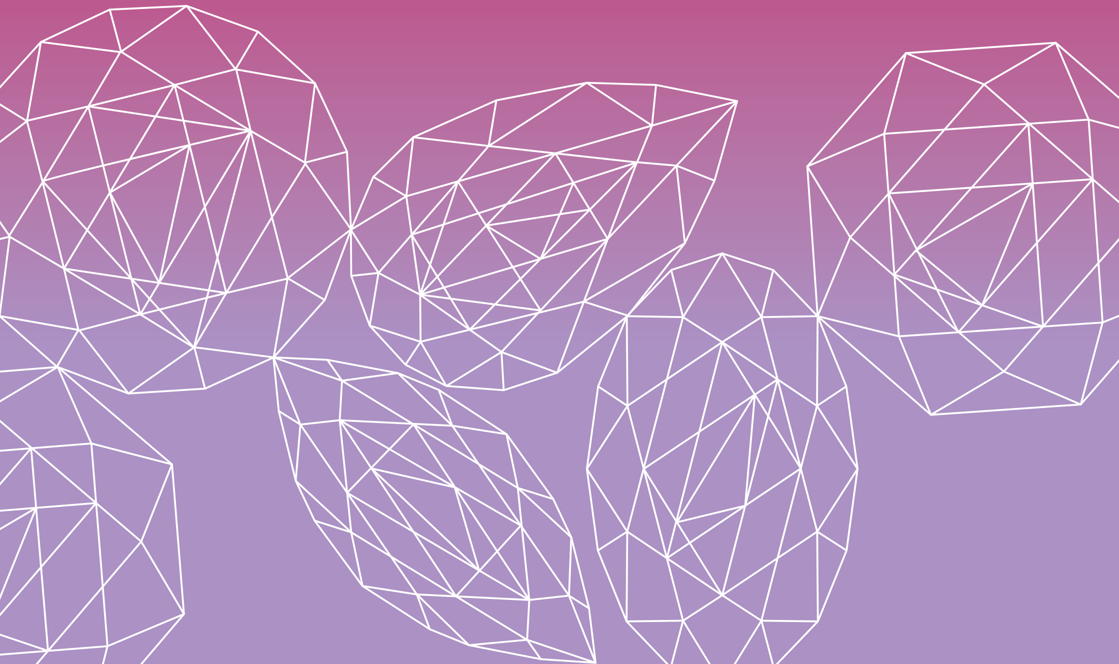
World Health
Organization

Dementia in refugees and migrants

Epidemiology, public health implications and global responses



Global Evidence Review on Health and Migration (GEHM) series

The GEHM series is an evidence-informed normative product of WHO Health and Migration to inform policy-makers on migration-related public health priorities. These reviews aim to respond to policy questions identified as priorities by summarizing the best available evidence worldwide and proposing policy considerations. By addressing data gaps on the health status of refugees and migrants, the GEHM series aims to support evidence-informed policy-making and targeted interventions that are impactful and make a difference in the lives of these populations.

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Dementia in refugees and migrants: epidemiology, public health implications and global responses

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Foreword

Globally more than 55 million people have dementia worldwide, and every year there are nearly 10 million new cases. Dementia can result from a variety of diseases and injuries that affect memory, thinking and the ability to perform daily activities; it is currently the seventh leading cause of death and one of the major causes of disability and dependency among older people globally.

In 2019 it was estimated that dementia costs economies US$ 1.3 trillion globally. Women are disproportionately affected by dementia, both directly, by experiencing higher disability-adjusted life-years and mortality, and indirectly as carers, by providing 70% of care hours for people living with dementia.

While there is no cure for dementia, a lot can be done to support people living with the illness, for example to be physically active, to take part in activities and social interactions that stimulate the brain and maintain daily function, and in the use of some medications. Providing care and support for a person living with dementia can be challenging, impacting the carer's own health and well-being.

Despite its high prevalence, unfortunately people living with dementia are frequently denied the basic rights and freedoms available to others. Appropriate and supportive legislative and services based on internationally accepted human rights standards are needed to ensure the highest quality of care for people with dementia, and properly to support their carers.

World Health Organization (WHO) considers dementia as a global public health priority. In May 2017 the World Health Assembly endorsed the *Global action plan on the public health response to dementia 2017–2025* as a comprehensive blueprint for action. The Global Action Plan is supported by a Global Dementia Observatory, a data portal that collates country data on 35 key dementia indicators across the Global Action Plan's seven strategic areas. WHO also launched the Knowledge Exchange Platform within the Global Dementia Observatory, which is a repository of good practice examples relating to dementia.

More older people are being forcedly displaced by food insecurity, climate change, natural disasters and conflict, and they also face specific challenges that are not being considered in preparedness and response plans to crises. Consequently, the number of older refugees and migrants is rapidly increasing worldwide, and dementia among refugees and migrants is attracting growing attention.

Ensuring that no older person is left behind is a key principle of the recently adopted United Nations Decade of Healthy Ageing (2021–2030). In the light of population ageing, it is imperative to develop health care policies and implement practices that are inclusive for all older people, including refugees and migrants.

All aspects of care for those with dementia, including primary prevention, access to health care resources and services, diagnosis and support for carers, can be influenced by the effects of migration, which is itself a determinant of health. Accordingly, refugees and migrants need good access to quality care, and to culturally and linguistically appropriate care, at all stages of the migration journey.

If evidence-informed policies to support refugees and migrants with dementia are to be put in place, it is imperative to collect data and provide information on dementia among refugee and migrant populations. The availability of good-quality data, disaggregated on both dementia- and migration-related variables, is fundamental to understanding the health needs of affected individuals, designing tailored health care pathways and delivering competent care and support.

However, in current practice, definitions and descriptions are often unclear or ill defined, and few data are available on determinants surrounding migration and other contextual factors, such as the reason for migration, length of migration, legal and socioeconomic status, acculturation, social network, living conditions, and language of the included participants.

Only a few countries have nationally representative data on the prevalence and incidence of dementia in refugees and migrants obtained by epidemiological studies or health care and administrative databases. There is also scant information on the characteristics of dementia occurring in refugees and migrants, with most studies failing to provide details on major clinical aspects of dementia. There is a dearth of knowledge surrounding the prevalence and impact of the established modifiable risk factors for dementia in refugees and migrants or concerning the role of potential protective factors.

This Global Evidence Review on Health and Migration sets out the background and the available evidence around the principal core issues, policies and practices involved; it includes several relevant policy considerations based on the identified evidence.

It is hoped this evidence review will be helpful and informative to all those involved in policy-making and service delivery in support of refugees and migrants with dementia.

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Preface

This Global Evidence Review on Health and Migration (GEHM) explores the magnitude of the challenge of dementia in refugees and migrants and focuses on the provision of care and support for these population groups.

It is estimated that dementia affects 55 million globally, including increasing numbers of refugees and migrants. The subject of dementia in refugees and migrants is attracting growing scientific and public health attention, as documented by the increasing number of dedicated publications and the inclusion of this issue in the national policies of several countries worldwide.

This GEHM includes information about the refugees and migrants themselves: their health needs and how these are determined in their place of origin, along the path of their journeys and in their host countries and communities; the legislation, policies and practices, and cultural norms that affected their health as well as their access to health and social care services; and their health outcomes.

The challenges faced by carers of those with dementia are very significant, reinforcing the need to invest in health and social policies to support all carers for people with dementia, including among refugees and migrants, throughout the illness.

Most refugees and migrants affected by dementia live in low- and middle-income countries, which are unfortunately underrepresented in the scientific and grey literature. However, based on the data that are available, albeit mostly from high- and upper-middle-income countries in Asia, Europe, North America and Oceania, the growing number of refugees and migrants living with dementia clearly requires improved access to health and social care services in host countries. Carers also need support and respite.

In addition, dementia is currently often underdiagnosed and undertreated among refugees and migrants. There may be low awareness of dementia in these population groups, a limited adoption of cross-cultural cognitive assessment tools, disruptions in the continuity of care and a lack of specific training for health care professionals. As a result, carers frequently experience challenges due to perceived barriers to seeking support and a lack of appropriately supportive health care pathways.

There are several knowledge gaps currently regarding dementia among refugees and migrants. These include major research barriers and challenges in dementia research areas (e.g. dementia epidemiology, diagnosis, care and support, and risk reduction), which have been recently systematically set out in the WHO document A blueprint for dementia research. Dedicated research efforts are needed to fill evidence gaps relating to refugees and migrants living with dementia in emergency settings and also in low- and middle-income countries. Evidence is also needed on the health needs, trajectories and outcomes for refugees and migrants with dementia.

It is against this background that this GEHM considers the available evidence concerning dementia, explores the magnitude of the challenge of dementia in refugees and migrants, and focuses on evidence for improving the provision of care and support for these population groups.

The GEHM also makes claims for renewed attention to developing disaggregated data on refugees and migrants with dementia and on their health and service needs to promote good outcomes.

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As for other reports in the Global Evidence Review on Health and Migration series, WHO Health and Migration collaborated with other WHO departments: with the Department of Mental Health, Brain Health and Substance Use, Director Devora Kestel and Katrin Seeher, for this publication.

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Interdivisional Working Group

With the overall objective of strengthening normative research and evidence gathering works of WHO Health and Migration, an Interdivisional Working Group has been established to support the overall production of the Global Evidence Review series. Representatives from Science and Data Divisions in the Interdivisional Working Group have kindly agreed to support this initiative from normative, methodological, research and data perspectives, and to advise technical staff from WHO Health and Migration and other relevant programme areas as appropriate in various stages of development of the Global Evidence Review series.

Abbreviations

GEHM	Global Evidence Review on Health and Migration (series)
LMIC	low- and middle-income country
MIPEX	Migrant Integration Policy Index
MMSE	Mini-Mental State Examination
NCD	noncommunicable disease

Executive summary

As a result of population ageing, the number of older refugees and migrants is rapidly increasing worldwide. These individuals face a number of specific challenges, including difficulties in the continued management of chronic conditions they may have, challenges in providing care to other family members in new unknown settings, barriers in access to services, and compounded discrimination based on their age and other characteristics such as their gender, the presence of disabilities or their refugee or migrant status. It is, therefore, imperative to develop health care policies and implement practices that are inclusive for all older people, including those with a refugee or migration background. Ensuring that no older person is left behind is also a key principle of the recently adopted United Nations Decade of Healthy Ageing (2021–2030).

Based on the available evidence, a growing number of refugees and migrants live with dementia and may require access to health care services in host countries. Indeed, all aspects of dementia care, such as primary prevention, access to health care resources and services, diagnosis and support for carers, may also be influenced by the determinants and effects of the migration cycle. Multiple barriers, such as the low awareness of dementia in these population groups, the limited adoption of cross-cultural cognitive assessment tools, disruptions in the continuity of care and the lack of specific training for health care professionals, can influence the accurate and timely detection of dementia in migrant groups. Dementia is, therefore, often underdiagnosed and undertreated among these individuals. Their carers frequently experience challenges due to perceived barriers to seeking support and the scarcity of tailored health care pathways.

Refugees and migrants living with dementia in host countries may be at risk of facing abuse and inequities in access to care and support. Those living in emergency contexts risk being left behind in humanitarian responses. According to the WHO *Global action plan on the public health response to dementia 2017–2025*, refugees and migrants must be empowered and adequately considered in the public health response to dementia.

Dementia in refugees and migrants is attracting growing attention, as documented by the increasing number of dedicated publications and the inclusion of this issue in the national policies of a number of countries worldwide. This Global Evidence Review on Health and Migration (GEHM) utilized a comprehensive scoping review to identify and synthesize scientific and grey literature in the field in order to explore the magnitude of the challenge of dementia in refugees and migrants, to focus on the provision of care and support for these population groups and to highlight existing evidence gaps.

There are still relevant knowledge gaps regarding migration and dementia, particularly a lack of information on refugees and migrants living with dementia in emergency settings and in low- and middle-income countries (LMICs) as the available information is largely for international migrants in high-income settings. Moreover, the risk profiles as well as the health needs, trajectories and outcomes of refugees and migrants with dementia have been poorly explored. Dedicated research efforts are warranted to fill these evidence gaps.

Policy considerations

Based on the findings of this GEHM, and considering the current conventions, frameworks and recommendations from international organizations, policy considerations are suggested, reflecting the following seven action areas.

Policy and legislation:

- inclusion of refugees and migrants in relevant national and subnational policies, legislation, plans and frameworks on dementia; and
- inclusion of dementia in the global, regional and national agendas dealing with the health of refugees and migrants.

Awareness and inclusion:

- organization of national and local campaigns and educational activities to raise awareness about dementia in refugees and migrants;
- creation of dementia-friendly environments for refugees and migrants, according to the different settings; and
- creation of dementia-inclusive environments for refugees and migrants living in emergency contexts.

Risk reduction:

- design and implementation of evidence-informed, multisectoral and culturally sensitive interventions aimed at dementia risk reduction in refugees and migrants;
- promotion of dementia risk reduction strategies in refugees and migrants living in emergency contexts;
- integration and link of dementia risk reduction with other ongoing policies for noncommunicable disease (NCD) prevention and control in refugees and migrants; and
- strengthen the evidence base on dementia risk and protective factors in refugees and migrants.

Diagnosis, treatment and care:

- development of integrated care pathways for refugees and migrants with dementia;
- reduction of barriers to health care access and development of diversity-sensitive care for refugees and migrants with dementia; and
- provision of dementia training for health and social care professionals and other relevant stakeholders working with refugees and migrants living in emergency contexts.

Support for carers:

- development and implementation of training and education programmes for carers of refugees and migrants with dementia;
- development and strengthening of legal protection for carers of refugees and migrants with dementia;
- provision of care and support for carers of refugees and migrants with dementia, including in emergency contexts; and
- involvement of family/informal carers of refugees and migrants with dementia in care planning and policy-making.

Health information system and monitoring:

- development of strengthened national surveillance and monitoring systems for dementia that include/stratify data for refugees and migrants;
- strengthen the evidence base on the epidemiology of dementia in refugees and migrants and its public health implications; and
- extension of the evidence base on refugees and migrants with dementia to encompass those living in emergency contexts.

Research and innovation:

- inclusion of dementia in refugees and migrants in the global research agenda; and
- promotion of investment and collaboration on the theme of dementia in refugees and migrants.

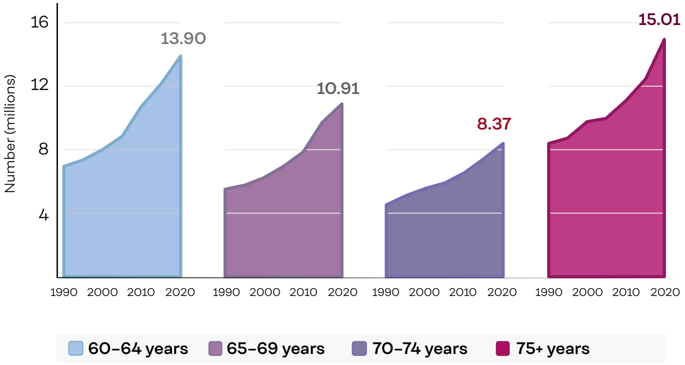
1. Introduction

1.1 Background

Populations around the world are rapidly ageing due to increasing life expectancy and decreasing fertility *(1)*. This demographic transition is particularly affecting LMICs. It has been estimated that, by 2050, nearly 80% of the world's older people will live in an LMIC or in conflict- and climate-affected regions, where humanitarian and emergency crises are more likely to occur *(2,3)*.

Ageing is profoundly transforming our societies and will impact refugees and migrants as much as their counterparts in host countries. Worldwide, the number of older international migrants (i.e. people living outside their country of origin who are older than 60 years) has nearly doubled in the last three decades, from 25.5 million in 1990 to 48.2 million in 2020 (Fig. 1) *(4)*. These include older people who aged in the host country as well as those who arrived when already at a more advanced age. Within international refugee and migrant communities, 3.6% and 17.2% are over 60 years of age, respectively *(4,5)*. All world regions are witnessing the ageing of refugee and migrant populations; in some areas (e.g. middle and western Africa, south-eastern and western Asia, southern and western Europe), this phenomenon has been particularly rapid (Figs 2 and 3).

Fig. 1. Older international migrants worldwide by age group, 1990–2020



Source: from World population ageing 2017: highlights, by United Nations Department of Economic and Social Affairs Population Division, ©2017 United Nations (4). Used with the permission of the United Nations.

