One FCG caring for her mother-in-law with dementia described her frustration over her caregiving role,³⁷ while others expressed pride about their caregiving duty.³⁵ Some described the formation of bonds with the older immigrants living with dementia that strengthened their relationship,³⁴ with feelings of satisfaction and fulfilment attributed as caregiving benefits,^{34 35 39} that in turn further motivated them to provide care.³⁴

Lack of knowledge about dementia

Lack of knowledge about dementia affected both the FCGs and healthcare workers. FCGs described their lack of dementia knowledge,^{32 38 39 48 50} which impacted their access to dementia care. Healthcare workers also described the limited dementia knowledge of FCGs³² while experiencing the need to upskill their knowledge about dementia.³⁸ FCGs felt that having a sound knowledge about dementia would increase their patience in caring for older immigrants living with dementia.³⁸

One FCG even expressed how their lack of dementia knowledge led to delayed diagnosis of dementia as they took too long to understand dementia,³² also due to their belief that forgetting was normal,⁴⁴ noting dementia to

be a result of one's bad deeds from a previous life.^{32 44} FCGs also expressed that not being aware of formal care made it difficult for them to avail themselves of appropriate dementia care.^{43 44} One study described how FCGs accidentally knew about formal care during their visit to a physiotherapist.⁴⁴

Interpersonal: family relationship

The interpersonal level included relationships among carers and family members under two subthemes: family conflict and helping the older immigrants living with dementia.

Family conflicts

Carers experienced conflicts within the family that arose from caring for older immigrants living with dementia.^{16 35 37 38 48 49} One healthcare worker described an incidence where family members argued over providing care as the caregiving role intensified.^{38 49} Family conflicts ensued when non-caregiving family members blamed FCGs for admitting older immigrants living with dementia to a hospital, for example.³⁵ FCGs expressed that the responsibility to provide care for older immigrants living with dementia fell on the principal caregiver as others left them behind.⁴³

Helping the older immigrants living with dementia

Few studies described the measures for helping the person with dementia (PWD).^{44 45 47 49} Carers described a need for speaking slowly and staying calm to help older immigrants living with dementia find words to express their needs.⁴⁵ They also indicated the importance of attending to the needs of older immigrants living with dementia immediately before they forget.⁴⁷ Caring with humour and kindness helped older immigrants living with dementia feel better emotionally and physically.⁴⁹ A nurse described that serving traditional foods and playing music in their language created a sense of closeness among older immigrants living with dementia.⁴⁵ Non-verbal communication, such as body language, helped older immigrants living with dementia understand and feel connected.⁴⁵

Organisational: barriers to dementia care

The organisational level included service and language barriers impacting dementia care provisions under three subthemes: service barriers, language barriers and hesitance towards formal care.

Service barriers

Service barriers to dementia care included a lack of culturally appropriate dementia services^{37 39 45–47 50} and difficulty in accessing dementia-related information.^{32 46 50} The lack of culturally sensitive diagnostic tools impacted the diagnosis of dementia among immigrants.⁴⁴ Healthcare workers described inadequate care services for immigrants living with dementia and stated that the available services, if there were any, were culturally inappropriate.⁵⁰ Lack of access to information about dementia services was



challenging for the FCGs.³² Educating FCGs on dementia and creating linkages between healthcare workers and FCGs were perceived to minimise barriers to care.^{43 46} Carers felt the need for culturally appropriate dementia services for immigrants living with dementia so that they felt that their cultural needs were understood.^{39 44}

Language barriers

Language barriers impeded the provision of care services for older immigrants living with dementia and their families.^{16 32 37 39 43 44 46 47} One FCG described the difficulties of not being able to communicate in English, as the dementia services were all provided in English.³⁷ Carers felt that dementia services needed to provide translators, bilingual caregivers and information translated into different languages,^{39 44} as older immigrants living with dementia were not able to express their needs to healthcare workers in English.⁴⁴ Healthcare workers also described that the language barrier hindered communication with older immigrants living with dementia and strained relationships with their family members.^{16 43 45} Healthcare workers also described the challenges of diagnosing dementia in immigrants due to language problems.³² Similarly, one FCG indicated a lack of bilingual and skilled formal carers, even if they wanted to engage in formal care.⁴⁶

Hesitance towards formal care

FCGs described their hesitance towards formal care due to their negative experience with healthcare workers,³⁵ noting formal care to be viewed as culturally insensitive,^{32 43 44 50} inadequate^{16 47 48} and not person-centred care.^{43 44} Some FCGs described that formal care was not set up to provide care for immigrants, where older immigrants living with dementia were left to suffer.^{34 47} Further, FCGs felt that using formal care was being unfilial³⁵ and described their reluctance to use formal care unless deprived of alternatives.³⁴ Another FCG mentioned formal care as lacking provisions for religious practices,³² leading some older immigrants living with dementia to refuse uptake of formal care.³⁹

Community: stigma and discrimination

The community level included dementia-related stigma and shame under two subthemes: hiding dementia and dementia-related shame and discrimination.

