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## 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.<sup>1</sup> However, older immigrants experience several barriers to accessing dementia care,<sup>2-4</sup> including delay in seeking diagnosis and care.<sup>5,6</sup> The number of migrants is increasing globally, with 34.3 million older immigrants (aged 65 years or above) worldwide.<sup>7</sup> Immigrants are at higher risk of developing dementia due to lower education levels,<sup>8</sup> social isolation caused by migration,<sup>9</sup> cultural differences and language barriers,<sup>10</sup> poor dietary habits, smoking and sedentary lifestyles.<sup>11</sup> Several studies have reported a higher prevalence of dementia in immigrants.<sup>12-14</sup>

Arora *et al*<sup>15</sup> 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.<sup>16</sup> 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.<sup>17</sup> 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.<sup>18</sup>

Understanding immigrants' experiences of living with dementia can help tailor person-centred services for people living with dementia and their families and carers.<sup>19</sup> 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.<sup>20</sup> 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.<sup>21</sup> 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.<sup>21</sup>

## METHODS

### Design

A meta-synthesis was deemed appropriate for this systematic review, as it allows for in-depth exploration of the findings of multiple studies<sup>22</sup> 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-Analyses<sup>23</sup> statement and Enhancing transparency in reporting the synthesis of qualitative research statement.<sup>24</sup> 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 residence<sup>25</sup> 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.<sup>26</sup> 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 translation<sup>27</sup> 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 Programme<sup>28</sup> tool to assess the methodological quality of included studies. This is the most frequently used tool<sup>29</sup> that addresses the principles and assumptions underpinning qualitative research.<sup>24</sup> 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.<sup>30</sup> 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.