Fig. 2. Older international migrants by region of residence, 1990–2020

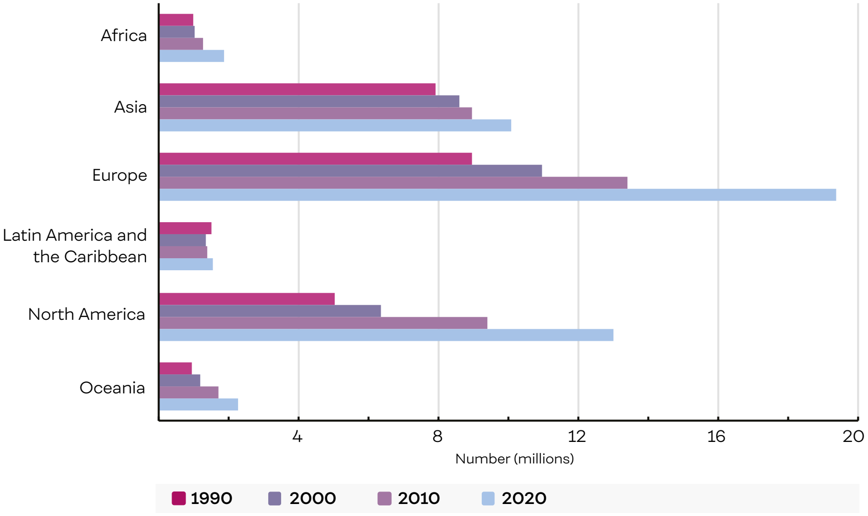


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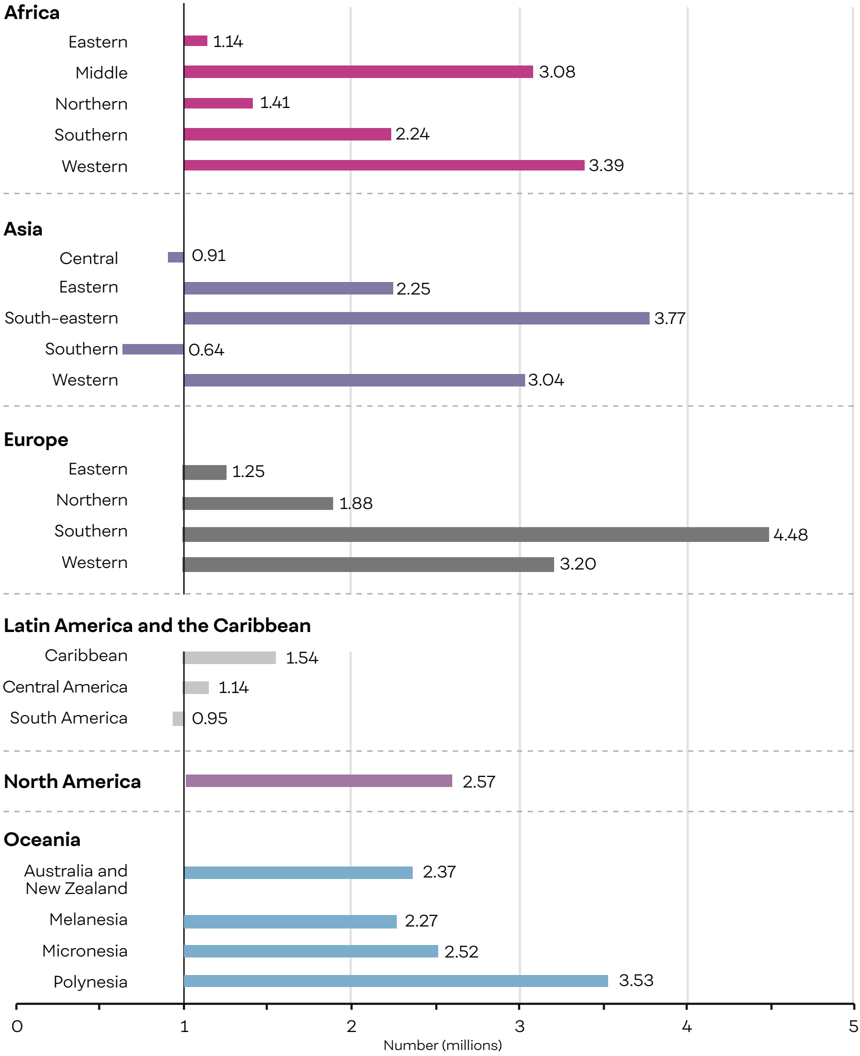
Fig. 3. Ratio between the number of older international migrants in 2020 and 1990, by subregion of residence



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The ageing of refugees and migrants is inevitably coupled with a shift in their morbidity patterns and health needs *(6)*. Indeed, they are increasingly exposed to the burden of age-related disorders and NCDs, such as cancer, cardiovascular diseases, chronic respiratory disease and diabetes *(7)*. NCDs represent the leading global cause of mortality and are a serious threat to the sustainability of health systems *(8)*. The social determinants of health surrounding migration and refugee or migrant status can exacerbate NCD risk factors, influence adherence to preventive strategies and result in profound inequalities and inequities in access to care and continuity of treatment *(7,9)*. Older refugees and migrants are also at risk of developing common age-related adverse health conditions, such as frailty, multimorbidity or disability, which can result in care dependency *(6,9)*. Ageist attitudes can intersect with other forms of discrimination, including those based on refugee or migrant status, and compound additional disadvantages *(10)*. Based on these epidemiological changes, these individuals need to be included in the ongoing and future policies focused on healthy ageing. Identifying and addressing their health care needs is fundamental to Sustainable Development Goal 3 (ensure healthy lives and promote well-being for all at all ages) advocated in the United Nations 2030 Agenda for Sustainable Development *(11)*. In line with the principles of the United Nations Decade of Healthy Ageing (2021–2030) *(3)*, it is imperative to develop policies and practices to optimize the functional abilities of all older people, including those with a migration background.

In this evolving scenario, dementia in refugees and migrants may assume particular relevance. In 2019 more than 55 million people were living with dementia worldwide *(12,13)*. This number is projected to reach 139 million in 2050, with larger increases in LMICs *(12)*. Dementia severely affects individuals and their carers and families, their communities and society as a whole. In 2019 it represented the seventh leading cause of death worldwide and is a major source of care dependence and disability *(12,14)*. The number of people living with dementia has increased substantially since the mid 1990s, with enormous associated social and economic costs, and is predicted to continue to increase *(13)*. The global expenditure for dementia (combining direct medical and social care and informal care) was estimated to be US$ 1.3 trillion in 2019 and is expected to increase to US$ 2.8 trillion by 2030 *(12)*. Globally, dementia has a disproportionate impact on women, in terms of both mortality and disability *(13)*. Moreover, women provide most of the informal care for people living with dementia, accounting for around 70% of primary caregiving. This means that the effects of being a carer on health and well-being and on financial security are likely to be greater for women. The formal care workforce is also predominantly female. A gender perspective is, therefore, crucial to capture the impact of dementia and the realities faced by the people dealing with this condition (15). More generally, an intersectional lens is required to understand the lived experiences of the disease by considering the interconnectedness and interplay of different social factors and categories (e.g. age, gender, ethnicity or socioeconomic status) (16).

While novel treatments are emerging for Alzheimer's disease, to date, no curative therapy exists for most causes of dementia. However, a growing body of evidence suggests that a relevant proportion of cases may be prevented through risk reduction strategies targeting modifiable medical conditions and lifestyle factors (17). Specifically, it has recently been estimated that nearly 40% of cases of dementia worldwide can be attributed to 12 modifiable risk factors (over the life-course: low education, hypertension, hearing impairment, smoking, obesity, depression, physical inactivity, diabetes, social isolation, excessive alcohol consumption, traumatic brain injury and air pollution), with important implications in terms of primary prevention (17,18). In the light of this evidence, dementia is increasingly recognized as a public health priority, and one where prevention can play a critical role (19).

In 2017 WHO published the *Global action plan on the public health response to dementia 2017–2025* to support the development of a multisectoral public health response to dementia (20). The goal of the Global Action Plan is to improve the lives of all people with dementia and their families and carers, while decreasing the impact of dementia on communities and countries. Seven areas for action were identified: (i) making dementia a public health priority through policy and legislation; (ii) raising dementia awareness and inclusion; (iii) reducing the risk of dementia; (iv) improving dementia diagnosis, treatment and care; (v) developing support and services for dementia carers; (vi) strengthening health information systems for dementia; and (vii) fostering research and innovative technologies. At least one global target to be achieved by 2025 is indicated for each area, together with a monitoring plan and action proposals addressed to Member States, the WHO Secretariat, international and regional organizations, and partners at country level (Table 1). To monitor the implementation of the Global Action Plan, WHO launched the Global Dementia Observatory, which collates information from Member States on key indicators to assess progress (21). Among the principles of the Global Action Plan, it is clearly stated that people facing heightened risks because of their circumstances or the context, including refugees and migrants, must be empowered and adequately considered in the public health responses to dementia (20). Therefore, dementia in these population groups is acknowledged for the first time as a global health issue in a policy document. In the 2021 Global status report on the public health response to dementia, the importance of addressing the needs of refugees and migrants is further discussed (12). Specifically, attention is drawn to understanding the specific impact of dementia, preventing marginalization and reducing inequities in health outcomes in such populations. It is also implicitly recommended that all seven action areas of the Global Action Plan include and reach these groups.

Table 1. Framework of the WHO *Global action plan on the public health response to dementia 2017–2025*

Action areas for dementia	Global targets	Indicators[a]	Impact
Policy and legislation (dementia as a public health priority)	75% of countries will have developed or updated national policies, strategies, plans or frameworks for dementia, either stand-alone or integrated into other policies/plans, by 2025	Governance *Policy/plan* Legislation for dementia Care coordination mechanism	Dementia is a public health priority for countries
Awareness and inclusion	100% of countries will have at least one functioning public awareness campaign on dementia to foster a dementia-inclusive society by 2025 50% of countries will have at least one dementia-friendly initiative to foster a dementia-inclusive society by 2025	Policy/plan *Awareness-raising campaigns* *Dementia-friendly environments* *Training and education of population groups*	Society is aware of dementia and inclusive of people with dementia and their carers

Table 1. contd

Action areas for dementia	Global targets	Indicators[a]	Impact
Risk reduction	The relevant global targets defined in the Global Action Plan for Prevention and Control of Noncommunicable Diseases 2013–2020 and any future revisions are achieved for risk reduction and reported	Policy/plan Standards and guidelines Risk reduction campaigns *Prevalence of dementia risk factors*	Dementia risk factors reduced at population level
Diagnosis, treatment, care and support	In at least 50% of countries, as a minimum 50% of the estimated number of people with dementia are diagnosed by 2025	Policy/plan Standards and guidelines Care coordination mechanism Workforce *Diagnostic rate* Community-based services Dementia care facilities Antidementia medicines/care products Dementia nongovernmental organizations	People with dementia are diagnosed in a timely manner and receive the services that they need
Support for carers	75% of countries provide support and training programmes for carers and families of people with dementia by 2025	Policy/plan Standards and guidelines *Carer support* services	Dementia carers receive the support that they need

Table 1. contd

Action areas for dementia	Global targets	Indicators[a]	Impact
Information systems and monitoring	50% of countries routinely collect a core set of dementia indicators through their national health and social information systems every 2 years by 2025	*Dementia monitoring* Prevalence and incidence Mortality/deaths Disability associated with dementia Economic costs	Disaggregated key dementia data are available at country level
Research and innovation	The output of global research on dementia doubles between 2017 and 2025	Research agenda Research investment Involvement of people with dementia in research *Research output*	Dementia research is strengthened and streamlined

[a] Indicators used to monitor global targets are shown in italic .

Source: adapted from WHO *(12,20)*.

There are several barriers that can challenge the detection of dementia in refugees and migrants, as well as the provision of care and support for affected individuals. Language difficulties, low education, poor health literacy and previous negative experiences with the health care system may discourage medical help-seeking *(22)*. Dementia can be differently perceived and experienced by people from diverse cultural backgrounds. Different cultural understandings of dementia may lead to stigma and negative stereotypes and contribute to an unfavourable delay in diagnosis and treatment *(23)*. Ageism and other discrimination can result in accelerated cognitive decline (24). Continuity of care can be hard to ensure, especially for refugees and migrants facing unpredictable displacements. In addition, most routinely used cognitive tests have not been designed and properly validated for use with culturally diverse populations; consequently, their adoption in refugees and migrants, especially in those with low education and language proficiency in the receiving country, may result in a biased assessment of their cognitive abilities and impairments (25). In 2021 the WHO Refugee and migrant health: global competency standards for health workers (26) was published to promote the provision of culturally sensitive health care to refugees and migrants as part of moving towards achieving universal health coverage for all populations and leaving no one behind. Particular emphasis is given to the importance of addressing mental health and the psychosocial support needs of refugees and migrants by providing trauma-informed care and interventions sensitive to experiences of chronic hardship, traumatic events, grief and loss, and to facilitating referrals. However, the challenges of cognitive assessment and dementia diagnosis are not mentioned. Health care professionals and services are still insufficiently prepared to assess and manage cognitive decline and to provide culturally competent care to refugee and migrant populations (27,28). Altogether, these factors may contribute to high rates of underdiagnosis and misdiagnosis of dementia. Once dementia is diagnosed, refugees and migrants may have a lower likelihood of receiving a specific treatment and may experience limited access to dedicated health care resources (e.g. day-care services or nursing homes) (29,30). Finally, these individuals risk being excluded from dementia prevention if risk reduction strategies are not adequately culturally situated (31).

Overall, all aspects of dementia care, from primary prevention to support after diagnosis, can be aggravated by the conditions surrounding the migration cycle. People living with dementia are at risk of negative health outcomes in humanitarian crises, especially when such emergencies happen in countries that are already inadequately prepared to support these individuals. These considerations, together with the expected increase in global migration and dementia prevalence, provide a solid foundation for considering dementia in refugees and migrants as a global health concern. Accordingly, patient associations such as Alzheimer's Disease International and Alzheimer Europe are drawing attention to the need to develop intercultural care and support for people with dementia and to address dementia in humanitarian emergencies and responses (32,33). It is striking that dementia is not addressed in current regional and global commitments on refugees and migrants, for example the World Health Assembly resolution on promoting the health of refugees and migrants 2019–2023 *(34)*, which was established to promote and secure refugees' and migrants' physical and mental health rights in the context of the human right to health and universal health coverage for all; the WHO Regional Committee for Europe resolution on a strategy and action plan for refugee and migrant health in the WHO European Region *(35)*; and the World report on the health of refugees and migrants *(36)*. However, international guidance on mental health, including on prevention and care for dementia, is lacking.

To date, there has been no attempt to identify and map the available evidence and major knowledge gaps on the impact of dementia in refugees and migrants. This step is fundamental to assist in formulating dedicated health policies and future research agendas.

The review considered individuals with different migration backgrounds and legal entitlements as the target population: refugees, international migrants, migrants in irregular situations and asylum seekers (Box 1).

Box 1. Definitions

Asylum seeker. An individual who is seeking international protection. In countries with individualized procedures, an asylum seeker is someone whose claim has not yet been finally decided on by the country in which he or she has submitted it. Not every asylum seeker will ultimately be recognized as a refugee, but every recognized refugee is initially an asylum seeker *(37)*.

Migrant. There is no universally accepted definition of migrant. For the purpose of collecting data on migration, the United Nations Department of Economic and Social Affairs defines an international migrant as "any person who changes his or her country of usual residence" *(38)*. It includes any person who is moving or has moved across an international border, regardless of legal status, duration of the stay abroad and causes for migration. The International Organization for Migration considers migration as an umbrella term covering all forms of movement within and outside a State. Its definition of a migrant includes "a person who moves

Box 1. contd

away from his or her place of usual residence, whether within a country or across an international border, temporarily or permanently, and for a variety of reasons" (37). Migrants can then be grouped as:

- **documented migrant:** a migrant who entered a country lawfully and remains in the country in accordance with his or her admission criteria; and
- **migrant in an irregular situation:** a person who moves or has moved across an international border while not authorized to enter or to stay in a State pursuant to the law of that State and to international agreements to which that State is a party.

Refugee. According to the United Nations Convention Relating to the Status of Refugees (Art. 1A(2)) (39), a refugee is a person who "owing to a well-founded fear of persecution for reasons of race, religion, nationality, membership of a particular social group or political opinions, is outside the country of his nationality and is unable or, owing to such fear, is unwilling to avail himself of the protection of that country".

Refugees in Africa. For State Parties to the African Union Convention governing the specific aspects of refugee problems in Africa (Art. 1(2)), the term refugee also applies to "every person who, owing to external aggression, occupation, foreign domination or events seriously disturbing public order in either part or the whole of his country of origin or nationality, is compelled to leave his place of habitual residence in order to seek refuge in another place outside his country of origin or nationality" (40).

