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# **Dementia, Ethnic Minorities and Migrants**

## **A Review of the Literature**



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Title: Dementia, Ethnic Minorities and Migrants. A Review of the Literature

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# Chapter 1: Introduction

Bernadette N. Kumar, Ragnhild Storstein Spilker and Mette Sagbakken

As the number of elderly migrants in Europe rises, dementia in migrant and ethnic minority populations warrant attention as a significant public health problem. Information on elderly migrants, in particular their health, is scarce as European public health research and policies focus largely on younger migrants, workers and refugees.

The main aim of this review was to provide an overview and analysis of the available research on elderly migrants and dementia with specific reference to the European context where available. The other objectives were to identify knowledge gaps relevant to the Norwegian situation to form our research questions and guide the methods deployed by our research in Norway.

Ageing in an unfamiliar landscape, as is the case for most migrants poses challenges that differ from retirement migration. Age is the biggest risk factor for Alzheimer's disease and from the age of 65 years, the incidence doubles every 5 years. Ageing is a known risk factor for dementia but the risk posed by migration and thereby ethnicity calls for further empirical research. This review therefore attempts to provide an overview of the incidence of and risk factors for dementia among immigrants / ethnic minorities and summarize whether there are differences in risk factors and incidence in different groups.

Ageing is considered a natural phenomenon globally, but the perceptions of and experiences with dementia among immigrants and ethnic minorities and their dependents vary considerably. Studies attribute cognitive impairment to a wide range of causes from normal age-related changes to illness to the will of God or fate. Understanding patients, their health seeking behavior or lack of it, must take many factors into consideration. Elderly migrants are a very heterogeneous group including different 'migrant life trajectories'. Migrants and minority populations experience constant change yet the description of their needs are often presumptuous and overlook the changes taking place in their lives, family structure, society as well as differences in attitudes and behaviors.

Migrant populations show largely the same signs of dementia as the majority population. However, differences both between migrant groups and with host populations have been documented. It is debatable whether these differences are due to genetic factors, social/economic factors or differences in the access to and the use of health care services. In order to reach a proper diagnosis besides good communication and skills, there is a need for appropriate and validated diagnostic

tools. Studies confirm that people with dementia from migrant or ethnic minority groups, receive diagnoses later, are prescribed and taking medication to a lesser degree, are admitted to a lesser degree in nursing homes and have different views on end of life care. These inequalities may be due to cultural differences, limited knowledge and awareness, previous negative experiences with health care personnel or systems, language barriers and the ability to utilize the services.

The lack of research on how to develop and adapt services to meet the needs of older ethnic minority immigrant background is evident from our search. In order to provide equitable care in nursing homes, care giving skills and good communication are necessary and staff training must be a priority. Stereotyping of immigrants and ethnic minorities prevents a person centered approach that takes into account the life histories, migration experiences, cultural and social norms and how these factors affects people with dementia and their families. Similarly, over-reliance on family support should be avoided not to be detrimental to the migrant elders.

Studies observed that information material about dementia are difficult to comprehend and dissemination of information about dementia to elderly immigrants and their families are fragmented and inadequate. Experiences from the United States, Australia and England shows that information and interventions are more effective if there are several components, f. Ex. film, brochures, team meetings and mass media, and when developed in cooperation with user representatives. It is important to simplify the language, to find appropriate illustrations, identify obstacles to dissemination and ensure that information is easily accessible.

Elderly migrants, given the heterogeneity of their life courses and migration trajectories, must be involved in formulation and shaping of their care. Existent mainstream approaches often fail to address the specific needs of elderly migrants. A 'person centred approach' should be adopted when approaching different categories of elderly migrants. The diversity of situations concerning elderly migrants and the changing patterns of migration in Europe calls for the development of responsive and culturally sensitive services. Appropriate training strategies for the development of multicultural competencies beneficial to all the practitioners who work and advocate for elderly migrants are a must. Migration, ageing and dementia are phenomena that compel further research, aimed at assisting involved stakeholders to a proactive response in adapting interventions and policies.

# Chapter 2: Method

Ragnhild Storstein Spilker

## Introduction

This review of literature in the field of dementia, migrants and ethnic minorities has been undertaken with the aim of summarizing current knowledge, and which together with the insights from the different subprojects will provide the scientific base for the recommendations to the Norwegian Directorate of Health.

The journey of exploring this rather broad topic of dementia, migrants and ethnic minorities has not been a straightforward passage and different strategies have been used to obtain the literature used in this research review.

The review started out by broadly searching google scholar in order to get an overview of the available studies. Various combinations of words describing migrants / ethnic minorities and dementia / Alzheimer's disease were used in order to do so. We then decided to conduct a systematic reference list (*systematisk literatursøk med sortering*) as described by the Norwegian Knowledge Centre for the Health Services (2013). A systematic reference list results from searching for relevant literature according to a specific search strategy. The references resulting from the search are then grouped and presented with their abstracts. In a systematic reference list there is no critical evaluation (grading) of study quality, no analysis or synthesis of the studies or recommendations (The Norwegian Knowledge Center for the Health Services 2013). The inclusion criteria and results of the search strategy search will be explained in the text below. In addition, other literature has been included by the authors of the different chapters in this review through additional data base searches, citation tracking, by manually searching references in retrieved articles and through recommendations from experts, colleagues and research networks.

## Search Strategy for the Systematic Reference List

Searches were conducted in the following databases: Ovid MEDLINE, PubMed Central, Cochrane Library, British Nursing Index and Centre for Reviews and Dissemination Databases of all articles published in English. A search in SweMed + for Scandinavian literature was also carried out. A variety of search words for migrants and ethnic minorities were used combined with dementia and Alzheimer. Both free text terms and MeSH terms were utilized. See enclosed table below.

## Inclusion criteria for Search Strategy

All empirical research (quantitative and qualitative) and theoretical articles concerned with migrants, ethnic minorities and dementia from the year 2000 and onward were included in the systematic reference list. All articles were published in scientific journals and both systematic reviews, primary studies and theoretical / discussion

articles were included in the list. Articles that did not include ethnic minorities or migrants and were not in the English/Scandinavian language were excluded. Reports, dissertations, meeting abstracts, conference proceedings, letters and correspondence were also excluded.

One person read titles and abstracts and those articles that were potentially relevant were included in the systematic reference list and grouped into eleven different categories (ageing, diagnostic assessment, employees, epidemiology, information and training, drug treatment, next of kin, research, health and care services, user involvement and voluntary work).

## **Results of the Search Strategy**

264 articles were found to be potentially relevant and included in the systematic reference list. Most of the articles were found in the searches in Ovid Medline and PubMed Central and the categories with most articles were epidemiology (19%), next of kin (17 %) and health and care services (17%) while the number of articles concerned with employees (3%), information and training (5%) and diagnostic assessment (9%) were fewer.

Majority of the articles originated from the US (39 %) and the UK (35%), and have mostly been published in clinical journals in the fields of Alzheimer and dementia, geriatric psychiatry, gerontology, ageing, nursing and social work.

This systematic reference list has been used as the basis for the synthesis of the research in this review. The authors of the different chapters scrutinized the articles in the reference list and decided individually which of the articles they would finally include in their chapters. All the systematic reviews that were found were included together with several primary studies of special relevance.