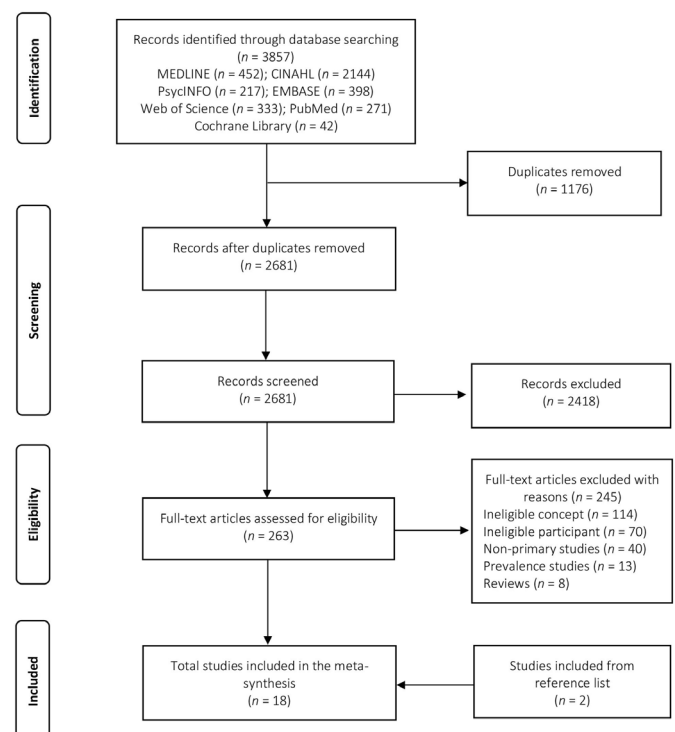
## RESULTS

### 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.<sup>23</sup>

### Quality assessment

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


**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> <sup>16</sup>	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Lawrence <i>et al</i> <sup>31</sup>	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Czapka and Sagbakken <sup>32</sup>	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
van Wezel <i>et al</i> <sup>33 34</sup>	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Ahmad <i>et al</i> <sup>35</sup>	Y	Y	Y	Y	Y	N	?	Y	Y	Y
Antelius and Kiwi <sup>36</sup>	Y	Y	?	?	?	N	?	?	N	N
Chaouni <i>et al</i> <sup>43</sup>	Y	Y	Y	Y	Y	N	Y	Y	Y	Y
Chaouni and De Donder <sup>44</sup>	Y	Y	?	?	?	N	?	?	?	?
Lee <i>et al</i> <sup>38</sup>	Y	Y	?	Y	Y	N	?	Y	Y	Y
Lee Casado <i>et al</i> <sup>37</sup>	Y	Y	?	Y	Y	N	?	Y	Y	Y
Mazaheri <i>et al</i> <sup>19</sup>	Y	Y	Y	Y	Y	?	Y	Y	Y	Y
Monsees <i>et al</i> <sup>39</sup>	Y	Y	Y	Y	Y	?	Y	Y	Y	Y
Söderman and Rosendahl <sup>45</sup>	Y	Y	N	Y	Y	?	Y	Y	Y	Y
Sun <i>et al</i> <sup>46</sup>	Y	Y	N	Y	Y	N	Y	Y	Y	Y
Kong <i>et al</i> <sup>47</sup>	Y	Y	Y	Y	Y	N	Y	Y	Y	Y
Neary and Mahoney <sup>48</sup>	Y	Y	Y	Y	Y	N	Y	Y	Y	Y
Yeo <i>et al</i> <sup>40</sup>	Y	Y	?	Y	Y	N	?	?	Y	Y
Boughtwood <i>et al</i> <sup>49</sup>	Y	Y	Y	Y	Y	N	Y	Y	Y	Y
Bowes and Wilkinson <sup>50</sup>	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).<sup>16 19 32–39 43–46</sup> The studies were conducted in nine different countries: USA (n=6),<sup>37 38 40 46–48</sup> The Netherlands (n = 3),<sup>33–35</sup> Sweden (n=3),<sup>19 36 45</sup> Belgium (n=2),<sup>43 44</sup> Norway (n=2),<sup>16 32</sup> Australia (n=1),<sup>49</sup> Germany (n=1),<sup>39</sup> Scotland (n=1)<sup>50</sup> and the UK (n=1).<sup>31</sup> Study participants were older immigrants living with dementia (n=2),<sup>19 31</sup> FCGs (n=9),<sup>33–35 37 39 40 47–49</sup> person care aides (n=1),<sup>38</sup> nursing staff (n=2)<sup>36 45</sup> and a mixture of FCGs and healthcare workers (n=6) consisting of general practitioners, nurses, and nurse assistants,<sup>16</sup> general practitioners, psychologist, neurologist, nurses and intercultural mediators<sup>43 44</sup>; representatives of immigrants and health professionals<sup>32</sup>; physicians, nurse, social workers, programme administrators<sup>46</sup>; general practitioners, community psychiatric nurses, consultants and voluntary sector providers.<sup>50</sup>

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,<sup>31–34 39 43 44 48–50</sup> followed by community organisations alone.<sup>16 19 37 38 40 46 47</sup> Purposive sampling<sup>16 31 35 37 38 47 48 50</sup> was commonly used to recruit participants, with snowball<sup>39 43 44</sup> and convenience<sup>40</sup> sampling in a few studies.

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

## Review finding

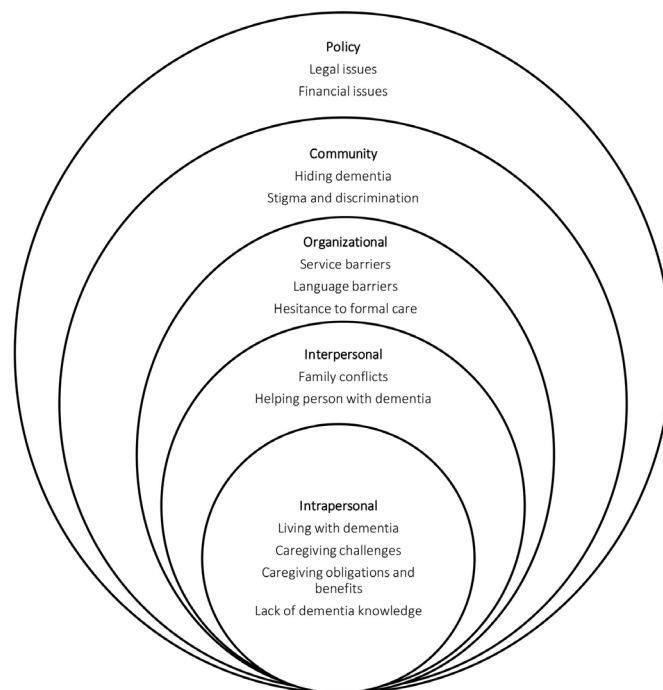
Five themes emerged from the meta-synthesis, arranged under each level of the SEM as shown in figure 2. Studies contributing to each of these themes and subthemes are listed in table 3. An overview of themes and illustrative quotes is provided in online supplemental table 2.