A full set of definitions related to refugees and migrants can be found in the United Nations High Commissioner for Refugees Master Glossary of Terms (41) and the International Organization for Migration's Glossary on Migration (37).

This report uses the term "refugees and migrants" in presenting evidence from studies in which the population was not clearly mentioned or included several groups.

1.2 Objectives of the report

The current GEHM addresses the following policy question: "What is the available evidence on the impact of dementia in refugees and migrants and on the provision of care and support for these population groups?"

Specifically, a scoping review was used to synthesize scientific and grey literature on the following:

- the epidemiology of dementia in refugees and migrants (global magnitude of the phenomenon, prevalence of dementia, dementia risk factors and potential for dementia prevention);
- health literacy about dementia in refugees and migrants and their carers;
- access to health care and social services for refugees and migrants with dementia and barriers/facilitators influencing resource use;
- preparedness of health care services to provide culturally sensitive diagnosis, care and support for refugees and migrants with dementia (availability of cross-cultural assessment tools, role of interpreters and cultural mediators, availability of culturally fair dementia-awareness material, and training of health care professionals);
- support for people providing care to refugees and migrants living with dementia; and
- inclusion of refugees and migrants in dementia policies.

Considerations for policies are also provided to support policy-makers to include refugees and migrants in the public health response to dementia.

1.3 Methodology

Based on preliminary searches of the Cochrane Database of Systematic Reviews, Open Science Framework, PROSPERO and PubMed in June 2022, no current or ongoing systematic or scoping reviews on the topic were identified.

A scoping review method was selected because the GEHM was intended to identify and synthesize scientific and grey literature in the field and highlight existing gaps in knowledge. Scoping reviews are useful for addressing broad research questions, examining emerging evidence and issues, including qualitative, quantitative and mixed-method studies, and informing future policies and research.

The identified documents that were included encompassed:

- **population:** groups of individuals with different migration backgrounds and legal entitlements and studies enrolling formal (professional, paid) and informal (family, friends, unpaid) carers of refugees and migrants living with dementia;
- **concept:** dementia (or major neurocognitive disorder) of any etiology defined as a condition of cognitive decline from a previous level of capacity that is sufficient to interfere with a person's daily life and independence, does not occur exclusively in the context of a delirium and is not primarily attributable to another mental disorder; and
- **context:** any world region and pertaining to any contextual setting.

Included studies were of any methodological design (quantitative, qualitative or mixed methods), published in any of the six United Nations official languages (Arabic, Chinese, English, French, Russian Federation and Spanish) and were original articles providing the findings of primary or secondary analyses of original data or policy papers/documents mapping existing original evidence in the field.

Full details of the search strategy, including inclusion and exclusion criteria, are given in Annex 1.

The analysis identified 147 documents that fulfilled the search criteria *(27,28,30,42–185)* and 39 policy documents that covered multiple actions *(3,6,12,15,19,20,23,32,33,186–216)*. Table 2 maps these onto the seven action areas of the *WHO Global action plan on the public health response to dementia 2017–2025* *(20)*. Evidence assignment to these areas was based on the main issues addressed in the quantitative and qualitative analyses of the original papers and so some studies were assigned to multiple action areas.

Table 2. Framework of the WHO Global action plan on the public health response to dementia 2017–2025

Action areas for dementia	No. studies	Identified articles[a]
Policy and legislation (dementia as a public health priority)	3	42–44
Awareness and inclusion	26	45–70
Risk reduction	17	71–87
Diagnosis, treatment, care and support	64	27,28,30,50–52,68,69,81,88–142
Support for carers	45	45–48,52,54,56,57,60–67, 70,88–91,97,131–134,143–161
Health information systems and monitoring	39	28,72,78,82–87,92,135–141,162–183
Research and innovation	2	184,185

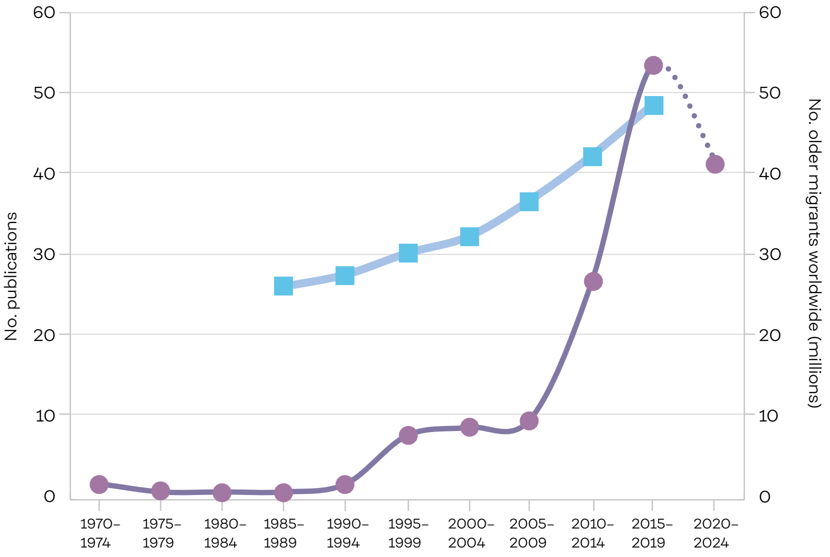
[a] Policy documents that covered multiple actions are not listed in the table (3,6,12,15,19,20,23,32,33,186–216).

2. Results

2.1 General findings

Scientific interest in dementia in refugees and migrants has grown considerably in recent years. Three quarters of the considered studies (74.1%; 109/147) have been published since 2012 (Fig. 4). The retrieved articles were published in a heterogeneous range of 76 journals belonging to different subject areas, from medicine to nursing, and from psychology to social sciences (Annex 2).

Fig. 4. Publication trend in research on dementia in refugees and migrants



Note: the dashed line indicates the estimated number of publications for the period 2015–2019 to 2019–2022.

The review identified 59 qualitative studies, 83 quantitative studies and five mixed-method studies for analysis. Among the qualitative studies, 38 were based on in-depth interviews, two on focus groups and 10 on both approaches; the remaining nine studies used other research methods (e.g. observations or surveys). Most quantitative studies (58; 69.9%) relied on cross-sectional analyses, 21 (25.3%) on longitudinal observations and four (4.8%) were interventional studies (three being structured as randomized controlled trials). Overall, most studies (87; 59.2%) were population- or community-based studies; 25 were conducted in outpatient services, 11 in residential facilities (e.g. nursing homes) and the others in hybrid settings. Study participants were older people with dementia (including refugees and migrants) in 75 studies, informal carers of migrants with dementia in 36 studies, and health care professionals caring for migrants with dementia in nine studies. In the remaining articles, different combinations of participants (e.g. patient–carer dyads, informal and formal carers) were recruited. A total of 6 614 034 participants were enrolled in the retained studies, with sample sizes ranging between 1 and 3 286 624 (median: 90; interquartile range: 20–757).

Studies were conducted in a total of 28 countries. Overall, evidence on dementia in refugees and migrants has been obtained only in high-income and upper-middle-income countries (Table 3), with data lacking for low-income settings. The Migrant Integration Policy Index (MIPEX) country score is a unique tool combining 58 indicators across eight policy areas in order to measure policies to integrate migrants *(217)*. Scores ranged from "halfway favourable" to "favourable". A non-statistically significant correlation was found between the number of studies and the MIPEX country score (Spearman's ρ, 0.35; $P = 0.08$). No correlation was shown between the number of publications and the country's proportion of migrants in the population aged 65 years or older living in the country.

Table 3. Countries where research on dementia in refugees and migrants has been conducted

Country	World Bank rating[a]	MIPEX score[b]	Percentage migrants in population aged ≥ 65 years[c]	No. studies	Studies (% of total 147 studies)
United States	HIC	73	13.3	39	26.5
United Kingdom	HIC	56	8.2	17	11.6
Netherlands	HIC	57	8.8	16	10.9
Sweden	HIC	86	13.4	14	9.5
Norway	HIC	69	5.7	11	7.5
Canada	HIC	80	27.6	10	6.8
Germany	HIC	58	18.6	9	6.1
Australia	HIC	65	35.9	8	5.4
Denmark	HIC	49	5.3	8	5.4
Belgium	HIC	69	12.3	6	4.1
Brazil	UMIC	64	0.8	5	3.4
Italy	HIC	58	3.2	5	3.4
Greece	HIC	46	6.3	3	2.0
Israel	HIC	49	68.0	3	2.0
Türkiye	UMIC	43	4.7	3	2.0
Switzerland	HIC	50	21.6	2	1.4
Bulgaria	UMIC	NA	1.6	1	0.7
Croatia	HIC	39	17.2	1	0.7
Finland	HIC	85	1.7	1	0.7
France	HIC	56	14.2	1	0.7
Ireland	HIC	64	10.6	1	0.7
Japan	HIC	47	0.6	1	0.7

Table 3. contd

Country	World Bank rating[a]	MIPEX score[b]	Percentage migrants in population aged ≥ 65 years[c]	No. studies	Studies (% of total 147 studies)
Poland	HIC	40	4.7	1	0.7
Portugal	HIC	81	4.4	1	0.7
Romania	HIC	49	1.4	1	0.7
Serbia	UMIC	50	18.4	1	0.7
Singapore	HIC	NA	44.5	1	0.7
Spain	HIC	60	6.6	1	0.7

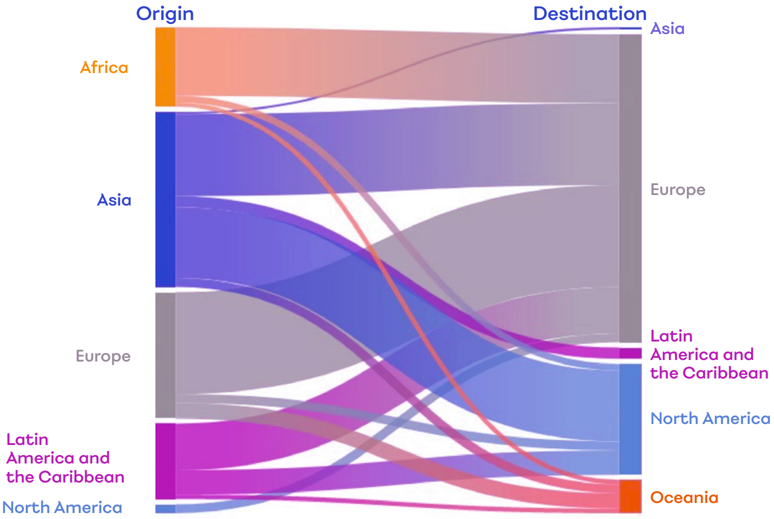
[a] World Bank rating *(218)*: HIC: high-income country; UMIC: upper-middle-income country.

[b] MIPEX score *(217)*: 80–100, favourable; 60–79, slightly favourable; 41–59, halfway favourable; 21–40, slightly unfavourable; 1–20, unfavourable; 0, critically unfavourable.

[c] Proportion of international migrants in the total population aged 65 years or over living in the country.

Most studies (93.2%) focused on international migrants, who were mostly defined using broad terms such as "migrant", "immigrant" or "foreign-born". Six studies enrolled both refugees and international migrants, two included only refugees, and one included only asylum seekers. The few studies that focused on refugees were conducted on people who had moved to the United States of America (*n* = 4), Australia (*n* = 1), Croatia (*n* = 1), Denmark (*n* = 1) or Sweden (*n* = 1). Most of the refugees considered in the selected studies came from Asia or the Middle East (Bhutan, Iraq, Myanmar and Viet Nam). Studies focusing on international migrants were conducted on people who had moved to Europe (*n* = 79) and North America (*n* = 49). Migrants were mostly from Asia (37.9%), Europe (27.2%), Africa (17.0%), and Latin America and the Caribbean (16.1%). The countries of origin and destination of study participants are presented in Fig. 5. Among the studies indicating both the country of birth and destination, the most represented migrant groups were Moroccan migrants in the Netherlands (*n* = 11), Turkish migrants in the Netherlands (*n* = 11), Chinese migrants in the United States (*n* = 8), Indian migrants in the United Kingdom (*n* = 6), Korean migrants in the United States (*n* = 6) and Pakistani migrants in Norway (*n* = 6). Only 31 studies reported the main sociodemographic features (i.e. age and/or sex) of refugees and migrants with dementia.

Fig. 5. Origin and destination of participants to the retained studies



Nearly all studies broadly focused on all-cause dementia, with only a few restricted to patients with Alzheimer's disease (*n* = 5), dementia with Lewy bodies (*n* = 1) or Creutzfeldt–Jakob disease (*n* = 1). Dementia etiology was only rarely reported (21.9% of studies). Regarding dementia diagnosis, 59.6% of studies did not specify how dementia was defined, 25.9% adopted different sets of international diagnostic criteria (e.g. Diagnostic and statistical manual of mental disorders *(219)*), 6.5% used a single cognitive test (e.g. the Mini-Mental State Examination, MMSE), and 5.0% reached a diagnosis by clinical consensus.

2.2 Thematic areas covered by the studies

The retrieved studies thematically addressed content covered by the seven action areas of the WHO *Global action plan on the public health response to dementia 2017–2025* (Table 2) and these are discussed in the following sections.

The main findings of these studies are presented together with the main indicators provided by the retrieved policy documents, which cover multiple action areas *(3,6,12,15,19,20,23,32,33,186–216)*.

2.2.1 Policy and legislation

This review identified three studies related to policy and legislation for migrants living with dementia *(42–44)*, updating two previous overviews *(42,43)*. Fifty national dementia plans and strategies were identified and accessed but only a fraction explicitly considered issues related to dementia in refugees and migrants. Eight countries considered this topic in their national dementia plans: Austria, Belgium (Flanders), Canada, Germany, the Netherlands, New Zealand, Norway and Sweden (Table 4).

Table 4. Existing national dementia plans/strategies of WHO Member States

WHO Member States whose dementia plan/strategy addresses the issue of dementia in refugees and migrants	
Austria	Netherlands
Belgium	New Zealand
Canada	Norway
Germany	Sweden
WHO Member States whose dementia plan/strategy does not address the issue of dementia in refugees and migrants	
Australia	Jordan
Belize	Luxembourg
Brunei Darussalam	Malaysia
Chile	Maldives
China	Malta
Costa Rica	Mauritius
Cuba	Mexico
Czechia	Morocco
Denmark	Oman
Dominican Republic	Portugal
Finland	Republic of Korea

Table 4. contd

WHO Member States whose dementia plan/strategy does not address the issue of dementia in refugees and migrants	
France	Russian Federation
Greece	Singapore
Iceland	Slovenia
India	Spain
Indonesia	Switzerland
Iran (Islamic Republic of)	Thailand
Ireland	Trinidad and Tobago
Israel	Türkiye
Italy	United Kingdom
Japan	United States of America

Sources: Monsees et al. (203), Alzheimer's Disease International *(220,221)*, Alzheimer Europe *(222)*.

Austria. The Austrian Dementia Strategy *(193)* recognizes the need to reduce the inequality of access to care for people with migrant backgrounds. In 2014 the Austrian Dementia Report had already devoted a full chapter to dementia in migrants, identifying the issues of delayed diagnosis, lower use of health care resources, the inappropriateness of diagnostic tests, lack of migrant-specific care and insufficient networking between migration and dementia experts.

Belgium (Flanders). The Flanders dementia plan, Building Further Together to a Dementia-friendly Flanders *(209)*, recognizes the increasing ethnical and cultural diversity of the Flanders population, including in higher age groups. In Brussels, almost one third of the older population is of migrant origin. The number of migrants is expected to rapidly increase, and so is the number of migrants living with dementia. The document reports ongoing efforts at increasing awareness about dementia across cultural minorities. In terms of care, the document recognizes the need to pay special attention to people at heightened risk, including those with a migration background.

Canada. The Dementia Strategy for Canada *(205)* stresses the importance of tailoring medical and public health messages to the specific needs and expectations of diverse communities, including migrants. Access to care for minority communities and populations can further be facilitated by approaches that take cultural specificities into due account.

Germany. The German National Dementia Strategy *(194)* considers provision of support for people with dementia and family carers with a migration background as an issue of overarching importance. Indeed, it is estimated that nearly 100 000 older migrants are currently living with dementia in Germany. The need to provide migrants with easily accessible information, to train relevant stakeholders regarding people with a migration background and inform employees of migrant support organizations on dementia are emphasized and will be the target of tailored initiatives. Moreover, activities aimed at expanding the nationwide database and network of culturally sensitive resources are planned.