Hiding dementia

FCGs expressed that they had hidden dementia from people outside their families.^{33 36 40 43 44} They articulated difficulties in talking about dementia openly when older immigrants living with dementia did not want the community to know about their condition.³³ One FCG described that they kept the dementia diagnosis of their family member a secret to stop people looking down on them.⁴⁶

FCGs stated a lack of dementia knowledge as one of the reasons for hiding dementia.³² One healthcare worker mentioned that people avoided disclosing dementia

conditions of their family members thinking it might impact marriages.⁵⁰ Some healthcare workers described dementia as a taboo, a reason why people were reluctant to be open about it.⁴⁴ However, some FCGs shared that they talked about dementia openly if the older immigrants living with dementia felt comfortable.³³

Shame and discrimination

Several studies have reported on dementia-related shame and discrimination.^{16 32 33 36 38–40 43 44 46 48 49} Healthcare workers noted they were concerned about being accused of discrimination and described being very careful about what they said to the family members of older immigrants living with dementia.⁴³ One FCG described how her father living with dementia was treated by a doctor without any respect,⁴³ while others experienced being racially discriminated⁴⁸ against and neglected by general practitioners.^{32 50}

FCGs recounted being looked down on by people when they placed their parents in a nursing home.³⁸ A relative described how one of her family members, out of concern for how people would treat her, provided care to an older immigrant living with dementia at home although she was always exhausted.¹⁶ Healthcare workers also cited that FCGs were ashamed about their parents' dementia.³⁶ A wife caring for her husband living with dementia conceded that they stopped going out for dinner ever since her husband developed dementia.⁴⁶

Policy level: financial and legal issues

The policy level included the impact of policies on dementia care under two subthemes: financial issues and legal issues.

Financial issues

FCGs stated that formal care is expensive,^{32 43} wishing for more flexibility in using the help provided by the state. One of the participants described the care allowance that they received from the state as minimal, with limited options for use as they were made to first avail themselves of services within the municipality.³²

Legal issues

One healthcare worker described not being able to use interpreters or other mediator services when dealing with immigrants living with dementia due to hospital procedures.⁴³ One FCG described how nurses refused help provided by FCGs in washing and dressing older immigrants living with dementia in home care.³² However, one of the nurses described how she often had to negotiate between the family expectancies, needs of older immigrants living with dementia and organisational rules, citing an example where she allowed family members to attend to their older relative when she was dying but made them leave the room once the dying woman was exhausted.³²

DISCUSSION

This review aimed to synthesise the experiences of older immigrants living with dementia and their carers; however, only two of the included studies explored the experiences of older immigrants living with dementia. As such, our findings relate more to caregiver (especially FCGs) experiences. Additionally, most of the included studies explored the experiences of female FCGs, which may be due to the gendered role of caregiving in many cultures. While the findings of this review have primarily focused on the experiences of female caregivers, as has been noted by other authors, efforts to engage male caregivers are needed.^{35 44 51}

Our findings indicate that the experiences of living with dementia are invariably complex and may depend on individual attitudes and belief systems (culture), the severity of dementia and the ability to navigate through health systems. For example, in our review, some older immigrants living with dementia felt comfortable going out and meeting people, whereas it remained distressing and stigmatising for many others.¹⁹ Hence, it is imperative to consider the influence of culture, social and economic aspects on the experiences of living with dementia. A synthesis of qualitative studies has found family love as a source of strength and inspiration for the PWD,⁵² helping to maintain their dignity.⁵³ Similarly, our review revealed that older immigrants living with dementia felt loved and respected within the family, demonstrating the importance of caring with love.

Our review has noted caregiving as physically and emotionally challenging. Lack of dementia knowledge, lack of culturally appropriate dementia services and language barriers challenged the meaningful experiences of living with and caring for dementia. A recent systematic review on barriers and facilitators of meaningful engagement among older immigrants living with dementia in residential aged care facilities has reported communication barriers to impact meaningful engagement among older immigrants.⁵⁴ The World Alzheimer Report 2021 also identified a lack of specialised diagnostic tests and diagnosis knowledge as key barriers to dementia diagnosis.⁵⁵

Echoing the findings of this review, the largest dementia attitude survey of 70 000 people across 155 countries by Alzheimer's Disease International has revealed that over 35% of carers globally have hidden the dementia diagnosis within their families.⁵⁶ This review shows that a lack of dementia knowledge aggravates dementia stigma that stems from differing cultural perceptions about dementia. Improved dementia knowledge can lessen the cultural perceptions of dementia and create a sense of belongingness for carers and families. This will be one step towards ensuring quality care for older immigrants with dementia, as Brijnath *et al.*⁵⁷ noted that communicating clearly and empathetically with PWD and their families is important in reducing dementia stigma.