## Overview of search terms used in the search strategy

**Tables 1 and 2:** The search strategy combined terms in table 1 and table 2 in various permutations and combinations.

**Table 1**

<b>MIGRANT</b>	
<i>MeSH terms</i>	<i>Key Words</i>
Emigration and Immigration	emigration
Emigrants and Immigrants	emigrant
Transients and Migrants	immigration
Refugees	immigrant
Ethnic Groups	migrant
Minority Groups	refugee
Cultural Diversity	ethnic
Minority Health	minority
Acculturation	minorities
Transcultural nursing	acculturation
Cross-Cultural Comparison	transcultural
Communication Barriers	cross-cultural
	innvandrere
	flyktning
	flygtning
	etnisitet
	etnisk
	minoritet
	transkulturell

**Table 2**

<b>DEMENTIA</b>	
<i>MeSH terms</i>	<i>Key Words</i>
Dementia	dementia
Alzheimer Disease	alzheimer
	demented
	demens

## References

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# Chapter 3: Aging and Health Among Migrant and Ethnic-Minority groups

Ruth Price

## Introduction

This chapter is concerned with presenting a general picture of the relations between aging, migration, minority status, and health in Western societies. Are there any differences in experiences of aging and in perceptions of aging and associated issues, such as elderly care, among different minority and immigrant groups? Furthermore, are there differences in experiences and perceptions of aging and care between minority/immigrant groups and majority populations? What factors feed into any differences that exist? These are important issues with regard to the question of how best to develop appropriate care interventions and policy-making with regard to dementia among elderly immigrants and minority populations in Norway.

The literature on the relations between migration and health in Europe, the US, and other Western countries such as Australia and Canada is large. Less attention has been paid to the relations between *aging*, migration, and health, partly because the status and experiences of elderly migrants are only now entering public consciousness and political calculations. This chapter draws on a diversity of sources: EU reports on migration and health; academic textbooks on aging and health; research reports from Norway and beyond; and journal publications covering public health, migration studies, and gerontology and focusing on the relations between aging, migration, health, illness, and care in “immigrant nations” (Scheffer, 2007).

We have been careful in approaching research on the extremely diverse and complex relations between migration, aging, and health and have taken care to assess the many complex factors feeding into migrants’ and minority groups’ experiences of aging and health. There is much diversity both within and between groups. However, as we discuss below, these groups also share particular structural positions and features, which allow for comparison (for further details on methodology, see chapter 2).

In this chapter, we first define the field: the aging of European populations and the challenge this poses to policymakers in terms of care for the elderly; definitions of migrant and minority populations; the importance of understanding processes of aging in diverse populations, including the commonalities and differences in experience of aging among majority and minority (including migrant) populations; and the question of what studies of aging among migrant and minority populations can

learn from studies of migrant and minority health and use of health-care services in Europe (and elsewhere).

We then address the question of whether there are patterns in the diversity of experiences of health, illness, care, and aging among minority and migrant populations. In this section, we assess the weight given to “cultural” explanations of difference in health, illness, health-seeking behavior, and aging among migrant and minority population and discuss other factors that may be important determinants of difference, such as socio-economic status, marginalization as well as family structures and social networks.

Addressing these questions leads to a more detailed exploration of the research on migration and health, and migration and aging, both in Norway and in other European and Western countries. This exploration then provides the context for subsequent chapters that address research on dementia and aging among migrant and minority populations, and the implications of this for policymaking concerning the aging of Norway’s increasingly diverse residents.

Aging is accompanied by challenges of caring. How will the specific care needs of elderly people, particularly those with poor health, be met? Health- and elderly-care services need to be sensitive to the specific needs of different populations. The policy should be based on an understanding of the life-situations, family structures, and socio-economic situation of the elderly, including those belonging to minority and migrant populations.

## **Migration and Ageing in Europe**

Europe’s population is aging, and Europe’s diverse migrant population is aging too. This poses several challenges with regard to care for the elderly. However, we know little about the experiences of elder migrants as concerns aging and care.

The UN Population Division observed that during the second half of the last century, the global population of persons aged 60 years or over almost trebled from 205 million to 606 million, and average global human life expectancy increased by 20 years from 46 years in 1950 to 66 years by 2000 (Rechel et al., 2011). The aging of populations in Europe means that policymakers and governments are facing new challenges. National social institutions are grappling with the policy implications of increasing longevity and population aging. Responses vary greatly from relatively scant attention paid to aging in many developing countries in the Global South to comprehensive aged-care policies and programs covering social security, health insurance, acute and chronic care, residential and community programs, treatment, rehabilitation, and long-term care services (Johnson, 2005).

As health is the foundation of a good old age (Marmot, 2004), the health status and health care of elderly persons is of key importance. Since aging is accompanied by increasingly poor health, however, the aging populations of Europe both face and pose particular challenges with regard to ill health, treatment, and care. One of the most important issues associated with aging is the issue of care. The aging of Europe's populations and associated changes in the population structure (the large proportion of elderly individuals) means that there are fewer younger people to look after elderly people. European countries are currently facing a crisis of elderly care, which will only worsen in the future (Johnson, 2005).

Given Europe's culturally, ethnically, and linguistically diverse populations, any consideration of aging and health should consider the relations between migration and aging. The wave of international migration to Europe, which gathered pace after the Second World War and in the 1960s and 1970s (particularly in Germany and the UK), means that Europe's populations are increasingly diverse—linguistically, ethnically, and culturally. This history of migration means that many migrants—both those who came in the 1960s and 70s and those who joined family members later in life—are elderly and are facing the challenges of old age, both physically and mentally. Just as majority populations in Europe are becoming older, migrant populations in Europe are also aging (White, 2006). This poses several challenges with regard to care for the elderly, in particular if policy is to be based on an understanding of the life situations, family structures, and socio-economic situation of the elderly, including those belonging to minority and migrant populations. However, research on the experiences of elder migrants and their families with regard to aging and care is still in its infancy (Kriliae, 2013).

## **Definitions of Migrants and Minority Populations**

How do we define migrants? What constitutes a migrant identity? We need to be sure that our definitions take account of the diversity of migrant groups and experiences. Does it make sense to place migrant populations together with minority groups in a review on migration, aging, and dementia? Given the relative scarcity of data on migrant and minority health in general, what do we know about aging and related health issues among migrant and minority populations in Europe?

As the 2011 EU report on migration and health points out, the very definition of migrants and of migrant populations differs from country to country. The UN Recommendations on Statistics of International Migration define a long-term migrant as a “person who moves to a country other than that of his or her usual residence for a period of at least a year” (UN Dept of Economic and Social Affairs, 1998, p. 18, quoted in Rechel et al., 2011, p. 4). However, not all countries follow this definition. In reviewing the relationship between migration and health, it is, moreover, important to look beyond the generation that has moved from one country to another. Rechel et al. (2011) point out that while the term “second-generation migrant” is a

contradiction in terms, the challenges for the health of the descendants of migrants are sometimes greater than for those who have migrated.

In this report, we focus on migrant populations in European countries, including second- and third-generation migrants, as it is these children and grandchildren of migrants who are facing the challenge of caring for their elderly parents. We also address aging and health among “minority” populations in Europe. The dividing line between minority and migrant populations is not clear-cut. In some EU countries, migrant policies are integrated into broader policies for “ethnic minorities.” While the Norwegian Sami are clearly an ethnic minority, and not a migrant group, Pakistanis living in Norway are both migrants and an ethnic minority. In this report, we therefore include research, reviews, and publications on both migrant and minority populations. We focus on research conducted in European countries, as this is most relevant to the situation in Norway. Where relevant, we also draw on the literature on migrant and minority health and aging in North America and Australia.

### **Aging and Health: Socio-Economic Inequality and Healthy Ageing**

What is key to healthy aging? Research suggests that socio-economic status and education, not surprisingly, have a positive relationship with healthy aging, just as they do with health status in general. Income inequality also plays a key role. Michael Marmot singles out inequality as an important factor in the production of the social gradient in health (what he calls the “status syndrome”), and he argues that “the opportunities for full social engagement and participation are crucial for health” (Marmot, 2004, p. 2). Research links socio-economic status to different subjective experiences of aging. For example, in a study of 2,864 Americans, Barrett found that persons of a lower socio-economic status have a higher “age identity” than persons of a higher socio-economic status (Barrett, 2003). According to Barrett, higher socio-economic status may result in the accumulation not only of material advantages but also of social psychological resources that can diminish the negative effects of aging in a youth-oriented society (Barrett, 2003). It is, moreover, not only a matter of socio-economic status: one’s position in the socio-economic system appears to affect the subjective experience of aging. The less advantaged have older identities than their privileged peers (see also Baum & Boxley, 1983; Markides & Boldt, 1983).