Netherlands. According to the National Dementia Strategy 2021–2030 *(201)*, migrants account for nearly 14% of people with dementia who have access to health care in the country. The number of people with dementia is increasing rapidly among some migrant groups, who seem to have a higher risk relative to the host population. Based on these facts and figures, improving dementia care requires a focus on the cultural diversity of patients.

New Zealand. The New Zealand Framework for Dementia Care *(202)* stresses the importance of awareness and risk reduction strategies specifically tailored to, inter alia, migrant community groups. Different interpretations of dementia among some migrant groups can result in issues of shame and prevent families from seeking intervention and treatment for the person with dementia.

Norway. The Norwegian Dementia Plans 2020 and 2025 *(197,198)* advocate that all people with dementia living in the country have equitable access to care. Nevertheless, older migrants tend to have delayed referrals to services, mostly linked to poor health literacy about dementia. To counter this, the Government intends to invest in information and knowledge dissemination concerning dementia in migrants and minority communities. The need to implement culturally situated measures is highlighted in the national professional guidelines on dementia.

> **Sweden.** The Swedish National Strategy for Care of People with Dementia (206) stresses the importance of improving the care and support for people with a migration background. It outlines the opportunities and challenges of interpreter-assisted clinical examinations of migrants. The Strategy contains a clear indication to use the Rowland Universal Dementia Assessment Scale for the cognitive assessment of diverse older people with low education and migration background.

Overall, in most countries, the topic of dementia in migrants is only marginally reflected in national dementia strategies. The few specific policies or initiatives regarding dementia in migrants are mostly limited to awareness campaigns and community engagement efforts. None of the eight countries with a national dementia plan outlined above provided a clear definition of migrants, nor did they provide information on the peculiarities of different migrant groups (e.g. migration type, origin, exposures or experiences). Noticeably, none of the existing plans or strategies addresses the issue of dementia in refugees.

However, even if not explicitly mentioning refugees and migrants, a higher proportion of national dementia strategies do call for more attention to cultural diversity. Actions aimed at enhancing the standards of care for people with dementia in minority communities are also frequently provided. Theoretically, these policies might be useful and appropriate for affected individuals with migration or refugee backgrounds.

In addition to specific national dementia plans, a growing number of national dementia care guidelines/policies developed by European countries consider the topic of migration (44).

2.2.2 Awareness and inclusion

Available qualitative studies relying on focus groups and in-depth interviews indicate that general awareness of dementia is low in certain groups of migrants and their informal carers. Most of these studies broadly focused on international migrants (24 of 26 studies (45–54,56–67,69,70)); one included both refugees and migrants living in Canada (68), and one enrolled Hmong refugees living in the United States (55).

In some languages and cultures (e.g. Punjabi, Urdu or Vietnamese), no word directly translates or resembles the concept of dementia

(65,70), which assumes different understandings and attributions (47,52,55,56,58,59,64,65,67). Some migrants tend to conceive of dementia as a natural part of the life-cycle of the individual rather than as a disease. Dementia is commonly presented as a natural consequence of the ageing process, and its manifestations, such as forgetfulness, as simply a result of getting older. Alternatively, dementia is frequently understood as a mental illness (46,58,64,65) or interpreted according to a wide array of physical aspects (e.g. past dehydration, substance abuse, exposure to medications or problems with the circulatory system (58,64,67)), psychological factors (e.g. personality traits, thinking or worrying too much (51,58,67)), psychosocial stressors (e.g. social isolation, trauma, interpersonal conflicts or loss of family support (51,52,56)) and spiritual/religious convictions (e.g. fate, God's will, bewitchment (56,64)). Wide variations between and within migrant groups emerge from the studies, suggesting how the significance of dementia is influenced by cultural as well as personal aspects. However, dementia interpretations are often surrounded by stigma and negative beliefs (58,65,68). Some people with dementia and some carers identify dementia as a cause of shame, involving loss of face and erosion of the social network (58). Openness about dementia is possible with close relatives whereas open communication within the broader community can be hampered by feelings of shame (67).

Based on these conceptions, some migrants with dementia and their family carers try to deny, normalize, rationalize or downplay the extent of the clinical manifestations (54,62,68). Even when dementia signs are prominent, this may not warrant concern for some. Before seeking medical attention, some family carers try to modify the physical and social environments to tentatively attenuate dementia symptoms (51). Moreover, only some of the multifaceted symptoms of dementia syndrome, such as memory loss, difficulty recognizing relatives, getting lost in previously familiar situations, hiding money or sphincteric incontinence, are recognized and interpreted as possible expressions of an underlying disease (54,62). Families of migrants with dementia are crucial to symptom recognition (50). Physicians treating other acute conditions can also represent important portals for the identification of clinical manifestations of dementia (51).

Overall, such low levels of knowledge and social care acceptance of dementia are deemed major deterrents to medical help-seeking in migrants (as in non-migrants) and prevent them from receiving timely diagnosis, treatment and support. Other factors that can negatively influence access to dementia care are a lack of information on dedicated services, lack of employment, dealing with financial difficulties, presence of other medical concerns that are given precedence, scarcity of culturally and religiously sensitive resources, and negative attitudes towards diagnosis by general practitioners *(46,52,61,65,68)*. Conversely, help-seeking can be facilitated by having a family member or friend with dementia, having a large social network, receiving care for other medical problems from health professionals, and obtaining information from patients' associations or through reading *(51,52,57,62,65)*.

Most of the studies identified the need to enhance dementia awareness in migrants and raise awareness in patients and their families about dementia's nature and the course of disease.

A cluster randomized controlled trial recently demonstrated the feasibility and acceptability of a tailored intervention consisting of a leaflet and a letter to improve knowledge of dementia and encourage timely help-seeking in minority groups (including migrants) living in the United Kingdom *(48)*. Another cluster randomized controlled trial conducted in the Netherlands showed that offering a culturally sensitive educational, peer-group education intervention to family carers with a migration background enhanced knowledge about dementia and had a small but positive effect on the support received by these groups *(49)*.

2.2.3 Risk reduction

There were 17 studies that provided information on risk reduction *(71–87)* in migrants, with a focus on risk and/or protective factors. Beyond age, the available evidence suggests that education plays a central role in determining the likelihood of developing dementia among individuals with a migration background. In several studies conducted in the United States, a substantial portion of the increased risk for dementia observed in some migrant groups (predominantly migrants from Mexico) was linked to lower educational attainment *(71,74)*. That is, controlling for education significantly reduced the odds of dementia among migrants relative to their counterparts in the host population. Migrants with a high school education and some further education such as college or more, versus those with less than high school education, exhibited a significant lower length and proportion of life spent with dementia *(79)*. In a study conducted in rural Israel, low education level completely explained the differences in dementia prevalence observed between migrant groups *(78)*. These studies concluded by pointing out the need to address existing inequities in both educational attainment and quality of education.

Inconclusive evidence exists on the influence of age of migration on dementia risk. Several studies suggest that late-life migration (i.e. after the age of 50 years) may be associated with higher dementia incidence *(71,80)*. However, in one study, this association was significantly mitigated by education *(71)*. Conflicting data also concern the role of bilingualism/multilingualism. In a study conducted in Canada, speaking two or more languages delayed the onset of Alzheimer's disease in migrants by 5 years *(77)*. Conversely, in a study involving Spanish-speaking migrants in the United States, bilingualism was not independently associated with dementia occurrence *(85)*. Similarly, non-native language use was not found to have an independent protective effect against incident dementia *(75)*. Nevertheless, limited English proficiency in migrants living in the United States emerged as an important predictor of undiagnosed dementia *(81)*.

In the only available study on refugees, two thirds of those who developed signs of dementia during a 30-month follow-up period were exposed to five or more war-related traumatic experiences *(82)*. This preliminary finding suggests war-related psychological trauma might influence dementia risk.

No evidence was found on the design and/or implementation of dementia risk reduction strategies for migrants.

2.2.4 Diagnosis, treatment and care

The review identified 64 studies covering some aspects of diagnosis, treatment and care for migrants *(27,28,30,50–52,68,69,81,88–142)*. Barriers and facilitators can influence the accurate and timely detection of dementia and have been explored repeatedly in international migrants but only rarely in refugees *(68,91)*.

From the patients' side, poor awareness of dementia (see section 2.2.2), limited knowledge of the language of the host country and difficulty navigating health care services in the receiving country have consistently been identified as the main challenges to accessing care *(81,96,132)*. These obstacles may be insurmountable for older migrants suddenly living in a new and unknown place. Several limitations and inadequacies at the health care system side may further challenge access to diagnosis and care for migrants. Qualitative studies involving general practitioners have shown that the identification of dementia in primary care can be delayed or even impeded by language barriers, the difficulty in involving family members and interpreters, the lack of sensitive screening tools, and poor specific knowledge and competence on how to assess and manage dementia in migrants *(94,99,106)*. A nationwide study based on hospital discharges in Denmark revealed that only a minority of migrants received an acceptable diagnostic workup and that the overall quality of the diagnostic assessment was lower than in the patient population as a whole *(92)*. Surveys of dementia specialist services in Europe (i.e. memory clinics) have documented how these facilities are mostly unprepared to provide culturally sensitive care and support to migrants with dementia *(27,28)*. Specifically, health care professionals are not adequately trained to assist patients with a migration background; professional interpreters and cultural mediators are only rarely available; and the cognitive assessment is frequently confined to tests and tools that have been developed and validated in the context of developed countries and are strongly influenced by cultural factors. This is further compounded by the ageism that older patients already face in the health care system, with age often determining access to treatment and preventive measures. Lastly, the lack of culturally oriented communication and activities (e.g. serving traditional foods, celebrating holidays and religious events, listening to traditional music) can result in lower standards of care for migrants in long-term care settings *(69,89,90)*. The need to adapt dementia services and care to migration-driven diversity is increasingly being recognized *(98)*.

A growing number of studies dealt with the development and validation of instruments for the cross-cultural cognitive assessment of people with a migration background living in Australia, Europe and the United States. Indeed, the adoption of a culturally adapted cognitive evaluation is fundamental for the correct and timely identification of dementia in migrants, especially in those with limited education and proficiency in the language of the receiving country *(23,33)*. Dementia screening tools *(95,103,119,120,122,123–125,127,128)*, comprehensive neuropsychological test batteries *(104,129,130)* and tests measuring specific cognitive domains (e.g. naming ability and visual association memory) *(121,142)* have been developed and investigated for use in migrants. Some of these tools, such as the Rowland Universal Dementia Assessment Scale *(110)* and Cross-Cultural Dementia Screening *(103)*, have been validated in multicultural migrant populations attending dementia services in different countries. Overall, these cross-cultural tests are not greatly influenced by relevant migration-related characteristics (e.g. preferred language and years of education) and are highly accurate in identifying dementia among culturally diverse older people *(121,124,127)*. Conversely, more conventional instruments (e.g. the MMSE and the Montreal Cognitive Assessment) are significantly influenced by education and can inadvertently lead to diagnostic errors and misclassifications when used in these population groups without incorporating relevant adjustments *(95,123)*. To date, most of the evidence regarding dementia in migrants has been generated using the Rowland Universal Dementia Assessment Scale, which has been found to be at least as accurate as the MMSE in distinguishing migrants with and without dementia and less affected by education and literacy *(110,122,128)*. Most studies on cross-cultural cognitive assessment emphasize the need to train neuropsychologists and other health care professionals in the use of culturally suitable tools and approaches, as recently pointed out also by patient associations and scientific consortia *(23,33,216)*. The collection of information regarding migration-related contextual factors potentially impacting test performance (e.g. culture and acculturation, quality of education, socioeconomic status or testing situation) has also been promoted *(216)*. No evidence was found for cognitive assessment of refugees.

Once diagnosed with dementia, migrants seem to have a lower likelihood of receiving specific pharmacological treatment. Two registry-based studies conducted in Denmark and Norway revealed that migrants (especially those described as coming from "non-Western countries") have lower odds of being prescribed antidementia drugs than the host counterparts *(30,140)*. Moreover, it has been shown that the treatment of some neuropsychiatric symptoms in dementia, such as hallucinations, delusions or aggression, is less common in patients with a migration background *(116,117)*. Possible reasons behind the identified reduction in pharmacological prescriptions were not considered in these studies. There is also evidence that migrants have less access to residential care and are mostly assisted at home through informal/family care *(30,141)*. These care trajectories are frequently influenced by the culture of the person with dementia and their family, who may consider nursing home placement as unacceptable *(55,61,134)*.

2.2.5 Support for carers

The experiences of formal and informal carers of providing care for international migrants with dementia have been collected and described in a number of studies using qualitative research approaches conducted in Europe, Australia and the United States (Table 5) *(52,54,56,57,60–65,70,88,90,97,132,147–149,151,153,154,157,159–161)*, but their experiences in a refugee context are less well documented. In this latter regard, only three studies were identified that focused on providing care for refugees with dementia: Vietnamese refugees living in Australia (65) or the United States (158) and refugees of Slavic origin living in Sweden (91).

Table 5. Qualitative studies exploring the experiences of formal and informal carers of migrants with dementia

Study	Carers	Country or area of origin	Country of destination	Main themes
Xiao et al., 2015 (65)	Formal and informal	Viet Nam	Australia	● ● ●
Gilbert et al., 2021 (133)	Informal	Speakers of Arabic, Chinese (Cantonese and Mandarin), Greek, Hindi, Italian, Tamil, Vietnamese	Australia	● ●
Chaouni et al., 2020 (147)	Formal and informal	Morocco	Belgium	● ● ● ● ● ● ●
Chaouni & De Donder, 2019 (151)	Formal and informal	Morocco	Belgium	● ● ● ● ● ●
Tezcan-Güntekin et al., 2017 (144)	Informal	Türkiye	Germany	● ●
Ahmad et al., 2020 (150)	Informal	China, India, Indonesia, Morocco, Suriname, Türkiye	Netherlands	●
van Wezel et al., 2016 (63)	Formal and informal	Morocco, Suriname, Türkiye	Netherlands	● ●
van Wezel et al., 2018 (67)	Informal	Morocco, Suriname, Türkiye	Netherlands	●

Table 5. contd

Study	Carers	Country or area of origin	Country of destination	Main themes
Czapka & Sagbakken, 2020 *(132)*	Formal and informal	Croatia, India, Pakistan, Poland, Somalia, Türkiye; islands in the Atlantic Ocean	Norway	● ● ●
Næss & Moen, 2015 *(70)*	Formal and informal	Pakistan	Norway	● ● ●
Sagbakken et al., 2018 *(131)*	Formal and informal	Afghanistan, Chile, China, Lebanon, Pakistan, Sri Lanka, Türkiye, Viet Nam	Norway	● ● ● ● ●
Kiwi et al., 2018 *(160)*	Informal	Iran (Islamic Republic of)	Sweden	● ●
Mazaheri et al., 2011 *(161)*	Informal	Iran (Islamic Republic of)	Sweden	● ● ●
Rosendahl et al., 2016 *(88)*	Formal and informal	Estonia, Finland, Hungary, Russian Federation	Sweden	● ● ●
Söderman & Rosendahl, 2016 *(90)*	Formal	Estonia, Finland, Hungary, Russian Federation	Sweden	● ●
Guerra et al., 2022 *(60)*	Informal	Argentina, Colombia, Ecuador, Peru, Uruguay	United Kingdom	●
Herat-Gunaratne et al., 2020 *(153)*	Informal	Bangladesh, India	United Kingdom	● ● ●
Hossain et al., 2017 *(61)*	Informal	Bangladesh	United Kingdom	● ●
Hossain & Khan, 2019 *(154)*	Informal	Bangladesh	United Kingdom	● ● ●

Table 5. contd

Study	Carers	Country or area of origin	Country of destination	Main themes
Casado et al., 2015 *(148)*	Informal	Republic of Korea	United States	🔵🟣🔴⚫
Kong et al., 2010 *(159)*	Informal	Republic of Korea	United States	🔵🟠🟡🟣🩵⚫
Lee & Choi, 2013 *(66)*	Informal	Republic of Korea	United States	🟡🟣🩵
Liu et al., 2021 *(157)*	Informal	China	United States	🔵🟢🟣🩵🩷
Neary & Mahoney, 2005 *(62)*	Informal	Argentina, Colombia, Cuba, Dominican Republic, Guatemala, Puerto Rico	United States	🔵🟠🟡⚪🟣🩵
Nkimbeng et al., 2022 *(146)*	Informal	African countries	United States	🔵🟠🟡🟣🔴🩷
Sun et al., 2014 *(149)*	Formal and informal	China	United States	🔵🟣🩷
Yeo et al., 2002 *(64)*	Informal	Viet Nam	United States	🔵🩷

🔵 Limited knowledge and misconception of dementia; 🩵 lack of culturally adequate and structured services; 🟠 difficulty in navigating the health care system; 🟣 attitudes towards providing care and preference for home care; 🟡 language barriers; 🔴 difficulty in accepting the diagnosis; 🟢 family tensions; ⚫ discrimination; ⚪ collaboration between formal and informal carers; 🩷 importance of the informal care network.