The distress, stigma and overwhelming human experience of dementia are shared by all those who live with the

condition and the people who love and care for them. The fact that there seems to be very little difference between the experiences of those who have migrated to a new country and those who were born and aged in the same country demonstrates the inequity that simply coming from a culturally and linguistically diverse (CALD) community brings. The experience is the same, the needs are the same, but the ability to access and use the available services is different. This means that more attention must be given to ensuring people from CALD backgrounds with dementia and their families have the information, education and support to access services for help and respite.

Strengths and weaknesses of the study

The strengths of this review include a systematic search to inform the meta-synthesis and the use of SEM as a theoretical framework that enabled interpretations of experiences of people with dementia from a more holistic multilevel approach. Further, to the best of our knowledge, no qualitative systematic review has examined this topic.

This review has several limitations. The lack of studies from countries other than the USA and Europe questions the applicability of findings to countries with different health systems, migration policies and cultures. Further, the inclusion of studies in our review irrespective of their quality cautions the interpretation of the findings. Additionally, the inclusion of English-only studies introduces selection bias while unclear titles and abstracts may have possibly omitted relevant studies during the screening process. Studies included in this review were conducted in a variety of settings which is a strength as the experiences of older immigrants living with dementia and carers represented different aspects of aged care settings. However, this affects the generalisability of certain findings. Most of the study participants in this review were female caregivers, which limits the generalisation of the findings to the male caregivers, but it is a strength in that we can have higher confidence in the findings related to female caregivers.

Future research and recommendations

Research focusing on the specific needs of the older immigrants living with dementia have begun to appear in the literature. However, several gaps in knowledge can be translated into more person-centred care for all people and families living with dementia. First, many studies included in this review came from the USA and Europe (high-income countries), highlighting the need for evidence from other multicultural countries with different health systems and migration policies. Similarly, only two studies in our review focus on the lived experiences of older immigrants living with dementia indicating challenges in recruiting PWD for research.

Second, current evidence has not considered the impact of socioeconomic status on the experiences of people living with dementia. This suggests the need to explore

the experiences of FCGs with various socioeconomic backgrounds. Third, the lack of data on family conflicts from non-caregiving family members indicates that the voices of non-caregiving family members are absent from the current evidence base. Finally, future studies may explore the experiences of living with dementia using the SEM for a better understanding of their experiences at each level of SEM.

Many countries, including Australia, welcome migrants and are working towards the goal of multiculturalism. For this to hold true for all citizens and residents, including well into late life, it means that aged care and dementia services must go the extra mile to give those who need to migrate and chose to stay in the new country the care they need at this vulnerable time in their lives. From an implementation angle, we suggest raising public awareness campaigns using appropriate and culturally sensitive language and increasing dementia training for carers, as also recommended by Alzheimer's Disease International,⁵⁶ to reduce dementia stigma.

CONCLUSIONS

The experiences of living with dementia and caregiving present many challenges. A lack of culturally appropriate dementia services, language barriers and dementia stigma can impede access to dementia care for older immigrants. Strategies to mitigate these barriers are urgently needed, in addition to further research that explores the experiences of CALD populations from multicultural countries.

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Table 1 Characteristics of included studies