Marmot (2004) argues that “autonomy,” along with income and education, is the key to healthy old age; how much control elderly people have over their lives plays an important role in how healthy they are and how healthy they remain, and he argues for a strong association between autonomy and socio-economic status. However, Marmot (2004) does not define what “autonomy” means beyond “having control over your own life.” His focus on autonomy overlooks the importance of social relationships for elderly people’s health, involving both family networks and support and neighborhood or community relationships. Families and communities provide care and support for elderly people; they are crucial life-lines during times of illness or

poor health, which often accompany aging. All this suggests the importance of a “human investment model” (Johnson, 2005) in relation to healthy aging.

If aging and health are key issues facing European societies today, and socio-economic inequality is an important, indeed key, factor in producing differential health and health outcomes among aging and elderly people, then it is important to consider the nexus between minority populations, migrant populations, aging, and health in Europe today. There is considerable evidence that minority and migrant groups in Europe occupy the lower rungs of socio-economic hierarchies, and that this lower socio-economic status has a negative effect on the health of migrant and minority populations (Viruell-Fuentes, 2007; Viruell-Fuentes et al., 2012; Rechel et al., 2011).

Many of the issues surrounding aging among immigrant groups and ethnic minorities are the same as those surrounding aging in majority populations. Aging is accompanied by increased risk of disease, disability, and poor health. It is accompanied by significant life changes: a transition from work to retirement (or unemployment), decreased mobility (physical, social, and—in some cases—mental), and associated issues such as social isolation and the increase of fears and worries (Johnson, 2005). However, migrant and minority elders face the additional burdens of marginalization and low socio-economic status, which may translate into both poor health and into problems accessing or using health-care services (Jackson et al., 2005; IOM, 2010).

Migrants also experience barriers related to language and health literacy when seeking health-care in the host country (Nguyen et al., 2013). Migrant and minority populations often face discrimination and prejudice in host countries, which feeds into the perpetuation of lower socio-economic status and into experiences of marginalization, exclusion, and political isolation (Jackson et al., 2005). These additional burdens may translate into both poor health and into problems with or barriers to accessing or using health-care services in the host country (Ingeby, 2006).

### **Possible Patterns in Diversity of Migrant and Minority Experiences of Ageing, Health, Illness, and Care**

The experiences of aging and health among migrants is complex and diverse, as migrants come from different countries of origin, and their migration takes different forms—economic, political, short-term and long-term. Moreover, migrants occupy different socio-economic groups, different ethnic and language groups, different levels of education and participation in the workforce, and different socio-economic statuses. Up to recently, there has been a scarcity of data on health determinants, health status and health service utilization by migrants in many EU countries (Rechel et al., 2011). Where data is available, it often points in different directions due to the diversity of migrant populations. Migrants come from different countries of origin,

they have diverse ethnic, religious, and cultural identities, and speak a great diversity of languages. When one assesses the impact of migration on health, all these factors may be important. It is also important to note that there is a strong correlation between migration background and lower socio-economic status, which makes it difficult to identify which of the two factors is an important determinant of health (Davies et al., 2009).

However, migrant groups share certain features deriving from their structural position in society and their status as migrants, which allows for valid comparison. Three features in particular are shared. First, migrant and minority populations tend to share a lower socio-economic status, which creates barriers to good health. This creates some shared patterns with regard to their experiences of health, illness, and aging. Second, migrants speak different languages, and some may not learn the majority language of the host country, which means that migrant populations also experience barriers related to language and health literacy when seeking health care in the host country. Third, migrant populations often experience or face discrimination and prejudice in host countries, which feeds into the perpetuation of lower socio-economic status and into experiences of marginalization, exclusion, and social and political isolation.

Minority populations may also experience these features. While minority populations have diverse histories with regard to their status in the larger society, they often share, with migrant populations, a place on the lower rungs of the socio-economic hierarchy together with a history of discrimination and marginalization. However, minority populations often enjoy better legal and political protection than migrant groups.

There are two further issues that should be taken into account, although they may not be shared by all migrant groups. Firstly, the fact that some migrant groups come from societies with diverse understandings of the relationships between body, health, and disease (in addition to, or alongside, biomedical ones) means that understandings of illness and response to it, in terms of treatment-seeking behavior and care patterns, may diverge in some ways from those of majority populations in Europe (although we should note that members of majority populations may also understand health in non-biomedical terms and be influenced by non-biomedical understandings of ill health). Secondly, migrant populations may originate from societies with kinship and family structures that differ from those of majority European populations. Family structures, and the cultural norms surrounding them, shape expectations surrounding aging and care for the elderly.

## The Relevance of “Culture” in Studies of Migrant Health

While socio-economic factors are found to have considerable influence on health status among non-migrant or majority populations, when it comes to migrant populations, health differentials are often explained by reference to their “culture.” Culture often seems to trump socio-economic status and discrimination when it comes to research on the diverse experiences of immigrant groups regarding health and health-care. Culture is not unimportant, but it is crucial that we do not rely solely on problematic notions of culture to explain difference, as doing so may obscure the impact of structural factors on immigrant health (Santiago-Irizarry, 1996).

An exclusive focus on culture can be misleading for several reasons. Culture itself is a term that is hard to define. It is generally taken to refer to shared values and norms, which give meaning and shape to concrete social structures such as gender and kinship relations as well as religious practices and worldviews. Moreover, the concept of culture raises questions about boundaries. Are cultures bounded? If so, where are the boundaries between them? Does it make sense to talk about culture in a globalized world, or in contemporary Europe, where people are raised in a society defined more by change than by stability? The issue of culture thus raises questions about change and transformation. Cultural values are historical, hence dynamic. While cultural differences certainly exist—and one of the responses of migrants to their life in a new place may be to cling on to or even elaborate their particular “culture”—it may be misleading to highlight culture as the major factor in producing differential health or health-seeking behavior.

Cultural explanations for immigrant health outcomes typically propose that culture influences social norms and individual health behaviors—such as smoking, drinking and dietary patterns—that impact health outcomes. Some studies argue that as immigrants shed cultural characteristics presumably associated with their country of origin and adopt those of the receiving society, their health changes for the worse. Studies of immigration in the US drew, from the 1950s, upon the concept of “acculturation,” understood as a process taking place over time: as migrants adapted to life in their new country, so they took on values, attitudes and behavior prevalent in US society. The concept of “acculturation”—typically defined as an individual-level process through which persons acquire behavior, attitudes, and values prevalent within (the majority) society—has been criticized for its individual and unidirectional assumptions and remains problematic for its focus on cultural values and attitudes in explaining health disparities rather than on socio-economic and political factors (Salant & Lauderdale, 2003). Employing acculturation as the central concept in immigrant-health studies ignores the socio-historical contexts of migration, the racialization of contemporary immigrants, and the role these factors play in the differential social integration of immigrants. It ignores the effect of residence on low-income communities, low socio-economic position, and institutional patterns of unequal treatment, all of which contribute to health disparities (Viruell-Fuentes et al., 2012). Complexity and context is more important (Helman, 2007).