The main concepts and themes that emerged from semi-structured/in-depth interviews or focus groups were as follows.

Attitudes towards providing care and preference for home care. A sense of familism, religious beliefs and cultural values commonly resulted in the motive, or obligation, to provide care for migrants with dementia at home. Some studies reported that women and men contribute differently to providing care, and certain aspects of caring were felt to be more often and more appropriately carried out by women. Even when overwhelmed, carers frequently expressed reluctance to admit their family members to a nursing home.

Importance of the informal care network. The obligation of caring for a person with dementia was often shared between family members and the informal care network. This network included closer relatives, friends and neighbours from the same cultural background. These informal carers were perceived as more acceptable to the care recipient and family and more able to provide culturally appropriate care than formal providers.

Family tensions. Some carers talked about disagreements, dissatisfaction and stress because of a lack of support, unwanted advice and poor involvement of other family members. Since family dynamics are complex, trust in relatives should not be taken for granted.

Limited knowledge and misconception of dementia. Most carers reported not being able to recognize the symptoms at the beginning of dementia. They had learned about the disease mostly through their experiences of providing care and frequently expressed the willingness to learn more about dementia care. Misconceptions of dementia often emerged: dementia was attributed to old age, craziness or influences related to spiritual beliefs or fate.

Difficulty in accepting the diagnosis. Sometimes, families reacted to initial symptoms with denial, normalization of symptoms and disbelief.

Difficulty in navigating the health care system. Lack of information about the available services was another barrier mentioned by the interviewed families and the representatives of migrant communities. Consequently, many migrants do not know whom to contact first or what kind of help is available.

Collaboration between formal and informal carers. Service professionals identified several difficulties in communicating and collaborating with informal carers in their work. They reported that patients and families tended to downplay the mental health problems. A lack of understanding of the cultural expectations and limited time and staff can increase frustration in communication.

Lack of culturally adequate and structured services. Carers reported a lack of culturally adapted programmes for migrants with dementia and their families. In nursing homes, most residents appreciated receiving traditional food and the opportunity to listen to music in their native language.

Language barriers. Both formal and informal carers emphasized the importance of the language barrier. The main benefit of speaking one's mother tongue was linguistic stimulation for migrant patients with dementia, enabling them to express their needs, socialize and participate in group activities.

Discrimination. Three studies reported perceived discrimination by formal carers and the fear of racism when seeking medical care.

Overall, the available evidence suggests that carers of migrants with dementia experience controversies and challenges due to perceived barriers to seeking health care support and the lack of tailored care pathways. Noticeably, these themes consistently emerged in studies conducted in different world regions and involving different groups of migrants (e.g. south-Asian migrants in Australia, international refugees and migrants in Europe, and African and Asian migrants in the United States), thus suggesting common unmet needs.

2.2.6 Health information systems and monitoring

The prevalence and incidence of dementia as well as other dementia-related outcomes/indicators in migrants have been increasingly explored, and 39 studies related to health information systems and monitoring were identified in the review *(28,72,78,82–87,92,135–141,162–183)*.

Several studies compared the prevalence and/or incidence of dementia between international migrants and individuals born in the receiving country and provide conflicting results (Table 6). Overall, most registry-based studies relying on administrative data conducted in developed countries (Canada, Denmark, Norway, Sweden and United States) reported lower dementia rates in migrants relative to individuals born in the receiving country *(140,168,179–181)*. The only exception is the observation of a higher dementia incidence in Faroese migrant women living in Denmark compared with Danish women *(182)*. In these studies, dementia in refugees and migrants was identified by linking records collected in administrative and health care databases (e.g. diagnosis of dementia in national patient registers, hospital admissions/discharges and death certificates; prescription of antidementia treatments) with information on the country of birth. One of these studies also included refugees in the broader group of migrants *(181)*. Such studies rely on the work of available diagnostic services; if they are less good at diagnosing dementia in particular populations then there will be a lower level of diagnoses found. With some exceptions, studies using direct clinical assessments/records for the identification of dementia conducted in Europe and the United States documented higher prevalence and incidence rates in migrants relative to the host population *(83,86,87,137,166,177)*. Among these clinical studies, the screening/diagnosis of dementia was only rarely based on culturally sensitive assessments and/or culturally adapted approaches. In a study conducted in the United Kingdom, dementia in African-Caribbean migrants was screened with a culturally valid version of the MMSE *(86)*. In a study involving migrants in the Netherlands, the presence of cognitive deficits was ascertained using the Cross-Cultural Dementia Screening instrument, which was validated in people of lower educational level from different cultures *(166)*. The discrepancy between registry-based and clinical-based studies may, therefore, suggest a structural inequity, with underdiagnosis of dementia and poor access to health care resources in migrants, rather than a more favourable risk profile. No consistent evidence exists on those attributes and determinants conferring a higher dementia risk in people with a migration background, although one study *(86)* pointed to a higher prevalence of vascular risk factors and one study *(166)* showed a link with low educational attainment. Moreover, regardless of the study design, wide variations in dementia rates were observed in different migrant groups (e.g. by sex, country of birth, ethnicity and age at migration). These variations might also reflect the different quality of the included studies, the use of different tools to diagnose dementia and the varying accessibility to services. Overall, migration emerged as a modifier of dementia risk or of likelihood of case ascertainment rather than a direct dementia risk factor.

Table 6. Studies comparing the prevalence and/or incidence of dementia between international migrants and individuals born in the receiving country and/or between migrant groups

Study	Condition	Source/ design (study population)	Culturally sensitive assessment	Migrant subgroups	Destination country	Country/ region of origin	Findings
Kahana et al., 1974 (170)	CJD	Hospital and autopsy records (2 152 839)	No	International migrants	Israel	Algeria, Iraq, Libya, Morocco, Tunisia; central, eastern, western Europe	Higher annual incidence of CJD in Libyan migrants (31.3 per million) relative to host population (1.0 per million) and other migrant groups (0.4–0.9 per million)
Livingston et al., 2001 (83)	Dementia	Cross-sectional community study (1085)	No	International migrants	United Kingdom	Cyprus, Greece, Ireland, Türkiye; Africa, Caribbean, other European countries, other countries	Higher dementia prevalence in African–Caribbean individuals (RR: 1.72; 95% CI: 1.06–2.81) and lower dementia prevalence in Irish-born individuals (RR: 0.36; 95% CI: 0.17–0.87) compared with those born in the United Kingdom

Table 6. contd

Study	Condition	Source/ design (study population)	Culturally sensitive assessment	Migrant subgroups	Destination country	Country/ region of origin	Findings
Lerner et al., 2008 (92)	Dementia	Retrospective study of inpatients and outpatients referred to a psychiatric service (740)	No	International migrants	Israel	Former USSR	Lower rates of dementia in new migrants (14.2% of overall diagnoses) relative to individuals who had either been born in Israel or were long-term migrants (20.4%)
Adelman et al., 2011 (86)	Dementia	Cross-sectional study in general practice (436)	Yes	International migrants	United Kingdom	Caribbean Islands, Guyana	Higher prevalence of dementia in the African–Caribbean group (9.6%) than the white group (6.9%) after adjustment for age and socioeconomic status (OR: 3.1; 95% CI: 1.3–7.3)

Table 6. contd

Study	Condition	Source/ design (study population)	Culturally sensitive assessment	Migrant subgroups	Destination country	Country/ region of origin	Findings
Nasseri & Moulton, 2011 *(168)*	Dementia	Death certificates (113 503)	No	International migrants	United States	Middle Eastern countries	Lower odds for dementia (proportional OR: 0.72; 95% CI: 0.58–0.88) among causes of death in female migrants relative to United States-born non-Hispanic white participants

Table 6. contd

Study	Condition	Source/ design (study population)	Culturally sensitive assessment	Migrant subgroups	Destination country	Country/ region of origin	Findings
Diaz et al., 2015 (140)	Dementia	National Population Register, Norwegian Health Economics Administration database, Norwegian Prescription Database, Regular General Practitioner Database (1 605 913)	No	International migrants	Norway	Not specified; both high- and other-income countries	Lower dementia prevalence in migrants from high-income countries (1.1%) and other-income countries (0.6%) relative to Norwegian individuals (1.7%)

Table 6. contd

Study	Condition	Source/ design (study population)	Culturally sensitive assessment	Migrant subgroups	Destination country	Country/ region of origin	Findings
Kristiansen et al., 2016 (181)	Dementia	National Patient Registry, Psychiatric Central Register (800 893)	No	Refugees and family-reunified migrants	Denmark	Not specified	Lower IRR for dementia among migrants compared with Danish-born individuals (IRR: 0.91; 95% CI: 0.83–1.00) Lower IRR for dementia among family-reunified migrants (IRR: 0.65; 95% CI: 0.55–0.76) but not among Afghani migrants (IRR: 1.50; 95% CI: 1.09–2.08)

Table 6. contd

Study	Condition	Source/ design (study population)	Culturally sensitive assessment	Migrant subgroups	Destination country	Country/ region of origin	Findings
Parlevliet et al., 2016 (166)	Dementia	Cross-sectional study in general practices (2254)	Yes	International migrants	Netherlands	Morocco, Suriname, Türkiye	Higher prevalence of dementia in Turkish (14.8%), Surinamese–Hindustani (12.6%), Moroccan Arabic (12.2%) and Moroccan Berber (11.3%) participants compared with Surinamese–Creoles (4.0%) and native Dutch (3.5%)
Moon et al., 2019 (177)	Dementia	Cross-sectional study of a nationally representative sample of Medicare beneficiaries (7609)	No	International migrants	United States	Not specified	Higher prevalence of dementia in migrants of different ethnic groups (except for non-Hispanic Black individuals) relative to their native counterparts

Table 6. contd

Study	Condition	Source/ design (study population)	Culturally sensitive assessment	Migrant subgroups	Destination country	Country/ region of origin	Findings
Wändell et al., 2019 (179)	Dementia	National Patient Register (3 286 624)	No	International migrants	Sweden	All world regions	Lower incidence of dementia among male migrants (HR: 0.85; 95% CI: 0.83–0.88) and female migrants (HR: 0.93; 95% CI: 0.91–0.95) compared with Swedish-born individuals Among migrant groups, higher incidence of dementia among men from Bosnia (HR: 1.61; 95% CI: 1.18–2.20), Estonia (HR: 1.25; 95% CI: 1.10–1.43), Finland (HR: 1.14; 95% CI: 1.08–1.20) and Russian Federation (HR: 1.37; 95% CI: 1.12–1.69) Higher incidence of dementia among women from Finland (HR: 1.20; 95% CI: 1.15–1.24) and Norway (HR: 1.14; 95% CI: 1.07–1.22)

Table 6. contd

Study	Condition	Source/ design (study population)	Culturally sensitive assessment	Migrant subgroups	Destination country	Country/ region of origin	Findings
Petersen et al., 2020 (182)	All-cause dementia, Alzheimer's disease, vascular dementia	Danish Central Population Register, Danish National Patient Register (57 373)	No	Intranational migrants	Denmark	Faroe Islands	Higher dementia (both all-cause and subtypes) standardized IRR in female Faroese migrants (including long-term migrants) compared with Danish individuals (standardized IRR: 2.1; 95% CI: 1.8–2.5) Non-significant excess risk in male Faroese migrants (standardized IRR: 1.2; 95% CI: 0.9–1.6)

Table 6. contd

Study	Condition	Source/ design (study population)	Culturally sensitive assessment	Migrant subgroups	Destination country	Country/ region of origin	Findings
Segers et al., 2021 (137)	DLB	Retrospective study of patients referred to a memory clinic (2702)	No	International migrants	Belgium	North and sub-Saharan Africa, Asia, Europe, Latin America, North America	Higher prevalence of DLB in migrants (5.2%) relative to host population (2.7%) Within migrant groups, higher prevalence in people from north Africa (6.3%) and Latin America (19.0%)
Wong et al., 2021 (180)	Dementia	Population-based study using administrative databases (387 937)	No	International migrants	Canada	China, south Asia	Lower dementia prevalence and incidence in recent (< 10 years) or longer-term (> 10 years) migrants than long-term residents

Table 6. contd

Study	Condition	Source/ design (study population)	Culturally sensitive assessment	Migrant subgroups	Destination country	Country/ region of origin	Findings
Hayes-Larson et al., 2022 (87)	Dementia	Population-based study of Kaiser Permanente members (155 536)	No	International migrants	United States	China, Japan, Philippines	Higher dementia incidence in foreign-born compared with United States-born Filipino individuals (HR: 1.39; 95% CI: 1.02–1.89) No nativity differences in Chinese (HR: 1.07; 95% CI: 0.92–1.24), Japanese (HR: 1.07; 95% CI: 0.88–1.30) or white individuals (HR: 1.00; 95% CI: 0.95–1.04)

CI: confidence interval; CJD: Creutzfeldt–Jakob disease; DLB: dementia with Lewy bodies; HR: hazards ratio; IRR: incidence rate ratio; OR: odds ratio; RR: relative risk.

Some studies investigated the prevalence of dementia in specific migrant groups, such as Japanese–Americans in the United States *(178)*, Japanese migrants in Brazil *(167)*, Korean migrants in the United States *(135)*, and south Asian migrants in the United Kingdom *(163)*. Varying prevalence rates emerged from these studies, probably because of the different characteristics of the enrolled populations (e.g. by age, sex or education) and the criteria adopted for the diagnosis of dementia. Two studies focused on the number/proportion of migrants attending dementia services in Belgium (18.6%) *(172)* and Italy (3.1%) *(138)*. One study reported the number of people with dementia identified among Syrian asylum seekers admitted to neurology outpatient clinics in Türkiye *(169)*.

Finally, to understand the magnitude of dementia among international migrants in Europe, some studies have applied age- and sex-specific rates of dementia to the number of migrants obtained from statistical offices. This has led to the estimate that about 500 000 people with a migration background live with dementia in Europe *(174,175,203)*.

2.2.7 Research and innovation

Only two studies focused on enhancing research participation for migrants with dementia and their carers *(184,185)*. These subjects are commonly underrepresented in research outputs. Cooperation between researchers and trusted gatekeepers/members in migrant communities and those attending daily and well-received leisure activities are indicated as possible tools to enhance participation *(184,185)*. However, ethical concerns (e.g. autonomy, information, trust and scepticism) and methodological issues (e.g. sampling bias) should be carefully considered and addressed *(185)*.

3. Discussion

3.1 Strengths, limitations and research gaps

3.1.1 Limitations

Although the scoping literature review included studies and documents published in any of the six United Nations official languages, the search strings were developed in English. Therefore, evidence published in other languages may not have been included.

Although the review was extended to grey literature, the search may have failed to identify relevant evidence from LMICs, since data from those countries are less likely to reach publication or are published in the grey literature in languages other than English.

The review specifically focused on dementia or major neurocognitive disorders. This may have led to the exclusion of studies exploring the impact of cognitive disorders of milder severity (mild cognitive impairment, minor neurocognitive disorder, subjective cognitive decline or other cognitive deficits) in refugees and migrants *(223)*. This choice was driven by the fact that dementia is the current focus of global health policies *(19,20)* and that other prodromal clinical constructs are still poorly understood in countries and settings with limited diagnostic resources. Extending the focus to pre-dementia conditions would have further limited the transferability of the present policy indications to less-resourced settings. However, future research efforts will be needed to understand the impact of overall cognitive impairments in refugee and migrant populations.

The review was restricted to studies explicitly focusing on refugees and migrants. Since the terminology used to describe these individuals is often unclear *(224)*, it is possible that some studies included refugees and migrants under broader terms such as ethnic minorities, minority groups or culturally diverse individuals and, thus, were excluded from the review.

A formal quality appraisal of the included evidence sources was not performed as it is not a priority in scoping reviews or part of the scoping review methodology (225,226); consequently, the policy considerations proposed are based on the evidence that the review did identify.

3.1.2 Knowledge gaps

There is a need for a solid evidence base on which to ground clinical and public health decisions aimed at improving the quality of care for refugees and migrants with dementia. However, major evidence gaps in the pertinent literature remain. To support better dementia policies for refugees and migrants, the following evidence gaps should be addressed in further research, disease surveillance and monitoring.