Study (year); Country	Study objectives	Participants; Setting	Design; Data collection	Main findings
Sagbakken, et al. ¹⁶ (2018); Norway	Explore and describe the views and experiences of family members and professional caregivers regarding the care provided to immigrants with dementia.	12 family caregivers and 27 health caregivers (GPs, doctors, nurses, and nurse assistants); Homecare, Nursing home, clinics, GP centres.	Qualitative study; In-depth, focus group, and dyad interviews using a semi-structured interview guide.	FCG struggled to find a balance between caregiving roles and personal life. Family conflicts occurred over caregiving decisions. Formal care was considered insecure and inadequate for individualized care. HCW struggled to collaborate with families of OIWD owing to language barriers.
Lawrence, et al. ³¹ (2011); United Kingdom	Examine the subjective reality of living with dementia from the perspective of people with dementia.	30 OIWD aged 67-96 (Black Caribbean, South Asian, White British); Homecare and Dementia specific day centre	Qualitative study; In-depth interviews.	OIWD experienced forgetfulness, lost their ability to do things on their own and became dependent on family support. OIWD were concerned about their condition straining family relationships and couldn't visit places unless there were other OIWD.
Czapka and Sagbakken ³² (2020); Norway	Explore the barriers and facilitators in accessing and using dementia care services by minority ethnic groups in Norway.	8 family caregivers and 11 health caregivers (representatives of immigrants and health professionals); Not specified	Qualitative study; In-depth semi-structured interviews.	FCG experienced a lack of knowledge and awareness of dementia and related services, language barriers and cultural differences in accessing dementia care. Having healthcare personnel in the family facilitated access to dementia care services.
van Wezel, et al. ³³ (2018); Netherlands	Study the insights into the differences and similarities in the explanations for dementia and how freely this illness can be discussed, from the perspectives of female family carers.	41 female family caregivers; Not specified	Qualitative study; Individual interviews and focus group interviews.	FCG experienced not being open about dementia outside their family circle as family members never wanted the wider community to know about their dementia diagnosis. They experienced embarrassment about the behaviours of OIWD.
van Wezel, et al. ³⁴ (2016); Netherlands	Describe the perspectives of female Turkish, Moroccan and Surinamese Creole family carers in the Netherlands about providing family care to a close relative with dementia.	41 female family caregivers; Not specified	Qualitative study; Individual semi-structured interviews and focus group interviews.	FCG experienced caregiving physically and mentally challenging, lack of time for social life and limited freedom of caring options due to community pressure and family expectations. They derived a sense of fulfilment from their caregiving roles and developed a strong relationship with OIWD.

Ahmad, et al. ³⁵ (2020); Netherlands	Elucidate cultural and social dynamics that impede care sharing.	12 female family caregivers; Not specified	Qualitative study; In-depth semi-structured interviews.	FCG found caregiving challenging and had limited time for themselves. They felt proud of their caregiving roles over the non-caregiving family members and experienced conflicts in the family occurring over caregiving decisions.
Antelius and Kiwi ³⁶ (2015); Sweden	Explore how dementia is understood, explained, and experienced among Iranian immigrants working as a care staff at a Persian-oriented dementia care facility.	Health caregivers (nurses, certified nurses, care managers); Residential care and homecare	Qualitative study; Interviews (and observations).	HCW encountered families refusing to accept the dementia diagnosis of their loved ones due to dementia stigma. Family caregiving was considered a filial responsibility and hence formal care was not sought. OIWD were ashamed of using formal care as it indicated the failure of their children to provide care.
Chaouni, et al. ⁴³ (2020); Belgium	Explore how dementia care is provided to these Moroccan older people with dementia, and what challenges do caregivers face in providing care.	12 family caregivers and 13 health caregivers (GP, Psychologist, Neurologist, Nurse, Intercultural mediator); Not specified	Qualitative study; Individual semi-structured interviews.	FCG experienced a lack of dementia knowledge, person-centred care, culturally sensitive care, and high costs of care. Negative experiences with, and discrimination by formal carers prevented them from seeking formal care. HCW experienced collaborating with families difficult, language barriers, fear of being accused of discrimination, and lack of knowledge about other cultures.
Chaouni and De Donder ⁴⁴ (2019); Belgium	Collect in-depth information about the experiences of informal and formal caregivers of older persons of Moroccan origin with dementia.	12 family caregivers and 13 health caregivers (GP, Psychologist, Neurologist, Nurse, Intercultural mediator); Not specified	Qualitative study; Individual semi-structured interviews.	FCG believed dementia as a part of normal ageing, struggled revealing dementia diagnosis to their elders, and had limited knowledge about available dementia services. HCW found a lack of culture-sensitive tools for dementia diagnosis, language issues and cultural differences impeding dementia care.
Lee, et al. ³⁸ (2018); United States	Examine Korean American personal care aides' experience and perspectives concerning dementia caregiving, knowledge and beliefs about dementia, and family caregiving.	10 female health caregivers (Personal Care Aides); Homecare	Qualitative study; Focus group interviews.	HCW reported limited dementia knowledge, difficulty managing BPSD, and encountered conflicts among families of PWD. Stress from families and caregiving role impacted their health. However, caregiving became easier as they learned more about dementia and caring with empathy.
Lee Casado, et al. ³⁷ (2015); United States	Understanding the experiences and concerns among family caregivers of Korean Americans with dementia in their own words.	23 family caregivers; Not specified	Qualitative study; Focus group interviews.	FCG reported caregiving as distress and impacted their health, but filial responsibility kept them going. Experienced conflicts with family members over caregiving duties. Language and cultural barriers hindered them from using dementia care services.