Some public-health scholars criticize the emphasis on culture as an explanation for patterns of immigrant health. Viruell-Fuentes, Miranda, and Abdulrahim, for example, contend that “cultural explanations often mask the effects of social inequalities on immigrant health outcomes” (2012, p. 2099). They argue for a shift from individual, culture-based frameworks to perspectives that consider the role of structural factors in producing health inequalities among immigrants and the ways in which multiple dimensions of inequality intersect to impact health outcomes. A richer understanding of the social determinants of immigrant health requires, they contend, “an intersectional approach,” one that considers the “simultaneous and mutually constitutive effects of the multiple social categories of identity, difference and disadvantage that individuals inhabit” (Viruell-Fuentes et al., 2012; see also Salant & Lauderdale, 2003; Viruell-Fuentes, 2007). Intersectionality theory was developed in writings by US black feminists, who challenged the notion of a universal gendered experience and argued that black women’s experiences were also shaped by race and class. The theory proposes that race, class, and gender are mutually constitutive and work together to produce inequality. Although intersectionality theory has had an impact on critical race theory, immigrant health is still dominated by the acculturation paradigm. Studies of immigrant health tend to overlook or ignore how immigrant-health trajectories are shaped by race-, class-, and gender-based systems of hierarchy simultaneously. We should keep this critique in mind in assessing any study of the relations between migrant or minority status and health.

Given the pitfalls of research on relationships between migration, culture, socio-economic status, and health, in this report we take care to strike a balance between recognizing the significance of cultural difference and giving proper weight to the importance of socio-economic inequality, marginality, and exclusion and their impacts on health status and treatment-seeking behavior among migrant and minority groups. While we are now seeing a move in both research and policymaking from a position of ignorance and neglect of the distinctive needs of elderly migrants to an interest in the specific needs of these citizens, we should be careful of an overreaction that problematizes all such groups because they are migrants and are therefore assumed to be “different.”

## **Migration, Ageing, and Health: Experiences, Challenges, and Opportunities**

While there is a growing literature on the relations between migration, migrant status, and health in the EU (and worldwide), there are, with exceptions (e.g., Whitfield & Baker, 2014), few reviews of the relations between migration and migrant status, aging, and health. Below, we summarize the literature on migration and health and review our knowledge of the health of immigrant populations in Norway, before going on to consider the literature on aging and health and discuss how the three issues—aging, health, and migration—may intersect.

## Migration and health

A comprehensive report on “Migration and health in the EU” (Rechel et al., 2011) explores key features of health and migration in the EU, arguing that the increasing diversity of populations in Europe creates new challenges for health systems, which have to adapt to remain responsive. The authors note that while a number of publications on migration and health in Europe have appeared, comprehensive information on different aspects of health and migration is “not easy to find” (Rechel et al., 2011, p. 4). This applies also to research on the relations between migration and aging.

The relation between migration and health is complex. There is considerable evidence that migration is an important social determinant of health (Davies et al., 2009; Ingeby, 2009). While new migrants are often comparatively healthy—a phenomenon known as the “healthy migrant effect”—this effect largely disappears with time: the longer the migrant stays in the host country, the poorer health status he or she has. Migrants face particular health challenges and are vulnerable to a number of threats to their physical and mental health. They are more vulnerable to occupational diseases, to poor mental health, and to communicable diseases—in part due to poor living conditions and precarious employment/working conditions, low socio-economic status and the trauma associated with various causes of migration as well as the experience of the host country (Rechel et al., 2011). Epidemiological evidence shows that particular diseases—for example, heart disease and diabetes—have higher prevalence among particular migrant groups and that this is related to, for example, lifestyle factors such as diet and exercise (see other chapters in this review).

Despite considerable evidence that migrants face particular health challenges, the specific health needs of migrants are often poorly understood by policymakers. Communication between health-care providers and migrant clients remains poor, and health systems are not prepared to respond adequately. The situation is compounded by “the problems migrants face in realizing their human rights, accessing health and other basic services, and being relegated to low paid and often dangerous jobs (with the most acute challenges being faced by undocumented migrants, trafficked persons and asylum seekers)” (Rechel et al., 2011, p. 4). Political attention to the health of migrants is patchy, and often it is related to prevailing populist attitudes towards migrants and immigration, with the emphasis being placed on restriction and control: “The overall political climate in a country is an important factor that can help or hinder health systems in becoming more responsive to the needs of migrants” (Rechel et al., 2011, p. 7). This is a pressing issue given the increasing political backlash against immigration and the rise in anti-Muslim rhetoric in many European countries (where anti-immigrant rhetoric is fanned by economic crisis and public-expenditure cutbacks). Given the importance of health to social well-being and economic development and the importance of addressing health inequities, a report for the EU

(Rechel et al., 2011) concludes that migrant health must be pushed up the political agenda (see Kumar & Vikan, 2010).

### **Migration and aging**

While migration has an effect on health status, independently of age, the process of aging brings with it specific health issues and challenges. As mentioned above, aging is accompanied by increased risk of disease, disability, and poor health. Aging also involves significant life changes: a transition from work to retirement (or unemployment), decreased mobility (physical, social, and—in some cases—mental), and associated issues such as social isolation and the increase of fears and worries (Johnson, 2005).

There is little systematic information on aging and migration in Europe, and the process of aging among migrant groups appears to be poorly understood. A 2011 EU report on migration and health (Rechel et al., 2011) has little to say about aging or about dementia. It does cite considerable evidence from across EU countries that migrant populations face steep increases in diabetes diagnoses and a higher incidence of stroke but lower rates of cancers than majority populations. However, the report also notes that there is great diversity within and between groups.

There is also diversity with regard to the life situations of elderly migrants and their experiences of aging. For example, some old people migrated when they were younger, others migrated when they were older, or in old age, to be near children who had previously immigrated. Key distinctions are between elderly people who migrate and former labor migrants (and those who accompanied them), who have “aged in place” (and thus have stronger connections to the host country). These diverse “aged-migrant trajectories,” such as those of return labor migrants and those of migrants who move internationally in late life to live near or close to relatives for support and care, have received much less attention, even in countries such as the UK, which have longer histories of migration (Warnes & Williams, 2006, p. 1257).

Several studies of migration and aging explore differences in perceptions of aging and the importance of fitness and health in old age (Baum & Boxley, 1983; Markides & Boldt, 1983). Adults with youthful identities in middle and later life have better mental health, life satisfaction, morale and self-esteem, and research has found that occupying lower socio-economic strata is associated with having older identities. Compared with the more advantaged, individuals of lower SES are more likely to classify themselves as “old” or “elderly” and feel older than their chronological age (Baum & Boxley, 1983). This pattern is found across indicators of SES, including education (Markides & Boldt, 1983) and income (Baum & Boxley, 1983). Barrett suggests this is not only about “perceptions” but perceptions that have physiological grounds. Rosow (1967) has argued that occupying lower socio-economic strata produces a more rapid rate of physiological aging as a consequence of cumulative

hardships over the life course; hence, “older” identities are found among the most disadvantaged. In other words, the cumulative effects of poor health and more limited access to health care among disadvantaged members of society may produce wider socio-economic differences in age identity in later life.

The significance of socio-economic status together with cultural and social values attached to aging and family life in experiences of aging have relevance for our understanding of aging among various migrant and minority groups. A recent study in the UK (Bowling, 2009) found that individuals belonging to ethnic minorities were less likely to define active aging as having physical health and fitness and to regard exercise as promoting this and were less likely to rate themselves as aging actively than individuals belonging to the majority (Caucasian) population (Bowling, 2009, p. 718).

Issues that are relevant to experiences of aging and challenges faced by elderly migrants are family and marriage structures (which influence care-giving relationships among marital partners or between parents and children) and whether the individual lives alone or not, working conditions and retirement conditions (which influence socio-economic status), education, and socio-economic status. Existing research from the US suggests that there are differences between elderly people who are native-born and elderly people who are foreign-born with regard to marital status, living alone or with family, and socio-economic status (Jackson et al., 2005). Jackson et al. argue that “immigrants, especially older immigrants, are facing the challenges of old age with fewer resources than native-born older adults” (Jackson et al., 2005, p. 478). The authors quote studies showing that in the US, for example, elderly immigrants are a third more likely than elderly native-born adults to be living in poverty, while elderly non-citizens are more than twice as likely (20%) to be living in poverty than elderly citizens (9%). Elderly men who are born outside the US are more likely to be married than elderly women born outside the US (79% compared to 46%). Native-born elderly people are much more likely to live alone (men 18%, women 41%) than foreign-born elderly people in the US (men 10%, women 25%). However, these findings say little about the diversity among immigrant groups in the US.