LMICs were underrepresented in the scientific and grey literature. All of the reviewed articles and policy documents were from high- and upper-middle-income countries in Asia, Europe, North America and Oceania. This observation contrasts with the current and future demographic and epidemiological scenarios of migration. Indeed, more than 13 million older international migrants currently live in less-developed countries, accounting for 27.5% of the overall population of older migrants (4). By the end of 2021, 85% of 27.1 million refugees were hosted in developing countries (227). Moreover, in 2019, 60% of the 55 million people living with dementia worldwide were residing in LMICs (12). Since population ageing is occurring at an unprecedentedly fast rate in these countries, they will be affected by a dramatic increase in the number of people with dementia in the coming decades (12). Importantly, formal systems of care are lacking in these contexts. Consequently, people with dementia in these countries have no option but to rely on informal care from family, friends or other community members, who will have received limited or no training and may have no support for their demanding roles as carers (228). Moreover, in sub-Saharan Africa, people often associate dementia with witchcraft and believe that mental illness is caused by evil spirits. This is the case in some of the countries that are major recipients of refugee and migrant populations in the region, including Ethiopia, Nigeria and Uganda (229,230). These beliefs can entrench stigma and discourage people with dementia and their families from seeking professional care and support where it is available. It is, therefore, imperative to collect data on dementia in refugees and migrants living in these regions.

Evidence was lacking for refugees with dementia. Most studies broadly focused on international migrants, with only a few articles describing the situation of people with dementia with refugee backgrounds *(55,65,68,82,91,118,158,169,181)*. However, these individuals face specific inequities in access to care and support for dementia. Migration-induced isolation and loss of social networks, exposure to trauma and stress, inability to meet basic needs (e.g. food, water and shelter), and poor management of other NCDs can increase the risk of developing cognitive impairment and dementia *(231)*. To date, much attention has been paid to the health of young and adult refugees, while the impact of age-related conditions on older refugees has received little emphasis. In the available guidance for the inclusion of older people in emergency assessments and response, the issue of dementia is still not recognized *(232,233)*. A paradigm shift is urgently needed. The number of older refugees is expected to dramatically increase, since, by 2050, 80% of older people globally will live in developing countries that are identified as hot zones for conflict *(3,5,227)*. More older people are being forcedly displaced by food insecurity, climate change, natural disasters and conflict, and they face specific challenges that are not being considered in preparedness and response plans to crises. Refugees with dementia and other disabilities are at risk of being left behind in the provision of humanitarian assistance and health care support *(32)*.

The terminology adopted to describe refugees and migrants was mostly unclear and ill defined. Almost all reviewed studies exclusively relied on the countries of birth and current residence to determine migrant status. Information on determinants surrounding migration and other contextual factors, such as the reason for migration, length of migration, legal and socioeconomic status, acculturation, social network, living conditions and language of the included participants, was often lacking. Migration experiences are not the same across different migrant groups and may influence dementia risk, assessment and access to care in different ways. Therefore, greater attention must be paid to the definitions used for a migrant and for different migrant groups, as these definitions can affect health system policies and migrant access to health *(224)*.

There was scant information on the characteristics of dementia occurring in refugees and migrants. Most studies failed to provide details on major clinical aspects such as dementia etiology, severity, clinical presentation, source of referral to clinical services, behavioural disturbance, diagnostic approach and definition, and pharmacological and nonpharmacological treatment. The availability of good-quality data on both dementia- and migration-related variables is fundamental to understanding the health needs of affected individuals, designing tailored health care pathways and delivering competent care and support.

Only a few countries have nationally representative data on the prevalence and incidence of dementia in migrants obtained by epidemiological studies or from health care and administrative databases. Lack of such evidence is a relevant barrier to estimate the burden of dementia and the costs of illness. In the few available studies *(140,168,179–181)*, wide variation was evident in the definition/coding of both dementia and migrant status. This limits the possibility of merging and comparing information from different countries *(234)*.

Among quantitative studies, longitudinal analyses were rare. Most studies compared cross-sectionally the clinical characteristics of migrants and individuals born in the receiving communities, the preparedness of services or the accuracy of screening and assessment tools, or they conducted stratified analyses by migrant status in health care and administrative databases. However, longitudinal studies exploring so-called hard outcomes (e.g. mortality, hospitalization, institutionalization or clinical worsening) are needed to explore the health trajectories of refugees and migrants with dementia, identify inequities and disparities in service use, and plan effective interventions.

There was also little knowledge regarding the prevalence and impact of the established dementia-modifiable risk factors in refugees and migrants. Moreover, limited and inconclusive evidence emerged on the role of additional potential protective factors (e.g. psychological resilience, strong community reliance after settlement, social integration, acculturation or developing bi- or multilingualism) *(235,236)*, or risk factors (e.g. isolation, psychological trauma and stress or socioeconomic deprivation) *(237,238)* in these groups. Data on dementia risk factors in refugees and migrants are necessary to guide the design and implementation of situated preventive strategies.

There was a lack of data on dementia among refugees and migrants living in detention camps or assisted in dedicated first-aid facilities (e.g. reception centres and outpatient services managed by nongovernmental organizations). This may be due to the low number of older people who are assisted in these settings, the difficulty of implementing dementia screening and assessment, and the prioritization of what are perceived as more urgent pathological conditions *(32)*. As suggested by the recent crisis in Ukraine *(239)* and given the evolving sociodemographic scenario, there is a need to extend the assessment and management of dementia in refugees and migrants outside usual settings of care (such as primary care services, memory clinics, hospitals and nursing homes).

Only seven qualitative studies explicitly adopted an intersectional perspective to explore the impact of dementia in refugees and migrants *(98,100,132,133,147,151,152)*. Intersectionality postulates that different social positions (e.g. age, sex/gender, education, ethnicity, refugee/migrant status or socioeconomic status) are expressed simultaneously to influence individual experiences and behaviours and to produce inequalities in health and health care *(16)*. This intersectionality framework can improve understanding of the realities faced by people with dementia and may be particularly relevant to reflect the lived experiences of refugees and migrants experiencing cognitive disorders *(16)*. Overall, qualitative studies indicate that the challenges and obstacles faced by carers of migrants with dementia appear to be similar to those experienced by carers of people with no migration background. This reinforces the need to invest in health and social policies to support all carers of people with dementia throughout their illness.

The problem of abuse was largely absent from the reviewed evidence. Yet, dementia and cognitive impairment constitute risk factors for the perpetuation of elder abuse and maltreatment *(240,241)*. Refugees and migrants are particularly vulnerable to abusive situations. People with disabilities are at high risk of abuse during a humanitarian emergency *(32)*. This issue warrants further research to develop effective protection and to ensure that refugees and migrants with dementia are safe from harms such as violence, abuse and exploitation *(32)*.

Other relevant elements of dementia research *(242)* were completely missing or only marginally addressed in the body of evidence. For example, the access to biomarker-based dementia diagnosis, the role of genetics in the development of dementia, clinical trial participation and outcome, compliance with therapies, and important ethical matters (such as legal capacity, self-determination and end-of-life care decisions) have not yet been investigated in refugees and migrants. Noticeably, only a few studies focused on neuropsychiatric or behavioural disturbances in these individuals *(109,112,116,117)*. However, these symptoms are common in people with dementia, are predictive of carer burden and poorer health outcomes, and are likely to be influenced by sociocultural factors *(243)*. Finally, there is still an almost complete lack of evidence from controlled studies that have tested the feasibility and effectiveness of interventions to improve the care and support provided to migrants with dementia and their carers.

Overall, the main knowledge gaps emerging from this analysis reflect major research barriers and challenges in dementia research areas (e.g. dementia epidemiology, diagnosis, care and support, and risk reduction) that have been recently systematically set out in the WHO document *A blueprint for dementia research* (242).

3.2 Policy considerations

Based on the present findings (arising from a scoping review of the literature rather than a systematic quality assessment of the available evidence) and considering the current conventions, frameworks and recommendations from international organizations, policy considerations are suggested in the seven action areas of the WHO *Global action plan on the public health response to dementia 2017–2025* (20). For each area, the key challenges for policy implementation are also discussed. Given the heterogeneity of refugee and migrant populations and the profound differences in the organization of local health care systems, these policy considerations should be tailored to the needs of specific migrant groups, specific care settings and available resources. This requires a multisectoral, multistakeholder alignment of efforts from both health care systems and emergency/humanitarian contexts for coordinated global governance. Ideally, policy-making should follow an intersectional lens to help to identify and respond to the specific needs of refugees and migrants with dementia and address the disadvantages they may be facing because of their intersecting social positions.

3.2.1 Policy and legislation

3.2.1.1 Inclusion of refugees and migrants in relevant national and subnational policies, legislation, plans and frameworks on dementia

According to the *Global action plan on the public health response to dementia 2017–2025* (20), governments of WHO Member States are urged to create national dementia strategies by 2025. When the Global

Action Plan was adopted in 2017, less than 20% of Member States had issued a national dementia plan *(221)*. Dementia plans are essential instruments for promoting a whole-of-government, broad and multistakeholder public health response to dementia *(12,20)*. Actions directly targeting refugees and migrants should be included in dementia plans and policies concerning related areas such as ageing and long-term care, according to local context and resources (e.g. estimated number of refugees and migrants with dementia living in the country, organization of dementia care pathways and financial resources). The proposed responses should adequately reflect the attributes of different migrant groups and be coordinated through collaboration and partnership of all relevant parties: health, justice, social sectors, civil society, migrants with dementia and their carers, patient associations and relevant representatives from migrant communities. Ideally, all of the themes mapped onto the seven action areas of the WHO *Global action plan on the public health response to dementia 2017–2025* should be covered in a plan concerning refugees and migrants. These policies may only be helpful if they are adequately resourced and implemented, and if actions are taken to monitor and evaluate their effectiveness and revise and update their content where required.

3.2.1.2 Inclusion of dementia in the global, regional, and national agendas dealing with the health of refugees and migrants

International and national commitments on refugees and migrants should recognize and address the complex needs of displaced and migrant people with dementia and their carers. It is essential to promote mechanisms and legislation aimed at safeguarding the protection of their human rights, wishes and preferences and prohibiting discrimination on any grounds, including their age, gender, cognitive capacity, and refugee or migrant status. Moreover, access to basic services (including health care and social resources) should be ensured for these population groups, in line with the principles of the Global Compact on Safe, Orderly and Regular Migration (Objective 15) *(244)*.

3.2.1.3 Key challenges to policy development and implementation

Challenges include:

- lack of a clear political commitment and governance for dementia care;
- lack of governance for the inclusion of refugees and migrants in health care systems;

- lack of funding for service provision for refugees and migrants;
- lack of funding for dementia;
- lack of multistakeholder partnerships between relevant actors;
- unavailability of robust national or subnational estimates of dementia in refugees and migrants; and
- prevailing ageism and other intersecting forms of bias, including discrimination against refugees and migrants.

3.2.2 Awareness and inclusion

3.2.2.1 Organization of national and local campaigns and educational activities to raise awareness about dementia in refugees and migrants

Dementia-awareness programmes should promote understanding of dementia as a clinical condition, reduce stigma and discrimination, foster social participation and access to care, and increase knowledge regarding prevention among refugees and migrants. These campaigns should be culture specific and situated on the particular characteristics of the target migrant groups. They should be developed, implemented and monitored through collaborative interaction between relevant stakeholders, including people with dementia and their carers, representatives of refugee and migrant communities, and patient associations.

3.2.2.2 Creation of dementia-friendly environments for refugees and migrants, according to the different settings

Refugees and migrants with dementia should be empowered to live independently, participate in society and enjoy freedom, equality and quality of life according to their personal preferences and cultural values. This can be pursued through environmental modification, provision of amenities, goods and services, and by creating opportunities for community participation and access to health and social care.

3.2.2.3 Creation of dementia-inclusive environments for refugees and migrants living in emergency contexts

Older people and, more specifically, people with dementia are still largely overlooked in humanitarian responses *(24)*. Their specific health needs must increasingly be recognized and addressed by humanitarian actors (32). Access to humanitarian action should be granted by eliminating existing physical, social and communication barriers. The basic health needs of people with dementia, such as food, drink and hygiene, must be delivered. It is also essential to ensure access to therapies and provide support to carers. Available humanitarian frameworks for the inclusion of older people and those with disabilities (32), even if not specifically referring to people with dementia, can be helpful in developing humanitarian programming and responses.

3.2.2.4 Key challenges to policy development and implementation

Challenges include:

- lack of guidance, awareness and knowledge;
- insufficient economic and human resources to run campaigns and educational activities;
- lack of partnership and collaboration between civil associations and policy-makers;
- non-routine inclusion of dementia in refugees and migrants in clinical curricula, and
- limited awareness of dementia in humanitarian preparedness and response efforts.

3.2.3 Risk reduction

3.2.3.1 Design and implementation of evidence-informed, multisectoral and culturally sensitive interventions aimed at dementia risk reduction in refugees and migrants

Refugee and migrant communities should receive culturally situated information on proactive management of the well-established modifiable risk factors for dementia. Indeed, measures that prevent or postpone dementia will also be valid in these population groups, such as increasing physical activity; preventing and reducing obesity; adhering to balanced and healthy dietary patterns; cessation of tobacco use and the harmful use of alcohol; social participation and engagement in cognitively stimulating activities; and prevention and management of mid-life diabetes, hypertension and depression. Available recommendations on dementia risk reduction *(13)* should be culturally adapted and disseminated to be effective in refugees and migrants. This can be achieved with the involvement of relevant stakeholders from migrant communities. The specific obstacles limiting lifestyle modifications and the adoption/adherence to healthy behaviours in these population groups should be recognized and addressed.

3.2.3.2 Promotion of dementia risk reduction strategies in refugees and migrants living in emergency contexts

Refugee and migrant communities in emergency contexts should be empowered to reduce exposure to dementia risk factors and mitigate the detrimental effects of issues such as social isolation, physical inactivity and nutritional imbalances. For this purpose, it is fundamental to ensure adaptation of risk reduction strategies to the attributes of these individuals.

3.2.3.3 Integration and link of dementia risk reduction with other ongoing policies for NCD prevention and control in refugees and migrants

Most modifiable dementia risk factors are shared with other NCDs. Consequently, preventive strategies targeting NCDs in refugees and migrants can support dementia risk reduction in these groups. The implementation of the available commitments on NCD prevention and control in refugees and migrants can, therefore, address risk factors for dementia in these individuals and enable a better allocation of available resources *(7)*.

3.2.3.4 Strengthen the evidence base on dementia risk and protective factors in refugees and migrants

The prevalence of the established modifiable risk factors for dementia, and thus the potential for primary prevention, may not be uniform in all refugee and migrant groups living in a country or region. It is likely that determinants, experiences and behaviours may favourably or negatively influence the risk for dementia in refugees and migrants. Extending knowledge on these issues is essential for planning and delivering focused and effective preventive strategies.

3.2.3.5 Key challenges to policy development and implementation

Challenges include:

- lack of national or regional risk reduction policies and services targeting dementia and other NCDs;
- lack of data on the prevalence of dementia risk factors in refugees and migrants; and
- poor awareness of dementia prevention among health care providers and refugee and migrant communities.

3.2.4 Diagnosis, treatment, and care

3.2.4.1 Development of integrated care pathways for refugees and migrants with dementia

Refugees and migrants with dementia should have access to equitable, person-centred and culturally appropriate care that (i) covers all aspects of dementia care, from diagnosis to end of life; (ii) integrates multiple services and sectors, from primary health care to palliative and home care; and (iii) is embedded in the existing health and social care systems. Depending on the specifics of individual countries (e.g. number and characteristics of refugee and migrant populations, organization of the health care system, availability of resources), diversity-sensitive care provision for refugees and migrants with dementia can be offered by specialized services in addition to mainstream facilities.

3.2.4.2 Reduction of barriers to health care access and development of diversity-sensitive care for refugees and migrants with dementia

The development of diversity-sensitive pathways of care for refugees and migrants with dementia should consider (i) the development and dissemination of user-friendly information to patients and carers concerning dementia and how to navigate available services in the host country; (ii) the development, validation and dissemination of cross-cultural cognitive screening and assessment tools; (iii) the specific training of health care providers and the introduction of dementia in refugees and migrants into clinical curricula; (iv) the training and involvement of relevant professions such as neuropsychologists, translators, cultural mediators, social care workers and rehabilitation professionals; and (v) the identification and dissemination of best practices for dementia management in refugees and migrants.

3.2.4.3 Provision of dementia training for health and social care professionals and other relevant stakeholders working with refugees and migrants living in emergency contexts

Health and social care providers should be trained on how to recognize dementia in emergency contexts. This may also result in increased awareness and promotion of health-seeking behaviours. In parallel, building dementia-supporting capacity in groups working with refugees and migrants (e.g. volunteers and representatives of nongovernmental organizations) may foster dementia-inclusive attitudes and environments.