Mazaheri, et al. ¹⁹ (2014); Sweden	Explore the subjective experiences of living with dementia among Iranian immigrants in Sweden.	15 OIWD aged 66-88 years with Iranian background; Homecare and group dwelling for OIWD	Qualitative study; Individual semi-structured interviews.	OIWD experienced forgetfulness and incompetence but felt loved and respected within their families. They felt confident and secure in the community but also worried about their condition causing conflicts in the family.
Monsees, et al. ³⁹ (2020); Germany	Explore caregiving experiences of family carers, identify barriers to using healthcare services and information for dementia patients, and assess recommendations from caregivers of people with dementia.	8 family caregivers; Not specified	Qualitative study; Individual semi-structured interviews. Not specified	FCG experienced caregiving as challenging managing BPSD. They suffered from stress, headaches, physical pain, sleep deprivation, depression, and lack of time for their work. A need for improved access to information and culturally appropriate services was felt.
Söderman and Rosendahl ⁴⁵ (2016); Sweden	Explore and describe the nursing staff's experiences of caring for non-Swedish speaking persons living with dementia in a Finnish speaking group concerning a Swedish speaking group home in Sweden.	27 health caregivers (Nursing staffs); Group homes	Qualitative study; Individual semi-structured interviews.	HCW experienced OIWD becoming aggressive due to communication barriers. Speaking to PWD in their native language lifted their emotions. Speaking slowly, repeating words, and using facial gestures, and eye contact helped OIWD. Traditional foods and music played in their native language helped OIWD.
Sun, et al. ⁴⁶ (2014); United States	Explore the perceptions on service barriers faced by Chinese American family caregivers and the service professionals in Arizona, United States.	6 family caregivers and 6 service professionals; Not specified	Qualitative study; Focus group interviews.	FCG experienced a lack of knowledge about accessing dementia services, lack of culturally appropriate services and bilingual formal caregivers. They experienced dementia stigma and were looked at differently by others.
Kong, et al. ⁴⁷ (2010); United States	Describe Korean immigrant caregivers' experiences regarding American nursing home placement of their non-English-speaking older relatives with dementia.	10 family caregivers; nursing home	Qualitative study; In-depth semi-structured interviews.	FCG experienced OIWD becoming aggressive due to their inability to express their needs because of communication problems. Cultural and language barriers made PWD feel isolated and formal care was considered inadequate.
Neary and Mahoney ⁴⁸ (2005); United States	Explore the phenomenon of dementia caregiving in an ethnically diverse group of Latino caregivers, to identify cultural influences on the caregiving experience.	11 family caregivers; Homecare and nursing home	Qualitative study; in-depth semi-structured interviews.	FCG experienced OIWD doing things that they normally wouldn't do, getting lost in familiar places and not recognizing family members. Experienced stress from managing BPSD, family conflicts, and limited time for themselves. Caregiving was considered a filial obligation. Experienced being discriminated against by health professionals.
Yeo, et al. ⁴⁰ (2002); United States	Elicit conceptions of dementia held by Vietnamese caregivers of elderly with dementia.	9 family caregivers; Not specified	Qualitative study; Individual structured interviews.	FCG experienced their inability to provide full care for OIWD due to their work. They have hidden dementia diagnosis of their elders from the community, and external support was not sought believing it was not in their culture.

Boughtwood, et al. ⁴⁹ (2011); Australia	Provide the first examination of the experiences and perceptions of family carers of the PWD from four Australian CALD communities.	121 family caregivers; Not specified	Qualitative study; Focus group interviews.	FCG experienced difficulties in managing BPSD, embarrassment from behaviours of OIWD and had limited time for themselves. They experienced family conflicts and health impacts from their caregiving role. Communicating with respect and kindness were found helpful for the OIWD.
Bowes and Wilkinson ⁵⁰ (2003); Scotland	Examine the views and experiences of dementia among older South Asian people, as well as their families and carers.	11 health caregivers (GPs, community psychiatric nurses, consultants, voluntary sector providers) and South Asia OIWD family caregivers; Not specified	Qualitative study; Individual semi-structured interviews and case studies.	FCG experienced poor quality of life, stress from managing BPSD, limited time for oneself, lack of dementia knowledge and access to appropriate services. Caregiving was considered an obligation. HCW encountered FCG hiding dementia diagnosis of their families. Lack of dementia knowledge and culturally appropriate diagnostic tools were barriers to dementia care.