### 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.<sup>19 31 48 50</sup> Older immigrants described living with dementia as sad and embarrassing, as their forgetfulness caused problems for their family members.<sup>19</sup> Some described being incompetent and dependent as they failed



**Figure 2** Socioecological model.

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

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.<sup>19</sup> Some described their efforts to keep things as normal as possible, not telling that they had forgotten anything when they experienced forgetfulness.<sup>19</sup> Living with dementia was described as having a profound impact on the daily lives of older immigrants as the condition intensified.<sup>50</sup>

### Caregiving: emotionally and physically challenging

Caregiving was described as physically and emotionally challenging.<sup>43 44 49</sup> Managing behavioural and psychological symptoms of dementia,<sup>35 37–40 43 45 48 50</sup> including changes in behaviours like wandering, night activity and getting lost in familiar situations,<sup>37–39 50</sup> 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.<sup>37 49</sup> One healthcare worker attributed her poor health to the demanding and stressful impact of the caregiving role.<sup>38</sup>

FCGs explained how their marriage had been impacted and some described marital breakdowns as a result of the caregiving burden.<sup>49</sup> 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.<sup>16</sup> 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> <sup>16</sup>	FCG	FCG	FCG	FCG/HCW	FCG HCW		FCG HCW	FCG	FCG				
Lawrence <i>et al</i> <sup>31</sup>	OIWD												
Czapka and Sagbakken <sup>32</sup>	FCG	FCG	FCG	FCG/HCW			FCG HCW	FCG	FCG	FCG	FCG	HCW	HCW
van Wezel <i>et al</i> <sup>33</sup>								FCG	FCG	FCG			
van Wezel <i>et al</i> <sup>34</sup>	FCG	FCG	FCG		FCG			FCG					
Ahmad <i>et al</i> <sup>35</sup>	FCG	FCG	FCG		FCG			FCG					
Antelius and Kiwi <sup>36</sup>									FCG	FCG	FCG		
Antelius and Kiwi <sup>36</sup>									FCG	FCG	FCG	FCG	FCG
Chaouni <i>et al</i> <sup>43</sup>	FCG	FCG	FCG				FCG	FCG	FCG	FCG	FCG	FCG	FCG
Chaouni and De Donder <sup>44</sup>	FCG	FCG	FCG			FCG	FCG HCW	FCG	FCG	FCG	FCG	FCG	FCG
Lee <i>et al</i> <sup>38</sup>	FCG	FCG	FCG				FCG	FCG	FCG	FCG	FCG	FCG	FCG
Lee Casado <i>et al</i> <sup>37</sup>	FCG	FCG	FCG				FCG	FCG	FCG	FCG	FCG	FCG	FCG
Mazaheri <i>et al</i> <sup>19</sup>	OIWD												
Monsees <i>et al</i> <sup>39</sup>	FCG	FCG	FCG				FCG	FCG	FCG	FCG	FCG	FCG	FCG
Söderman and Rosendahl <sup>45</sup>	FCG	FCG	FCG				FCG	FCG	FCG	FCG	FCG	FCG	FCG
Sun <i>et al</i> <sup>46</sup>	FCG	FCG	FCG				FCG	FCG	FCG	FCG	FCG	FCG	FCG
Kong <i>et al</i> <sup>47</sup>	FCG	FCG	FCG				FCG	FCG	FCG	FCG	FCG	FCG	FCG
Neary and Mahoney <sup>48</sup>	FCG	FCG	FCG				FCG	FCG	FCG	FCG	FCG	FCG	FCG
Yeo <i>et al</i> <sup>40</sup>	FCG	FCG	FCG				FCG	FCG	FCG	FCG	FCG	FCG	FCG
Bowes and Wilkinson <sup>50</sup>	FCG	FCG	FCG				FCG	FCG	FCG	FCG	FCG	FCG	FCG
Boughtwood <i>et al</i> <sup>49</sup>	FCG	FCG	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 dementia<sup>16</sup> and the stigma associated with dementia<sup>40</sup> that augmented their caregiving challenges. FCGs described a lack of support from family members in providing care for older immigrants living with dementia,<sup>35 37 43 50</sup> with struggles to work full time and provide care as other family members abandoned them.<sup>35</sup>