Diverse groups may have diverse experiences of and expectations surrounding aging and its relations to health. Several studies explore perceptions of aging among majority and minority populations (e.g., Bowling, 2009, in Britain; Burholt, 2004, on South Asian groups in the UK; Lane et al., 2012, on Gypsy families in the UK), focusing in particular on family structures and values such as respect for the elderly. They found that good networks, close-knit families, and community support are all factors associated with lower morbidity, both throughout life and with increasing age (Bowling, 2009). For people with close extended-family relations and networks, whose values include respect for elderly family members, and who continue to have a valued role in old age, old age is experienced as a blessing rather than a burden (e.g.,

Lane et al., 2012; Cohen, 2000). This positive valuation of aging may offset negative experiences of illness, as elderly family members can count on being cared for and supported by their families. These studies suggest that some of the challenges old people face can thus be mitigated, if not offset, by family structures, family relations, and family support. They also show that intergenerational relations among immigrant and ethnic groups differ in important ways from those of the dominant society (Jackson & Antonucci, 2005).

With regard to dementia, the position of the sufferer within family structures may affect perceptions of disease, the experience of the disease, and responses to it, including care-giving and care-seeking. It is therefore important to consider what the evidence says about relationships between family structures, migration, and care-giving. Unsurprisingly, research suggests that family structure and family relations are diverse both within and between immigrant and ethnic-minority groups and in majority populations (Ajrouch, 2005). Due to histories of migration, political-economic conditions in the host country, and individual life histories, some immigrants face old age living alone or with a spouse. Others live in multigenerational households and are looked after by other family members (Burholt, 2004).

With regard to familial *expectations* regarding old-age care, there is evidence that they differ among different ethnic groups and migrant groups (Harper & Levin, 2005). Although a general case can be made that many people belonging to ethnic minority and migrant groups live in larger, multigenerational family structures and have higher expectations of familial care in old age than majority (Caucasian) populations, there is much diversity. To take one example, strong family-caring networks persist and continue to be important among many groups from the Indian subcontinent living in Britain. Bangladeshis in the UK often live in multigenerational households where elderly people expect and receive care from younger generations as part of family life (Burholt, 2000). However, it is difficult to generalize even within these groups, and family living arrangements are also changing. Burholt (2004) found that different groups from the Indian subcontinent—Gujaratis and Punjabis—had vastly different histories of migration and employment, different levels and aspirations regarding education, and different family structures. While they share cultural expectations regarding caring for elderly family members, the prevalence of multigenerational-family living arrangements has declined in these two groups. It should also be noted that cultural preference and expectations regarding family structures, family life, and old age may be impossible to achieve for immigrant families, who may have been separated by migration.

Studies from Europe show considerable diversity even among native-born populations with regard to family structures and care-giving relationships. For example, a study of ethnic white (Caucasian) populations in the UK and Norway (Jackson et al., 2005) found that people did not expect their adult children to provide care for them when

they reached old age. Instead, they expected to be taken care of by professional carers in an old people's home. Again, there was diversity between majority populations in different countries. In response to the question "Should elders depend on children for help when they need it?", 41% of respondents in England agreed compared to 58% in Norway, 55% in Germany and 60% in Spain (Jackson et al., 2005). The authors underline that differences in experiences and expectations of government also influence people's attitudes to elderly care. Whereas only 26% of American respondents believed that providing financial support to needy elders was the responsibility of the state, 79% of Norwegians agreed with this statement.

Further research on the preferences among majority populations in Europe for familial care in old age gives similarly diverse results, which suggests that care preferences may be dynamic and influenced by factors other than family and kinship structures. Research conducted in the 1980s indicated that elderly people expected less care from their families than their family members expected and were prepared to provide (Antonucci & Jackson, 1989). While a 1980s study (Cantor & Little, 1985) suggested that elderly Caucasians prefer help from informal family providers over formal non-family providers, more recent evidence suggests that there are circumstances in which people from the same population prefer help from social services (Daatland, 1990; both studies quoted in Johnson, 2005, p. 477). There is thus not only considerable diversity within and between all groups in society regarding expectations surrounding elderly care but also considerable diversity within one group across time. This underlines the dynamism of expectations, experiences, and practices concerning family relationships and professional care within any society.

All European countries are facing a crisis of elderly care. With the aging of Europe's populations, there are fewer younger people to look after elderly people. Whereas in the Europe of the 1950s, cultural and gendered expectations meant that women cared for elderly family members, the fact that many women have full-time jobs means either that elderly family members are placed in care homes or that the care burden is placed on working women (and men), who combine full-time work with looking after elderly family members. Adult children of immigrant parents, or of ethnic-minority parents, may be under increased pressure given the expectations that face them regarding familial care together with lower socio-economic status and the diverse problems that their elderly parents may face navigating the health-care system and old people's or care homes (Aranda et al., 1997).

## **Migration, Aging, and Health in Norway**

Norway has a much shorter history of immigration than the UK or Germany. However some immigrant groups—particularly Pakistanis—are now aging, and the younger generations are facing the challenge of caring for elderly family members. In order to both understand the challenges they are facing and develop appropriate health care

policies and services that are responsive to these challenges, we need to assess the information that is available on aging, migration, and health from across Europe.

While there is increasing research on the health of immigrant populations in Norway (Attanapola, 2013), issues surrounding aging and care for elderly immigrants have, with exceptions (e.g., Næss & Moen, 2015), received less attention. Kumar and Viken (2010) argue that as the numbers of elderly immigrants is increasing, issues surrounding the health of elderly immigrants and care services available to them should be placed high on the political agenda (see Thyli et al., 2007, 2010). Studies of aging and migration in Norway mostly focus on interactions with care services. Magnussen and Johannesson (2005) and Ingebretsen (2005) map the need for care for elderly immigrants in five cities in Norway, and there are several reports that explore the needs of elderly immigrants and the availability of care services for them (Ingebretsen & Nergård, 2007; Ingebretsen, 2010). These studies identify considerable diversity in the life and living situations of elderly immigrants, for example, cultural differences, differences in linguistic abilities between migrants who have lived in Norway for more than ten years and those who arrived recently or those who arrived in Norway in relatively old age, and differences between those living in extended families and those living alone. The studies also review the availability and quality of care for elderly immigrants and their needs for special health care and elderly care and for home care versus institutional care.

The focus of these Norwegian studies and reports is on the need for care for elderly immigrants rather than on aging and health status as such. However, recently published research (Thyli, Hedelin, & Athlin, 2014) takes a broader perspective to explore elderly immigrants' experiences of growing old in Norway, with a focus on health and care. Nine immigrant groups were represented in the study, which concludes that "the most important issue when growing old in a new homeland as an ethnic minority immigrant was to be surrounded by one's family" (Thyli, Hedelin, & Athlin, 2014, p. 52). For many respondents, the family was seen as the only option when needs for care increased owing to changes in age and health. This was due to preferences for familial care; expectations that the younger generation take responsibility for their parents' care needs; feelings of fear and distrust; and, finally, language barriers in using health-care services. Importantly, several studies find that health workers often impose imagined cultural values on women from ethnic-minority backgrounds or on immigrant women who seek their care (Johansen, 2006).

## Summary

This chapter has focused on broad issues surrounding aging, health, and migration in Europe, with a view to facilitating an understanding of the structural, linguistic, cultural, and social factors that shape aging within migrant and minority populations. Understanding the dynamics of migration and the experience of belonging to a minority group is crucial for a better understanding of migrant experiences of aging.