FCG: Family caregivers; HCW: Healthcare workers; OIWD: Older immigrants living with dementia
 BPSD: Behavioural and psychological symptoms of dementia; GP: General Practitioners

Table 2 Themes, subthemes, and illustrative quotes

SEM level: Themes	Subthemes	Illustration
Intrapersonal: living with dementia and caregiving	Living with dementia – being forgetful and dependent	“... So she could say where she felt pain when she was in pain right at that moment. But she forgot afterwards... That was the problem. That’s the problem with old dementia patients.” (FCG, p326) ⁴⁷
		“I myself get upset when I misplace things, which makes them [her family members] search a lot to find them...” (OIWD, p3) ¹⁹
		“So she went to do something that she was doing all her life and doesn’t remember what [ingredient] she has to put in next. ...” (FCG, p165) ⁴⁸
		“I call someone to ask them to bring something to me. When they come, I have forgotten what I wanted. Then I just greet and thank them, without saying I forgot what I wanted.” (OIWD, p4) ¹⁹
		“...I get embarrassed when they are not able to find things. I regret that I took those things. But, you know, I cannot stop myself organizing my surroundings.” (PWD, p5) ¹⁹
		“... You have your own place, you have money. Why should you worry then... you know here, I can go out whenever I want.” (OIWD, p5) ¹⁹
		“It makes me feel how far am I going, what is the worst that can happen, you know it make me feel inadequate . . . sometimes I think oh Lord what is going on, am I getting off my brain or what?” (OIWD, p44) ³¹
		“I would rather be dead than drive somebody least of all my own wife to that sort of situation.” (OIWD, p45) ³¹
		“Because before I used to do everything for myself, go out, go to help people and do different things you know, around. I did everything for myself. But now I can’t do anything, I always forgetting you see.” (OIWD, p46) ³¹
		“... It’s a really bad disease to have, not knowing who you are, what time it is or where you are, anything ... It was degrading. We didn’t know it would get that bad, and we didn’t know that it was so degrading for the person.” (FCG, p389) ⁵⁰
Caregiving – emotionally and physically challenging		“I have to be at her side all the time, going to the bathroom, etc. How could I have time to take care of myself? Making a doctor’s appointment for my wife becomes my first priority, but my health? I don’t have time to think about it.” (FCG, p38) ³⁷
		“... My back becomes extremely sore after all that.” (FCG, p293) ⁴⁹
		“I was pretty healthy, but actually after starting taking care of patients with dementia, I got sick due to stress.” Lee et al. (HCW, p429) ³⁸
		“Despite of my full-time job and voluntary work, I was always there for my father... I kept going, I wanted to do everything for my father... The others [non-caregiving siblings] wouldn’t do that.” (FCG, p344) ³⁵
		“She [caregiver’s daughter] is busy most of the time, so I don’t go to her for little stuff . . . and ask her help only for really important things.” (FCG, p39) ³⁷
		“... It’s not about me, but about her... I expected them to do the same as I’m doing.” (FCG, p344) ³⁵
		“There were times that I screamed [at her]: “You ruined my life!” But it’s my mother, and later when I look at her and see a person who’s half dead... I think: “Why do I say those things? But it happens when I’m tired.” (FCG, p346) ³⁵

	<p>"I took three years off because of my father [...] and I haven't gone anywhere [...] it wasn't possible with my father." (FCG, p870)³⁹</p>
	<p>"Until January he was working and now we closed our shop because we have to watch my mother." (FCG, p870)³⁹</p>
	<p>"... But I have other things (i.e., responsibilities) in my life too, so if I only endure, it is not fair to my kids... I have had to accept a lot of criticism, bad criticism." (FCG, p24)¹⁶</p>
	<p>"My circle of friends is getting smaller and smaller. I can't make any time for myself to go outside for a bit." (FCG, p79)³³</p>
	<p>"I don't have time for myself or my children or my home." (FCG, p869)³⁹</p>
	<p>"I didn't know much details about the disease, so I had a very difficult time when she asked me the same question over and over—like fifteen times. ... We need to know more about the disease so we can be more patient while dealing with them." (HCW, p431)³⁸</p>
	<p>"What if she outlives me? Her life will become even more miserable. Yes, she's got our children to look after her, but it's different to the care from a husband." (FCG, p295)⁴⁹</p>
	<p>"I don't know whether there are any supportive services available in the community and nobody told us." (FCG, p129)⁴⁶</p>
	<p>"... But we do not have mechanisms for how to manage stress, to handle all these tasks—and the migration process has in many ways isolated us..." (FCG, p21)¹⁶</p>
	<p>"... I can't decide how I want to care for my mother because they consider it a bad choice. If I share the care for my mother with a professional they'll tell me I'm a bad daughter for not caring for my mother after all she has done for me." (FCG, p78)³³</p>
Caregiving – obligation and benefits	<p>"That's how it is in our culture. It is not forced. It is love I got from him when I was small. Now I am returning what I got. It is my responsibility. He has only me." (FCG, p6)³²</p>
	<p>"I did it for Allah. It's for my religion. I don't expect anything [in return]..." (FCG, p345)³⁵</p>
	<p>"I feel very happy taking care of her because she was a good mother and she deserves to get back a little of that—of everything she did for us." (FCG, p168)⁴⁸</p>
	<p>"This is our mother, this is our father, we have to watch them. They have done so much for us, so we have to take care of them now." (FCG, p868)³⁹</p>
	<p>"... Sending him to a nursing home made me feel like I was abandoning him because I didn't care about him anymore and that made me feel like I was an unfilial daughter, which broke my heart." (FCG, p323)⁴⁷</p>
	<p>"When we grew up, we saw my mother dealing with my grandmother. So we just sort of pass it on." (FCG, 166)⁴⁸</p>
	<p>"She [caregiver's daughter] is busy most of the time, so I don't go to her for little stuff . . . and ask her help only for really important things." (FCG, p39)³⁷</p>
	<p>"... I really, really don't like it at all. I don't know how long I can take care of her [mother-in-law], but as long as I can, I will do it, so I do not ask any help from other family members." (FCG, p39)³⁷</p>