3.2.4.4 Key challenges to policy development and implementation

Challenges include:

- lack of dementia-specific national standards, guidelines, and protocols;
- poor availability, accessibility and affordability of dementia services;
- human resource limitations;
- insufficient training of the workforce;
- limited coordination between relevant sectors nationally and locally;
- lack of data on the characteristics and health outcomes of refugees and migrants with dementia; and
- misconceptions and ageism among health and social care providers.

3.2.5 Support for carers

3.2.5.1 Development and implementation of training and education programmes for carers of refugees and migrants with dementia

Carers of refugees and migrants with dementia should have access to affordable, evidence-based, culturally sensitive resources to improve knowledge and skills, reduce emotional burden, improve coping and self-efficacy, and obtain social support. Internet and mobile phone technologies can facilitate the dissemination and implementation of training and education programmes among carers with access to these technologies. Existing resources (e.g. the WHO iSupport *(245)*) should be adapted to the needs and peculiarities of specific migrant groups.

3.2.5.2 Development and strengthening of legal protection for carers of refugees and migrants with dementia

Carers of refugees and migrants with dementia must be protected from stigma and discrimination in communities, health care settings and workplaces. They must receive full support through financial and security benefits.

3.2.5.3 Provision of care and support for carers of refugees and migrants with dementia, including in emergency contexts

Carers of refugees and migrants with dementia should have access to health care services as the available evidence indicates diminished health status and poorer health outcomes among people with a caregiving role *(12)*. Opportunities for respite care should be available for carers.

Humanitarian responses must ensure the safety and well-being of carers of refugees and migrants with dementia in emergency contexts. Carers should be supported in fundamental activities such as collecting food, water and other emergency supplies.

3.2.5.4 Involvement of family/informal carers of refugees and migrants with dementia in care planning and policy-making

The involvement of family/informal carers is crucial to assist in the development and adaptation of policies aimed at improving the provision of care for refugees and migrants with dementia and to support their families. This participatory approach is required to develop diversity-sensitive information and resources and adapt care pathways to the needs and cultural values of the different migrant groups.

3.2.5.5 Key challenges to policy development and implementation

Challenges include:

- lack of accessible and quality training and education;
- lack of legislation to ensure carers' social and financial protection;
- difficulty in involving carers of people with dementia in care planning;
- reluctance to consider carers as core members of the care team and in care planning;
- limited awareness of dementia in humanitarian responses; and
- limited time that carers have to devote to training opportunities.

3.2.6 Health information systems and monitoring

3.2.6.1 Development of strengthened national surveillance and monitoring systems for dementia that include/stratify data for refugees and migrants

Dementia and migration-related indicators should be integrated into health and social information systems to monitor dementia in refugees and migrants. The routine collection, recording, linkage and disaggregation of data (based on age, gender, country of origin, etc.) for these indicators is of strategic value to guide evidence-informed actions to improve care and measure progress towards implementing dementia policies. Gathering information on the migration status of people with dementia can support useful stratifications to identify disparities in access to care and services. Harmonizing these indicators is required to compare the magnitude and impact of dementia in refugees and migrants at the national and international levels.

3.2.6.2 Strengthen the evidence base on the epidemiology of dementia in refugees and migrants and its public health implications

Data collected in health care and administrative databases should be used to generate robust estimates of the prevalence and incidence of dementia among refugees and migrants. Moreover, such data can provide useful information on access to care and health resources and are crucial to design and calibrate relevant policies and plans.

3.2.6.3 Extension of the evidence base on refugees and migrants with dementia to encompass those living in emergency contexts

The availability of data on the scale of dementia among refugees and migrants in emergency settings and on their health conditions and needs is essential to design and implementing solutions for dementia-inclusive humanitarian programming.

3.2.6.4 Key challenges to policy development and implementation

Challenges include:

- lack of adequate digital infrastructure and use of electronic records;
- lack of human resources to streamline data collection efforts and transfer written records into electronic databases;
- heterogeneous coding of dementia and migration status in health information systems; and
- lack of prioritization of data collection on refugees and migrants with dementia living in emergency contexts.

3.2.7 Research and innovation

3.2.7.1 Inclusion of dementia in refugees and migrants in the global research agenda

The generation of high-quality evidence is a prerequisite to the provision of better care and support for refugees and migrants living with dementia, and for their families and carers. According to A blueprint for dementia research *(242)*, the principles of equity and diversity must be pursued in all aspects of dementia research such as epidemiology and economics, disease mechanisms and models, diagnosis, drug development and clinical trials, care and support, and risk reduction. All of these research themes should, therefore, be explored in refugees and migrants, including those living in emergency contexts.

3.2.7.2 Promotion of investment and collaboration on the theme of dementia in refugees and migrants

Despite the increasing research interest in the subject, there is still a need for dedicated research funding and coordination regarding dementia in refugees and migrants, especially in those settings and sectors that are systematically underrepresented in dementia research (e.g. LMICs). The creation of platforms and other data-sharing initiatives may sustain important advancements in research outputs.

3.2.7.3 Key challenges to policy development and implementation

Challenges include:

- insufficient funding for dementia research;
- insufficient research capacity in many settings;
- lack of regulations and policies that prohibit the systematic exclusion of older people from dementia research; and
- lack of support available to researchers to overcome some of the barriers preventing increased inclusion of older people in clinical trials, including refugees and migrants with dementia.

4. Conclusions

Dementia in refugees and migrants is attracting growing scientific interest, as indicated by the increasing number of scientific articles identified in this scoping review. This publication trend reflects the increase in older refugees and international migrants evident in recent years. The inclusion of this issue in the national policies of several countries suggests that it is also gaining relevance from a public health perspective.

The available evidence confirms that, due to global ageing, a growing number of refugees and migrants live with dementia in host countries and may require local health care resources that are adapted to their specific needs. Moreover, it is increasingly evident that migration and forced displacement may affect many aspects of dementia care, including prevention and risk reduction, diagnosis and support. Overall, refugees and migrants are at risk of facing inequities in access to care and support for dementia.

Relevant gaps in the literature pertaining to migration and dementia were identified, such as the lack of data for refugees and migrants living in emergency contexts and from LMICs. To date, the available evidence is largely derived from international migrants living in high-income contexts. This is worrying given that a large and growing number of refugees and migrants with dementia live in LMICs and there is little understanding about the services available and the specific challenges that these population groups may be facing in these contexts. Evidence is sparse on the health trajectories of refugees and migrants with dementia, on risk factors and risk reduction strategies in these individuals, and on determinants influencing access to health care resources. These knowledge gaps should be included in the global dementia research agenda.

Based on the findings of this review, refugees and migrants should be adequately included in global health commitments on dementia, and dementia must be regarded as an important health issue for these population groups. Further efforts are needed to develop and implement integrated, diversity-sensitive care pathways for refugees and migrants with dementia, design situation-specific risk reduction strategies and support carers. The health needs of refugees and migrants living with dementia in emergency situations should be recognized and addressed.

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Annex 1. Search strategies

Databases and websites

Embase, PsycInfo, PubMed and Web of Science databases were searched from inception to 1 July 2022 using a search strategy developed by an experienced librarian. The final search results were then exported into Rayyan, a free screening assisting software *(1)*, and duplicates were removed. Additional sources were identified by snowball searching of reference lists of the key articles and systematic reviews identified through the initial search and through consultations with the international experts in the research groups.

An extensive review of grey literature and policy papers/documents was also conducted using Google and Google Scholar and websites of international organizations, nongovernmental organizations, government ministries, research institutes and networks, using key terms for dementia, refugees and migrants. Among the websites searched were those of Alzheimer's Disease International, Alzheimer Europe, Doctors of the World, HelpAge International, International Federation of Red Cross and Red Crescent Societies, International Organization for Migration, Médecins Sans Frontières, Refworld, United Nations High Commissioner for Refugees, WHO and the WHO regional offices.

Search terms

Searches were conducted by an experienced librarian using two broad blocks of search terms referring to dementia and to refugees and migrants. The Boolean operator "OR" was used to combine multiple search terms. The two areas were then combined with the Boolean operator "AND". Full search terms and strategies are given in Tables A1.1–A.1.5.

Table A1.1. Embase

Theme	Terms
1. Dementia	"dementia"/exp OR "Alzheimer disease"/exp OR "frontotemporal dementia"/exp OR "multiinfarct dementia"/exp OR "disorders of higher cerebral function"/exp OR "diffuse Lewy body disease"/exp OR "dementia assessment"/exp OR dement*:ti,ab OR Alzheimer*:ti,ab OR frontotemporal:ti,ab OR fronto-temporal:ti,ab OR "neurocognitive disorder*":ti,ab
2. Refugees and migrants	migrant*:ti,ab OR migrat*ti,ab OR immigrant*:ti,ab OR immigrat*:ti,ab OR emigrant*:ti,ab OR emigrat*:ti,ab OR refugee*:ti,ab OR asylum*:ti,ab OR "foreign born":ti,ab OR foreign-born:ti,ab OR foreigner*:ti,ab OR nomad*:ti,ab OR displaced:ti,ab OR stateless:ti,ab OR state-less:ti,ab OR noncitizen*:ti,ab OR non-citizen*:ti,ab OR outsider*:ti,ab OR newcomer*:ti,ab OR "newly arrived":ti,ab OR "new arrival":ti,ab OR "recent entrant*":ti,ab OR "non national":ti,ab OR non-national:ti,ab OR "emigration"/exp OR "migration"/exp OR "immigration"/exp OR "population migration"/exp OR "migrant"/exp OR "emigrant"/exp OR "immigrant"/exp OR "refugee"/exp
3	1 AND 2

Table A1.2. PsycInfo

Theme	Terms
1. Dementia	(AB (dement* or alzheimer* or frontotemporal or fronto-temporal or "neurocognitive disorder*" or "lewy body") OR TI (dement* or alzheimer* or frontotemporal or fronto-temporal or "neurocognitive disorder*" or "lewy body"))

Table A1.2. contd

Theme	Terms
2. Refugees and migrants	(AB (migrat* or immigrat* or emigrat* or refugee* or migrant* or immigrant* or asylum* or emigrant* or "foreign born" or foreign-born or foreigner* or nomad* or displaced or stateless or state-less or noncitizen* or non-citizen* or outsider* or newcomer* or "newly arrived" or "new arrival*" or "recent entrant*" or "non national" or non-national) OR TI (migrat* or immigrat* or emigrat* or refugee* or migrant* or immigrant* or asylum* or emigrant* or "foreign born" or foreign-born or foreigner* or nomad* or displaced or stateless or state-less or noncitizen* or non-citizen* or outsider* or newcomer* or "newly arrived" or "new arrival*" or "recent entrant*" or "non national" or non-national))
3	1 AND 2

Table A1.3. PubMed

Theme	Terms
1. Dementia	dement*[tw] OR Alzheimer*[tw] OR frontotemporal[tw] OR fronto-temporal[tw] OR "neurocognitive disorder*"[tw] OR Dementia[MeSH] OR Frontotemporal Dementia[MeSH] OR Dementia, Vascular[MeSH] OR Mental Status and Dementia Tests[MeSH] OR Alzheimer Disease[MeSH] OR Lewy Body Disease[MeSH] OR Neurocognitive Disorders[MeSH]
2. Refugees and migrants	migrant*[tw] OR migrat*[tw] OR immigrant*[tw] OR immigrat*[tw] OR emigrant*[tw] OR emigrat*[tw] OR refugee*[tw] OR asylum*[tw] OR foreign born[tw] OR foreign-born[tw] OR foreigner*[tw] OR nomad*[tw] OR displaced[tw] OR stateless[tw] OR state-less[tw] OR noncitizen*[tw] OR non-citizen*[tw] OR outsider*[tw] OR newcomer*[tw] OR "newly arrived"[tw] OR "new arrival*"[tw] OR "recent entrant*"[tw] OR "non national"[tw] OR non-national[tw] OR Emigration and Immigration [MeSH] OR Refugees[MeSH] OR Emigrants and Immigrants[MeSH] OR Human Migration[MeSH] OR Transients and Migrants[MeSH] OR Undocumented Migrants[MeSH] OR Human Trafficking[MeSH]
3	1 AND 2

Table A1.4. Web of Science

Theme	Terms
1. Dementia	TI=(dement* OR alzheimer* OR frontotemporal OR fronto-temporal OR "neurocognitive disorder*" OR "lewy body") OR AB=(dement* OR alzheimer* OR frontotemporal OR fronto-temporal OR "neurocognitive disorder*" OR "lewy body")
2. Refugees and migrants	AB=(migrant* OR migrat* OR immigrant* OR immigrat* OR emigrant* OR emigrat* OR refugee* OR asylum* OR "foreign born" OR foreign-born OR foreigner* OR nomad* OR displaced OR stateless OR state-less OR noncitizen* OR non-citizen* OR outsider* OR newcomer* OR "newly arrived" OR "new arrival*" OR "recent entrant*" OR "non national" OR non-national) OR TI=(migrant* OR migrat* OR immigrant* OR immigrat* OR emigrant* OR emigrat* OR refugee* OR asylum* OR "foreign born" OR foreign-born OR foreigner* OR nomad* OR displaced OR stateless OR state-less OR noncitizen* OR non-citizen* OR outsider* OR newcomer* OR "newly arrived" OR "new arrival*" OR "recent entrant*" OR "non national" OR non-national)
3	1 AND 2

Table A1.5. Grey literature and policy documents

Theme	Terms
1. Dementia	dementia; Alzheimer; neurocognitive disorder
2. Refugees and migrants	Migrant; refugee; asylum seeker; foreign born; immigrant; emigrant; nomad; stateless; migration; immigration; emigration

Study selection

Inclusion and exclusion criteria were developed using the population, concept and context framework of the JBI manual for evidence synthesis (Table A1.6) (2).

Table A1.6. Inclusion and exclusion criteria

Term	Inclusion criteria	Exclusion criteria
Language	Any of the six United Nations official languages (Arabic, Chinese, English, French, Russian and Spanish)	–
Studies	Original articles providing the findings of primary or secondary analyses of original data Policy papers/documents mapping existing original evidence in the field Additional references identified by snowball searching of identified articles	Not reporting findings of primary or secondary analyses of original data (i.e. editorials, narrative reviews, study protocols, methods papers, systematic reviews, meta-analyses)
Population	Individuals with dementia of different migration backgrounds and legal entitlements Studies enrolling formal (professional, paid) and informal (family, friends, unpaid) carers of refugees and migrants living with dementia	Studies other than human studies (e.g. animal studies, plant studies, genetic studies, cell studies) Unrelated to refugees and international migrants (e.g. internal migration/displacement, families left behind by migrants, second-generation migrants) Ethnic minority groups without any clear definition of the migration status of their members

Table A1.6. contd

Term	Inclusion criteria	Exclusion criteria
Concept	Dementia (or major neurocognitive disorder) of any etiology defined as a condition of cognitive decline from a previous level of capacity that is sufficient to interfere with a person's daily life and independence	Milder cognitive disturbances (e.g. subjective cognitive decline, mild cognitive impairment, minor neurocognitive disorder) not meeting the criteria for dementia/major neurocognitive disorder Occurring exclusively in the context of a delirium
Context	Any world region Any contextual setting	None

Data extraction

The scoping review used the methodology for scoping reviews in the JBI manual for evidence synthesis (2) and reported following the Preferred Reporting Items for Systematic Reviews and Meta-analyses extension for scoping reviews checklist (Table A1. 7) (3). The final protocol was registered with the Open Science Framework database (https://osf.io/gxwpv/). Ten reviewers working in pairs sequentially evaluated the titles and abstracts of the retrieved publications using Rayyan. The full texts of all potentially eligible studies were then independently screened by two reviewers (MC and MV). To increase consistency among reviewers, the review of the first 50 publications was completed by both reviewers and used as a training session to ensure a minimum of 95% agreement between reviewers. Any discrepancy was discussed to reach consensus.