While reviewing the current state of knowledge about migration, health, and aging, the chapter has pointed to the gaps in knowledge and the paucity of research on this issue, particularly in the Nordic countries.

The health status of elderly people from minority and immigrant groups and their access to and use of health and care services is becoming an important policy issue in Norway, as in the rest of Europe. Elderly migrants face challenges similar to those faced by elderly people belonging to majority populations with regard to deteriorating health and mobility associated with aging. However, research from Europe and the US suggests that migrant and minority groups face additional burdens and challenges regarding aging and health, which are associated with lower socio-economic status and experiences of discrimination. Migrants face barriers in accessing health services, and some migrants face language barriers. Research on the experiences of elderly migrants and their families in Norway, as in other European countries, is still in its infancy. However, recent studies and reports, reviewed in this chapter, point at the importance of family networks and intergenerational relations when it comes to mitigating the negative effects of aging and providing care.

The following chapter takes up these issues in relation to dementia and reviews the state of knowledge about dementia, aging and care among migrant and minority populations in Norway and beyond.

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# Chapter 4: Epidemiology of Dementia in Migrant and Ethnic-Minority Populations

Samera Qureshi and Esperanza Diaz

## Introduction

This chapter summarizes both the current epidemiological knowledge about the occurrence (prevalence and incidence) of dementia and the risk or protective factors associated with the disease based on a review of published studies. The global burden of dementia is presented by absolute figures from different studies. An overview of the figures points to the scale of the problem and highlights dementia as a public health issue. We try to address the risk and protective factors for dementia and how it can impact the aging immigrant population especially in Norway.

Dementia is a chronic and progressive disorder, and although it mainly affects elderly people, it is not a normal part of aging. Among neurologic conditions, dementia was estimated to be the third leading cause of years lived with disability at a global level by the Global Burden of Disease 2010 Study (Rizzi, Rosset, & Roriz-Cruz, 2014). It is caused by a variety of brain illnesses that affect memory, thinking, behavior, and the ability to perform daily tasks. Dementia usually implies a long period of mental handicap and suffering for the patient, as well as severe strain and financial burden on the patient's family, caregivers, and society.

Dementia has for more than a decade been declared as one of the major challenges of the century (Livingstone 2017; Van der Flier & Scheltens, 2005). Due to increasing life expectancy, the number of people suffering from dementia will increase rapidly in both developed and developing countries. According to the World Alzheimer Report 2013, "Journey of Caring: An Analysis of Long-Term Care for Dementia," as the world population ages, the traditional system of "informal" care by family, friends, and community will require much greater support. It is estimated that 13% of people aged 60 or over require long-term care globally. Between 2010 and 2050, the total number of elderly people with care needs will nearly triple from 101 to 277 million (Alzheimers Europe, 2013; Prince et al., 2013). According to a review report by Reitz et al., people 60 years or older, from North America and Western European regions are believed to have the highest prevalence and incidence rate of dementia, followed by those from Latin America and China and its western Pacific neighbors (Reitz & Mayeux, 2014). However, a recent Lancet review report an unexpected decline in age-specific dementia incidence and prevalence in some countries, such as the USA, the UK, Sweden, the Netherlands and Canada. Conversely, an increase in the incidence of dementia in China and prevalence in Japan are reported (Livingstone, 2017). Result from two US studies show that the decrease in age-specific prevalence of dementia was associated with an increase in education (Livingstone, 2017).

Alzheimer's disease (AD) is the most common cause leading to dementia. AD is a progressive condition for which no single cause is yet identified. However, several risk factors are linked to it, of which age is the most relevant, in addition to heredity. Women have a slightly higher age-adjusted probability of developing dementia due to AD than men (WHO, 2014). Vascular dementia (VaD) is the second most prevalent cause of dementia. It is caused by decreased supply of blood to the brain (Ueno, Chiba et al. 2015). Frontotemporal dementia (degeneration of the frontal lobe of the brain) and dementia with Lewy bodies (abnormal aggregates of protein that develop inside nerve cells) are other frequent causes of dementia. However, it is often clinically difficult to reliably distinguish between the various subtypes of dementia, and mixed forms often co-exist (Karantzoulis and Galvin 2011). It is therefore common that most epidemiological studies focus on dementia and give numbers on the two most common types, i.e., AD and VaD (Forette and Boller 1991). A recent Lancet review conclude that globally Alzheimer's disease is the most common, vascular dementia is the second most common, followed by dementia with Lewy bodies (Livingstone, 2017).

A majority of the epidemiological research on dementia from a population point of view has been done on host populations in Western countries. Immigrants and ethnic minorities constitute 9% of Europe's population (Mazaheri, Eriksson et al. 2014); but they have not been well represented in dementia research. However, a population based prevalence study of mild cognitive impairment (MCI) and dementia across the most common ethnic groups (Turkish, Moroccan Arabic, Moroccan Berber, and Surinamese-Creoles, Surinamese- Hindustani and Dutch) in Netherland, found that MCI and dementia was three to four times more prevalent in the majority of non-western immigrant groups when compared to the native Dutch population (Parlevliet et al., 2016). The authors conclude that their results are comparable to four other recent studies that have found that the prevalence of dementia in immigrant groups is more than twice as high as in native populations in the Western world (Parlevliet et al., 2016).

Migration is considered a complex and dynamic process that can influence the health of migrants in different ways. Research on ethnic minority groups does not give a clear picture of any potential impact of the migration experience may have on development of dementia. What one does know is that factors such as social isolation and depression are risk factors associated with development of dementia (Livingstone 2017), and that these risk factors are highly prevalent among many immigrants (Parlevliet et al., 2016; Opaas & Varvin, 2015; Rosenbaum & Varvin, 2007). Further, little cognitive reserve, as expressed by few years of education and lower socio-economic status, are suggested to influence higher prevalence rates among dementia (Parlevliet et al., 2016).

This summary includes results from five systematic reviews/narrative reviews and meta-analyses and 9 individual studies on the occurrence of dementia. Table 1 gives a summary of the epidemiological studies and reviews included in this chapter. This summary also includes a few review articles on risk factors for dementia published in 2014. In addition to national and international research articles, publications from international organizations working with dementia and immigrants were also reviewed (for more details, see chapter 2).

**Table 1:** Methodological Features and Findings of Studies Included in the Review.

Author, year of pub.	Country	Type of study and frequency measure	Population studied	Aims	Findings
Parlevliet et al., 2016	Netherland	Population based prevalence study of mild cognitive impairment (MCI) and dementia across ethnic groups	Turkish, Moroccan Arabic, Moroccan Berber, and Surinamese-Creoles, Surinamese-Hindustani and Dutch.	Investigate differences in the prevalence of MCI and dementia between the most common immigrant groups and native Dutch.	MCI and dementia was three to four times more prevalent in the majority of non-western immigrant groups when compared to the native Dutch population.
Livingstone et al., 2017	Global	Narrative review of Dementia prevalence, prevention, intervention and care	Global, mainly high-income countries	Review of evidence of Dementia prevalence, prevention, intervention and care	Different types of evidence based advices in regards to prevention, intervention and care (see review)
Littlejohns et al., 2014	USA	Prospective, population-based study Association study	White and black Americans	To find out if low vitamin D concentrations, specifically 25(OH)D deficiency (25 nmol/L) and (25 to 50 nmol/L), are associated with an increased risk of <ul style="list-style-type: none"> <li>• incident all-cause dementia and</li> <li>• Alzheimer's disease.</li> </ul>	Vitamin D deficiency is associated with <ul style="list-style-type: none"> <li>• a substantially increased risk of all-cause dementia, 2.25 (95% CI: 1.23–4.13) and 1.53 (95% CI: 1.06–2.21), and</li> <li>• Alzheimer's disease, 2.22 (95%CI: 1.02–4.83) and 1.69 (95%CI:1.06–2.69).</li> </ul>