		<p>“It is very fulfilling for me - I’m pleased to be with her and pleased that I’ve got her, and so I’m fully committed to it. It’s fulfilling for me, and yes it’s very tough. ...I get a lot out of it.” (FCG, p79)³⁴</p>
		<p>“I get a lot of satisfaction from it because I think that there’s nothing better in the whole world. . . I hope I’m doing it right and well, when I hear him talking about me and about the care I’m giving, that is very fulfilling.” (FCG, p78)³⁴</p>
	Lack of knowledge about dementia	<p>“I think that people often don’t know that their relatives suffer from dementia. they can’t read the symptoms. Perhaps they don’t know about illnesses such as dementia.” (HCW, p4)³²</p>
		<p>“I didn’t know much details about the disease, so I had a very difficult time when she asked me the same question over and over – like fifteen times... We need to know more about the disease so we can be more patient while dealing with them.” (HCW, p431)³⁸</p>
		<p>‘I would say it might be that we were too slow in getting help for her and that it took a while for us to understand that she had dementia. I think it would have been different if we had more knowledge. It was after she burnt something at home that we decided that was enough and that we had to find out what was wrong’. (FCG, p5)³²</p>
		<p>‘It was by chance. I was talking to my physiotherapist...he asked me if I knew about night care, and gave me the name of the organization. ... I wouldn’t know about it if he hadn’t told me’. (FCG, p9)⁴⁴</p>
Interpersonal: family relationship	Family conflicts	<p>“They would argue like “why don’t you take care, why only I have to do it?” If it’s just one or two years, it’s okay, but when it becomes like 5, 6, 7 years, then conflicts occur within the family...Like the old saying “there is not piety for a lingering illness.” When the disease becomes prolonged, the conflicts get worse.” (HCW, p431)³⁸</p>
		<p>“Look, you only see him for two hours; you don’t know what happens the other hours.” (FCG, p347)³⁵</p>
		<p>“We are left only with two of us, me and my sister K – my other sisters and brother don’t help anymore.” (FCG, p4)⁴³</p>
	Helping the PWD	<p>“I say to her “this dementia is not working well for you” and I kind of make it a joke for her to have a laugh.” (FCG, p293)⁴⁹</p>
		<p>“When I used to see her repeating a lot without making sense I would grab her hand and pray for her ... she would feel better, emotionally.” (FCG, p293)⁴⁹</p>
		<p>“It’s hard to say how much they understand, it is clearly visible from their faces and their expressions and so... how they react...” (HCW, p319)⁴⁵</p>
		<p>“... I notice that she becomes very happy when I go to her... for us, she has a lot to tell, when nobody else is in there...” (HCW, p320)⁴⁵</p>
Organizational: barriers to dementia care	Service barriers	<p>“People with dementia – I don’t think they have any services. There is no access and if they have tried using them, then they are not appropriate to their needs.” (HCW, p394)⁵⁰</p>
		<p>“Immigrants know very little about how to help an elderly person with dementia in Norway. I must tell you that I have lived here for 22 years and there is a problem with it, because we don’t know where to get information and help.” (FCG, p5)³²</p>
		<p>“People often lack sufficient information. You get everything in Norwegian. When you go to doctor, everything is in Norwegian. When you go to other places, everything is in Norwegian.” (HCW, p8)³²</p>