Table A1.7. Preferred Reporting Items for Systematic Reviews and Meta-analyses, extension for scoping reviews checklist

Section	Item	PRISMA-ScR checklist item
Title		
Title	1	Identify the report as a scoping review
Abstract		
Structured summary	2	Provide a structured summary that includes (as applicable) background, objectives, eligibility criteria, sources of evidence, charting methods, results and conclusions that relate to the review questions and objectives
Introduction		
Rationale	3	Describe the rationale for the review in the context of what is already known; explain why the review questions/ objectives lend themselves to a scoping review approach
Objectives	4	Provide an explicit statement of the questions and objectives being addressed with reference to their key elements (e.g. population or participants, concepts and context) or other relevant key elements used to conceptualize the review questions and/or objectives
Methods		
Protocol and registration	5	Indicate whether a review protocol exists; state if and where it can be accessed (e.g. an Internet address); and, if available, provide registration information, including the registration number
Eligibility criteria	6	Specify characteristics of the sources of evidence used as eligibility criteria (e.g. years considered, language and publication status) and provide a rationale
Information sources[a]	7	Describe all information sources in the search (e.g. databases with dates of coverage and contact with authors to identify additional sources), as well as the date the most recent search was executed

Section	Item	PRISMA-ScR checklist item
Search	8	Present the full electronic search strategy for at least one database, including any limits used, such that it could be repeated
Selection of sources of evidence[b]	9	State the process for selecting sources of evidence (i.e. screening and eligibility) included in the scoping review
Data-charting process[c]	10	Describe the methods of charting data from the included sources of evidence (e.g. calibrated forms or forms that have been tested by the team before their use, and whether data charting was done independently or in duplicate) and any processes for obtaining and confirming data from investigators
Data items	11	List and define all variables for which data were sought and any assumptions and simplifications made
Critical appraisal of individual sources of evidence[d]	12	If done, provide a rationale for conducting a critical appraisal of included sources of evidence; describe the methods used and how this information was used in any data synthesis (if appropriate)
Synthesis of results	13	Describe the methods of handling and summarizing the data charted
Results		
Selection of sources of evidence	14	Give numbers of sources of evidence screened, assessed for eligibility and included in the review, with reasons for exclusions at each stage, ideally using a flow diagram
Characteristics of sources of evidence	15	For each source of evidence, present characteristics for which data were charted and provide the citations
Critical appraisal within sources of evidence	16	If done, present data on critical appraisal of included sources of evidence (see item 12)

Section	Item	PRISMA-ScR checklist item
Results of individual sources of evidence	17	For each included source of evidence, present the relevant data that were charted that relate to the review questions and objectives
Synthesis of results	18	Summarize and/or present the charting results as they relate to the review questions and objectives
Discussion		
Summary of evidence[d]	19	Summarize the main results (including an overview of concepts, themes and types of evidence available), link to the review questions and objectives, and consider the relevance to key groups
Limitations	20	Discuss the limitations of the scoping review process
Conclusions	21	Provide a general interpretation of the results with respect to the review questions and objectives, as well as potential implications and/or next steps
Funding		
Funding	22	Describe sources of funding for the included sources of evidence, as well as sources of funding for the scoping review; describe the role of the funders of the scoping review

[a] Where sources of evidence (information sources) are compiled from, such as bibliographic databases, social media platforms or websites.

[b] A more inclusive/heterogeneous term used to account for the different types of evidence or data sources (e.g. quantitative and/or qualitative research, expert opinion and policy documents) that may be eligible in a scoping review as opposed to only studies; not to be confused with information sources.

[c] The JBI manual for evidence synthesis (2) refers to the process of data extraction in a scoping review as data charting; further details of frameworks are given in Tricco et al. (3).

[d] The process of systematically examining research evidence to assess its validity, results and relevance before using it to inform a decision; the term is used for items 12 and 19 instead of "risk of bias" (which is more applicable to systematic reviews of interventions) to include and acknowledge the various sources of evidence that may be used in a scoping review (e.g. quantitative and/or qualitative research, expert opinion and policy document).

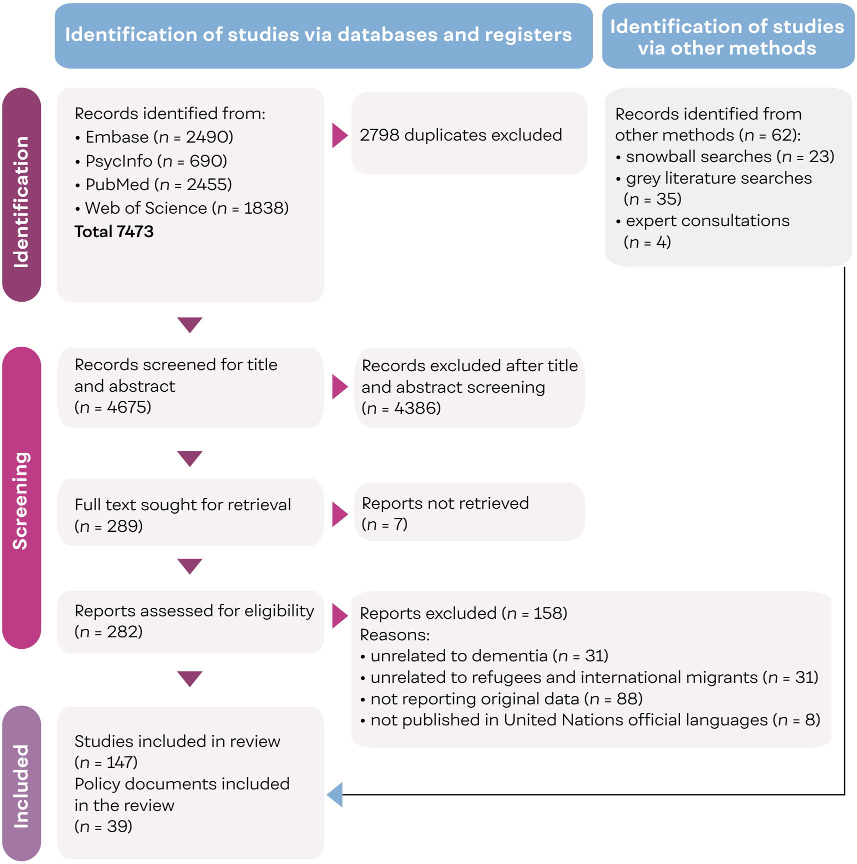
Source: taken from Tricco et al. (3).

Two reviewers (MC and MTB) jointly developed a data-charting form for the extraction and collection of the variables of interest. Each reviewer independently charted the data, discussed the results and iteratively updated the data-charting form. Consensus was reached collaboratively by discussion.

Data categories extracted were (i) publication (year, journal, subject area, country of first author's institution); (ii) study (methodology, design, location, setting, population, primary outcome, main findings); (iii) refugee and migrant groups (subgroups, country of origin and destination, age and sex of migrants with dementia); and (iv) dementia (definition/diagnosis, etiology). These were then used for mapping of the results (Annex 2).

The search yielded 7473 results, which were reduced to 4675 by removal of duplicates. A further 4386 articles were excluded based on the title or abstract. Full text could not be retrieved for seven, leaving 282 full documents to be assessed for eligibility. Among them, 124 met the full eligibility criteria. These were supplemented by 62 articles obtained from other methods. A total of 147 studies (137 full-length articles and 10 abstracts) were included in the evidence synthesis plus 39 policy papers/documents from the grey literature search (Fig. A1.1).

Fig. A1.1. Selection of studies



References[1]

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3. 3. Tricco AC, Lillie E, Zarin W, O'Brien KK, Colquhoun H, Levac D et al. PRISMA extension for scoping reviews (PRISMA-ScR): checklist and explanation. Ann Intern Med. 2018;169(7):467–73 (https://doi.org/10.7326/M18-0850).

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[1] *All references were accessed on 11 November 2023.*

Annex 2. Mapping of results

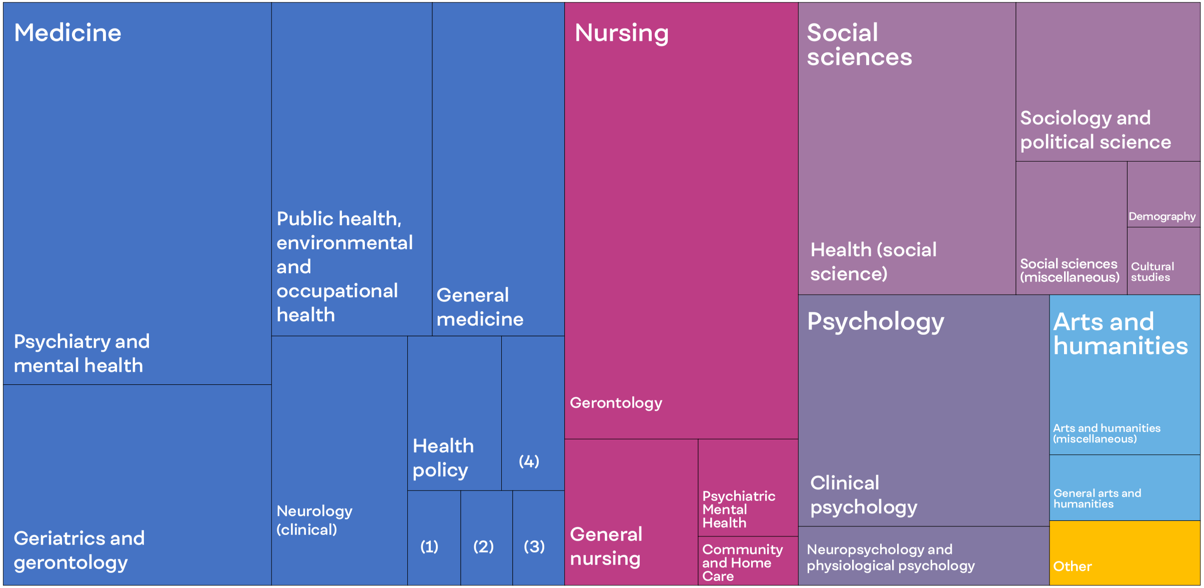
Source areas for review documents

The journal's main subject area was defined according to the Scopus CiteScore highest percentile *(1)*. Countries were grouped by geographical region according to the United Nations classification *(2)* and by income according to the World Bank classification *(3)*. For each country, the MIPEX country score was obtained *(4)*.

The retrieved articles were published in a range of journals, with 76 identified across widely different subject areas, from medicine to nursing, and from psychology to social sciences (Fig. A2.1). The journals that have published most articles on dementia in refugees and migrants are listed in Table A2.1.

Evidence on dementia in refugees and migrants from the included studies was then mapped onto the seven action areas of the WHO Global action plan on the public health response to dementia 2017–2025: (i) policy and legislation; (ii) awareness and inclusion; (iii) risk reduction; (iv) diagnosis, treatment, care and support; (v) support for carers; (vi) health information systems and monitoring; and (vii) research and innovation *(5)*. Evidence assignment to these areas was based on the main issues addressed in the quantitative and qualitative analyses of the original papers and so some studies were assigned to multiple action areas.

Fig. A2.1. Subject areas of the journals publishing research on dementia in refugees and migrants[a]



[a] The size of areas of the treemap represents the number of studies in each subject area: (1) epidemiology; (2) endocrinology, diabetes and metabolism; (3) medicine (miscellaneous); (4) family practice; other includes multidisciplinary and agricultural and biological sciences.

Table A2.1. Ranking of journals that have published most articles on dementia in refugees and migrants

Journal	No. articles (% of the 147 articles identified)
International Psychogeriatrics	9 (6.1)
The Gerontologist	7 (4.8)
International Journal of Geriatric Psychiatry	7 (4.8)
Dementia	6 (4.1)
Dementia and Geriatric Cognitive Disorders	5 (3.4)
Journal of Cross-Cultural Gerontology	5 (3.4)
Journal of Alzheimer's Disease	5 (3.4)
Ageing & Society	3 (2.0)
Aging Clinical and Experimental Research	3 (2.0)
Alzheimer Disease & Associated Disorders	3 (2.0)
Alzheimer's & Dementia	3 (2.0)
BMC Public Health	3 (2.0)
Clinical Gerontologist	3 (2.0)
European Journal of Public Health	3 (2.0)
Journal of American Geriatrics Society	3 (2.0)
Journal of Applied Gerontology	3 (2.0)

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1. Scopus sources: CiteScore [online database]. Oxford: Elsevier; 2023 (https://www.scopus.com/sources).
2. Definition of regions [website]. In: World population prospects 2022. New York: United Nations, Department of Economic and Social Affairs, Population Division; 2022 (https://population.un.org/wpp/DefinitionOfRegions/).
3. World Bank country and lending groups: country classification [online database]. In: World Bank Help Desk. Washington (DC): World Bank; 2023 (https://datahelpdesk.worldbank.org/knowledgebase/articles/906519-world-bank-country-and-lending-groups).
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5. Global action plan on the public health response to dementia 2017–2025. Geneva: World Health Organization; 2017 (https://apps.who.int/iris/handle/10665/259615).

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[1] *All references were accessed on 11 November 2023.*

Annex 3. Articles identified in the literature search

NB. All references were accessed on 11 November 2023.

Identified articles that could be mapped to specific action areas of the WHO Global action plan on the public health response to dementia

Adamson J. Awareness and understanding of dementia in African/Caribbean and south Asian families. Health Soc Care Community. 2001;9(6):391–6 (https://doi.org/10.1046/j.0966-0410.2001.00321.x).

Adelman S, Blanchard M, Rait G, Leavey G, Livingston G. Prevalence of dementia in African-Caribbean compared with UK-born white older people: two-stage cross-sectional study. Br J Psychiatry. 2011;199(2):119–25 (https://doi.org/10.1192/bjp.bp.110.086405).

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Bosma C, Smits C. Behavioral changes in migrants with dementia: experiences of professional caregivers. Z Gerontol Geriatr. 2022;55(4):281–6 (https://doi.org/10.1007/s00391-022-02057-z).

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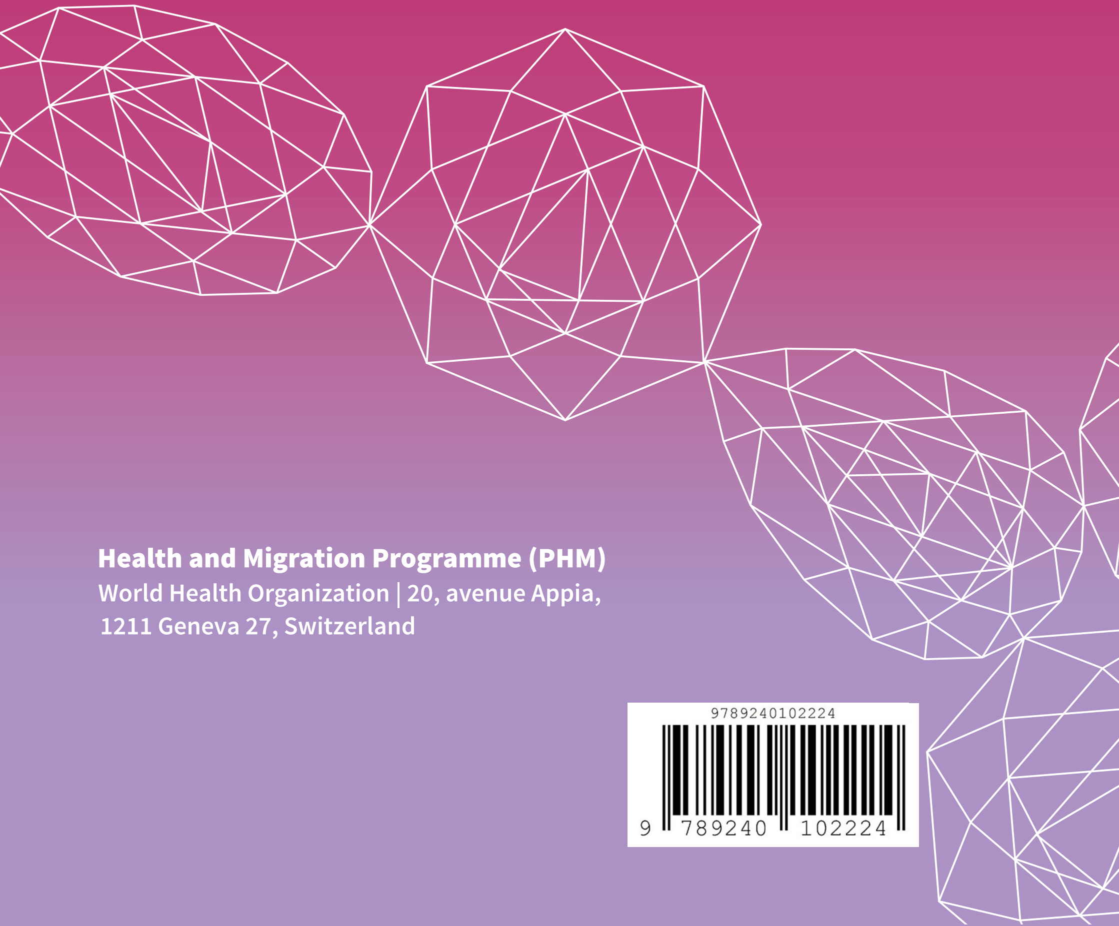

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