Author, year of pub.	Country	Type of study and frequency measure	Population studied	Aims	Findings
Annweiler, Llewellyn, & Beauchet, 2013		Systematic review and meta-analysis (10 studies) Association study		<ul style="list-style-type: none"> <li>• To do a systematic review of literature to determine the association of low serum 25-hydroxyvitamin D (25OHD) concentrations with AD in adults</li> <li>• To perform a fixed and random-effects meta-analysis of bias-corrected effect size of the difference in serum 25OHD concentrations between AD cases and controls using an inverse-variance method</li> </ul>	<ul style="list-style-type: none"> <li>• AD cases had lower serum vitamin concentrations than matched controls.</li> <li>• The pooled effect size in random-effects meta-analysis was 1.40 (95% CI: 0.26;2.54), a “large” effect size that indicates that serum 25OHD concentrations were 1.4 standard deviation units lower in AD cases than in cognitively healthy controls (<math>p = 0.016</math>).</li> </ul>
Prince et al., 2013	UK	Systematic review and meta-analysis (135 studies) Prevalence	Global	<ul style="list-style-type: none"> <li>• To do a systematic review of the global literature on the prevalence of dementia (1980–2009)</li> <li>• To perform a meta-analysis to estimate the prevalence and numbers of those affected, aged <math>\geq 60</math> in 21 countries</li> <li>• To determine Global Burden of Disease regions</li> </ul>	<ul style="list-style-type: none"> <li>• Age-standardized prevalence for those aged <math>\geq 60</math> varied in a narrow band, 5–7% worldwide.</li> <li>• There was a higher prevalence in Latin America (8.5%).</li> <li>• There was a lower prevalence in the four sub-Saharan African regions (2–4%).</li> </ul>

Author, year of pub.	Country	Type of study and frequency measure	Population studied	Aims	Findings
Ikejima, 2012	Japan	Community-based surveys Prevalence	Japanese	<ul style="list-style-type: none"> <li>• To investigate the prevalence of dementia and illnesses causing dementia</li> </ul>	<ul style="list-style-type: none"> <li>• Alzheimer's disease (67.4%),</li> <li>• Vascular dementia (18.9%),</li> <li>• Dementia with Lewy body disease (4.6%),</li> <li>• Mixed dementia (4.2%) and other illnesses.</li> <li>• Prevalence of dementia between 65 and 99 years was 5.8–7.7%.</li> </ul>
Adelman, 2009	UK	Systematic review (11 studies) Prevalence	Afro-Caribbean	<ul style="list-style-type: none"> <li>• To collate evidence regarding the prevalence of dementia</li> <li>• To determine predictors of dementia or relative cognitive impairment in African-Caribbean people in Britain, as compared to their white, British peers.</li> </ul>	<ul style="list-style-type: none"> <li>• All studies found an excess of dementia in Afro-Caribbean people when compared to the indigenous white population.</li> <li>• The magnitude of this difference and the associated risk factors are not clear and warrant further investigation.</li> </ul>
Llibre Rodriguez et al., 2008	International	Cross-sectional survey Prevalence	Latin Americans, Indians, and Chinese	<ul style="list-style-type: none"> <li>• To determine if prevalence of dementia is lower in developing than in developed regions.</li> <li>• To determine the prevalence and severity of dementia in low-income and middle-income countries.</li> </ul>	<ul style="list-style-type: none"> <li>• The prevalence of DSM-IV dementia varied widely, from 0.3% (95% CI 0.1–0.5) in rural India to 6.3% (5.0–7.7) in Cuba.</li> <li>• 10/66 dementia prevalence was higher than that of DSM-IV dementia and more consistent across sites, varying between 5.6% (95% CI 4.2–7.0) in rural China and 11.7% (10.3–13.1) in the Dominican Republic.</li> </ul>

Author, year of pub.	Country	Type of study and frequency measure	Population studied	Aims	Findings
					<ul style="list-style-type: none"> <li>• In comparison with the 10/66 dementia algorithm, the DSM-IV dementia criterion might underestimate dementia prevalence, especially in regions with low awareness of this emerging public-health problem.</li> </ul>
Prince, 2004	International	Journal article Prevalence and incidence	Developing countries	<ul style="list-style-type: none"> <li>• To determine prevalence &amp; incidence of dementia</li> <li>• To estimate trends in dementia over-time and its impact</li> </ul>	<ul style="list-style-type: none"> <li>• In general both prevalence &amp; incidence of dementia are lower in developing than the developed countries</li> <li>• Early-onset cases are rare in developing countries</li> <li>• Trends are changing due to demographic ageing in countries such as China, India and Latin America.</li> </ul>
Fratiglioni et al., 2000	Europe	Collaborative study Incidence		<ul style="list-style-type: none"> <li>• To examine the association of incident dementia and subtypes with age, sex, and geographic area in Europe</li> </ul>	<ul style="list-style-type: none"> <li>• A higher proportion of cases were diagnosed with AD (60 to 70% of all dementia cases) than with vascular dementia (VaD).</li> <li>• The incidence of dementia and AD continued to increase with age up to the age of 85.</li> <li>• After the age of 85, rates increased in women but not in men.</li> <li>• Higher incidence rates of dementia and AD were found</li> </ul>

Author, year of pub.	Country	Type of study and frequency measure	Population studied	Aims	Findings
					in the very old in northwestern countries than in southern countries.
Lobo et al., 2000	Europe	Collaborative study Prevalence		<ul style="list-style-type: none"> <li>• To compare the age- and sex-specific prevalence of dementia, AD, and vascular dementia (VaD) across European population-based studies of persons aged 65 and above</li> </ul>	<ul style="list-style-type: none"> <li>• The age-standardized prevalence was 6.4% for dementia (all causes), 4.4% for AD, and 1.6% for VaD.</li> <li>• The prevalence of dementia increased continuously with age and was 0.8% in the group aged 65–69 and 28.5% at the age of 90 and above.</li> <li>• The corresponding figures for AD (53.7% of cases) were 0.6% and 22.2% and for VaD (15.8% of cases) 0.3% and 5.2%.</li> <li>• Dementia is more prevalent in women, and AD is the main contributor to the steep increase of prevalence with age.</li> </ul>

Author, year of pub.	Country	Type of study and frequency measure	Population studied	Aims	Findings
Jorm & Jolley, 1998	International	Meta-analyses Incidence		To perform a meta-analysis of the age-specific incidence of all dementias including AD and vascular dementia	<ul style="list-style-type: none"> <li>• The incidence of dementia rises exponentially to the age of 90.</li> <li>• Any sex differences are small, and the incidence is lower in East Asia than in Europe.</li> </ul>
Rocca et al., 1998	USA	Analytical study Incidence	White Americans	<ul style="list-style-type: none"> <li>• Reanalyze previously reported data on the incidence of dementia</li> </ul>	<ul style="list-style-type: none"> <li>• Age-specific incidence rates were similar in men and women.</li> <li>• Incidence rates continued to increase after the age of 84 and remained stable over time for both dementia and AD.</li> <li>• No birth cohort effect was present for either dementia or AD.</li> </ul>

## Literature Review

### Geographic distribution

A systematic review and meta-analysis (Prince et al., 2013) summarized that age-standardized prevalence for those aged  $\geq 60$  showed a small variation, 5–7%, in most world regions, with a higher prevalence in Latin America (8.5%) and a distinctively lower prevalence in the four sub-Saharan African regions (2–4%). The prevalence of dementia in Japan stratified into 5-year age groups for those between 65 and 99 years was 5.8–7.7% (Ikejima et al., 2012). A cross-sectional study (Llibre Rodriguez et al., 2008) reported that the prevalence of dementia varied widely, from 0.3% (95% CI 0.1–0.5) in rural India to 6.3% (5.0–7.7) in Cuba. An unexpected decline in age-specific dementia incidence and prevalence have been reported in some countries, such as the USA, the UK, Sweden, the Netherlands and Canada. Conversely, an increase in the incidence of dementia in China and prevalence in Japan has recently been documented (Livingstone, 2017). Result from two US studies show that the decrease in age-specific prevalence of dementia was associated with an increase in education (Livingstone, 2017).