		<p>“There are low-income housing apartments for older Chinese adults, but there are no special housing facilities for Chinese dementia patients (like my husband).” (FCG, p129)⁴⁶</p>
		<p>“If you send them to a proper good day center [i.e., a mainstream service], nothing is available for them. They don’t understand their religious needs or anything ... They should have water in the loo, you know, because they don’t use tissues, and then, if they have a home help, they need a male home help in the house not a female, if he is living on his own.” (HCW, p392)⁵⁰</p>
		<p>“Well, I think it is important, so that they can identify themselves with it [...] that’s why it is important that there are services that consider the culture or language. So one feels more understood, also as a family member.” (FCG, p871)³⁹</p>
		<p>“For us, you see, it is normal to wash someone in a dry way, just using a toilet glove, but he (patient with dementia) started to get agitated. We didn’t know what to do. We finally called the intercultural mediator, who explained to us that he needed to be wet washed...” (HCW, p6)⁴³</p>
	Language barriers	<p>“We wanted to look for a home taker [formal caregiver] for my mother, but we could not find bilingual and skilled formal caretakers, and there are few residential care facilities for Chinese patients.” (FCG, p129)⁴⁶</p>
		<p>“Because we don’t speak English, we can’t take advantage of available services... When I look for services, they are available, but I can’t use them even though I know that they are there... I can’t take her [care recipient] there [nursing home] because she doesn’t speak English, and she can’t live eating American food.” (FCG, p41)³⁷</p>
		<p>“... same language would be important, although my grandmother can speak German [...] but not in a way that she can express emotions...” (FCG, p871)³⁹</p>
		<p>“People often lack sufficient information. You get everything in Norwegian. When you go to doctor, everything is in Norwegian. When you go to other places, everything is in Norwegian.” (HCW, p8)³²</p>
	Hesitance toward formal care	<p>“They leave people there, suffering. They have no contact at all with the patients. It’s just their job and that’s it - just waiting for them to kick the bucket...” (FCG, p77)³⁴</p>
		<p>“I felt that the nursing home did not treat dementia at all, and I think the nursing homes are not the place for providing the treatment or the prescription for improvement of dementia.” (FCG, p325)⁴⁷</p>
		<p>“It’s part of the culture, isn’t it? A kind of taboo... I mean, putting your father in a care home is a big no-no for us.” (FCG, p77)³⁴</p>
		<p>“... If the life of the ill person is in danger or if their illness means that they are harming others and if we cannot resolve the situation ourselves and if it really cannot go on like that anymore, then a care home could be an option...” (FCG, p77)³⁴</p>
Community: stigma and discrimination	Hiding dementia	<p>“We do not want to tell the neighbors or the friends in church, first, it is not an honorable thing to share and, second, people will look at mother and us differently when they hear it.” (FCG, p130)⁴⁶</p>
		<p>“The problem is that they don’t wish to admit or accept that their loved one is demented.” (HCW, p8)³⁶</p>
		<p>“These relatives carry a sense of shame about their parent’s dementia.” (HCW, p8)³⁶</p>

		“It is kept closed. People don’t want to reveal that it is in their families. It may bring problems when marriages are being arranged.” (HCW, p392) ⁵⁰
	Shame and discrimination	“I’m very careful about what I say (to the family members), to avoid being blamed for discrimination.” (HCW, p6) ⁴³
		“They know you’re Spanish, and I’m telling you, they do discriminate, especially if they hear you on the phone and they know you have an accent.” (FCG, p167) ⁴⁸
		“She (family member) was totally exhausted, had responsibility for her own children, to follow them to school and kindergarten. Her GP advised her to apply for help from the home-based services, but she did not want to receive such help. She worried about what people around her would think about that.” (FCG, p21) ¹⁶
		“When Korean people hear that somebody sent their parents to a nursing home, they point finger at (look down on) them.” (HCW, p431) ³⁸
		“You should have seen the way how he (a doctor) talked to me and to my father. Without any respect, like we were animals... it hurts me that my father has to endure such racism at this stage of his life.” (FCG, p6) ⁴³
		“My daughter and son-in-law used to take us out to eat, but ever since my husband had dementia [at very early stage], neither my husband nor I are willing to eat outside.” (FCG, p130) ⁴⁶
Policy: legal and financial issues	Legal issues	“You see, we could call intercultural care mediators or translation services when we had a patient with a different background – that was helpful, but due to hospital decisions we cannot use these services anymore.” (HCW, p6) ⁴³
	Financial issues	“There is something called omsorgslønn [care allowance] but it is very low pay. The municipality pays for this care allowance. The municipality always wants people to use the services from the municipality first. If that is not enough, then they say, ‘We can pay a little bit of care allowance.’” (HCG, p9) ³²