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

### 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.<sup>16 32 34 35 37–40 44 48 50</sup> FCGs described sending their loved ones to a nursing home as disheartening, disrespectful and unfilial.<sup>47</sup> FCGs expressed caregiving as a payback for the love and care they received from their parents when they were young.<sup>16 39 44</sup> 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.<sup>48</sup>

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

### Lack of knowledge about dementia

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

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

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

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

#### Helping the older immigrants living with dementia

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

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



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

### Language barriers

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

### Hesitance towards formal care

FCGs described their hesitance towards formal care due to their negative experience with healthcare workers,<sup>35</sup> noting formal care to be viewed as culturally insensitive,<sup>32 43 44 50</sup> inadequate<sup>16 47 48</sup> and not person-centred care.<sup>43 44</sup> 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.<sup>34 47</sup> Further, FCGs felt that using formal care was being unfilial<sup>35</sup> and described their reluctance to use formal care unless deprived of alternatives.<sup>34</sup> Another FCG mentioned formal care as lacking provisions for religious practices,<sup>32</sup> leading some older immigrants living with dementia to refuse uptake of formal care.<sup>39</sup>

### 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.<sup>33 36 40 43 44</sup> They articulated difficulties in talking about dementia openly when older immigrants living with dementia did not want the community to know about their condition.<sup>33</sup> One FCG described that they kept the dementia diagnosis of their family member a secret to stop people looking down on them.<sup>46</sup>

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

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

### Shame and discrimination

Several studies have reported on dementia-related shame and discrimination.<sup>16 32 33 36 38–40 43 44 46 48 49</sup> 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.<sup>43</sup> One FCG described how her father living with dementia was treated by a doctor without any respect,<sup>43</sup> while others experienced being racially discriminated<sup>48</sup> against and neglected by general practitioners.<sup>32 50</sup>

FCGs recounted being looked down on by people when they placed their parents in a nursing home.<sup>38</sup> 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.<sup>16</sup> Healthcare workers also cited that FCGs were ashamed about their parents' dementia.<sup>36</sup> A wife caring for her husband living with dementia conceded that they stopped going out for dinner ever since her husband developed dementia.<sup>46</sup>

### 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,<sup>32 43</sup> 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.<sup>32</sup>

#### 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.<sup>43</sup> One FCG described how nurses refused help provided by FCGs in washing and dressing older immigrants living with dementia in home care.<sup>32</sup> 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.<sup>32</sup>

## 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.<sup>35 44 51</sup>

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.<sup>19</sup> 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,<sup>52</sup> helping to maintain their dignity.<sup>53</sup> 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.<sup>54</sup> The World Alzheimer Report 2021 also identified a lack of specialised diagnostic tests and diagnosis knowledge as key barriers to dementia diagnosis.<sup>55</sup>

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.<sup>56</sup> 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.*<sup>57</sup> 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,<sup>56</sup> 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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