### Types of dementia

Alzheimer's disease (AD) has become nearly twice as prevalent as vascular dementia (VaD) in Korea, Japan, and China since transition in the early 1990s (Prince, 2004). Prior to this, in the 1980s, VaD was more prevalent than AD in these countries. American and European studies consistently reported AD to be more prevalent than VaD (Prince, 2004). According to another study from Japan (Ikejima et al., 2012), Alzheimer's disease was the most frequent (67.4%), followed by vascular dementia (18.9%), dementia with Lewy body disease (4.6%), mixed dementia (4.2%), and other illnesses.

### Occurrence of dementia

Occurrence of the disease is normally expressed as prevalence or incidence. Prevalence is the number of patients with a disease at a certain moment in time, whereas measures of incidence refer to the number of new cases over a period of time. Although both of these measures of frequency of disease are important for health care planners, to determine the frequency of disease is not the only goal of epidemiology. In fact, the aim is to gain insight into the mechanisms that cause disease, and eventually how one can be able to cure or prevent disease.

### *Global prevalence and incidence of dementia*

Because the population is aging, the dementia rates are growing at an alarming pace in all regions of the world. According to WHO, there were 35.6 million people with dementia worldwide in 2010 (WHO, 2014). Among them, 58% were living in low- and middle-income countries, and this proportion is projected to rise to 71% by 2050 (WHO, 2014). A recent Lancet review conclude that around 47 million people were

living with dementia worldwide in 2015. The number of people with dementia is expected to increase to 66 million by 2030, and 131 million by 2050, driven by the rise in numbers of older adults (Livingstone, 2017).

Most of the studies on the occurrence of dementia have been based on prevalence, and studies on incidence are limited (Rocca, Cha, Waring, & Kokmen, 1998). The incidence of dementia rises with age. According to the figures reported by EURODEM meta-analyses (Fratiglioni et al., 2000), the annual incidence rates of dementia are approximately one quarter of the prevalence. Another meta-analysis (Jorm & Jolley, 1998), which included 23 studies, reported an exponential increase in incidence of both dementia and AD up to the age of 90 with no signs of leveling off. However, there was variation in the incidence rates for VaD between studies, but there was a similar trend of an exponential rise with age. Although there was no sex difference in the incidence of dementia, the incidence of AD was higher in women for the very old, whereas for the younger old, the incidence of VaD was higher in men (Jorm & Jolley, 1998).

**Table 2:** Incidence and prevalence rates of Dementia from the EURODEM Meta-Analyses for European Studies (Fratiglioni et al., 2000)

Age groups	Annual incidence per 100		Prevalence (%)	
	Men	Women	Men	Women
60–64	0.2	0.2	0.4	0.4
65–69	0.2	0.3	1.6	1.0
70–74	0.6	0.5	2.9	3.1
75–79	1.4	1.8	5.6	6.0
80–84	2.8	3.4	11.0	12.6
85–89	3.9	5.4	12.8	20.2
90+	4.0	8.2	22.1	30.8

There is substantial variation in the global prevalence of dementia due to the lack of methodological uniformity among studies, differences in diagnostic criteria, and different mean ages in populations. There are around 7.7 million new cases of dementia worldwide every year. This amounts to a new case being diagnosed every four seconds (WHO, 2014). As reported by Prince (2004), due to the pace of demographic aging in countries such as China, India, and Latin America, by 2020 the comparison of oldest population will have increased by 200% and 68% in developing countries and the developed world, respectively (Murray & Lopez, 1996). However, there is uncertainty in the reporting of frequency of dementia in the developing world due to there being few studies and wide variation in the estimates (Greenberg, Tanev, Marin, & Pitman, 2014; Prince, 2000). Generally, as compared to the developed

countries, both incidence and prevalence of dementia is lower in the developing countries (Prince, 2000).

#### *Prevalence of dementia in Norway*

According to Alzheimer Europe's estimates, there were 77,158 people with dementia in Norway in 2012 (Table 3). This approximates to 1.56 % of the total population of 4,960,482, which is quite similar to the EU average of 1.55%. Table 3 shows the estimated number of people with dementia in Norway between 30 and 59 and for every 5-year age group thereafter in 2012. However, it is not known how many people with dementia who are not diagnosed (Alzheimer Europe, 2013). According to new national guidelines for dementia published by the Norwegian Directorate of Health (2017) this estimate is probably too low because there are a significant proportion of individuals with dementia who do not receive a diagnosis.

As the number of inhabitants over the age of 80 is expected to increase sharply in the coming years, the prevalence of dementia disorders will probably double to around 135,000 cases in Norway by 2040. Until recently, there were no data on dementia concerning immigrants in Norway. A recent study (Diaz, 2015) has however showed that a significantly lower proportion of immigrants are diagnosed by GPs with dementia or memory impairment compared to ethnic Norwegians. This could be due to lower prevalence of dementia in certain groups or due to milder forms of dementia being more common. Validity of assessment tools, linguistic barriers and challenges for general practitioners should however be further investigated to get a clearer picture (Diaz, 2015).

**Table 3:** Estimated Number of People with Dementia between 30 and 95+ in Norway 2012 (Alzheimer Europe, 2013)

Age group	Men	Women	Total
30–59	1,641	880	2,520
60–64	313	1,377	1,690
65–69	2,240	1,763	4,003
70–74	2,457	3,244	5,701
75–79	4,056	5,448	9,504
80–84	6,374	10,418	16,792
85–89	5,467	13,920	19,387
90–94	2,855	10,999	13,854
95+	529	3,177	3,706
Total	25,932	51,226	77,158

## The risk or protective factors associated with dementia

Risk or protective factors associated with disease are also subject of epidemiological studies. Various factors have been explored so far as regards the etiology of AD and dementia. Age is the most significant risk factor for both dementia and AD (for AD, from age 65, prevalence doubles every 5 years, reaching 47% for people  $\geq 85$ ). A new review article show that less education is an early life (potentially modifiable) risk factor; hearing loss and life style factors such as hypertension and obesity are potentially modifiable risk factors at midlife (45-65 years), and smoking, depression, physical inactivity, social isolation and diabetes are potentially modifiable risk factors in later life ( $>65$ ) (Livingston *et al.* 2017). Even if these are risk factors *across* ethnic groups, we know that factors such as social isolation and depression are highly prevalent among many immigrants (Parlevliet *et al.*, 2016; Opaas & Varvin, 2015; Rosenbaum & Varvin, 2007). Further, little cognitive reserve, as expressed by few years of education and lower socio-economic status, are suggested to influence higher prevalence rates among dementia; life-course risk factors for many people with immigrant background.

In the following, we give a summary of the risk or protective factors associated with dementia described in earlier studies. The majority of the studies are from the USA.

### Age of onset

A study done in the US comparing Latinos with white non-Latinos, reported a 6.8 years earlier mean age of onset of symptoms of AD among Latinos as compared to whites (Clark *et al.*, 2005). A comparison study in the UK between Afro-Caribbean-born immigrants and their white UK-born counterparts reported that Africans with dementia were almost 8 years younger than their white counterparts after adjusting for age and socio-economic status (Adelman, Blanchard, Rait, Leavey, & Livingston, 2011). In general, dementia usually occurs in people aged over 65 years, when comorbidity is common. In other words, age-related physical health problems, such as diabetes and hypertension, co-occur with dementia more often than chance allows. The more physical illness a person have, the more likely they are to develop dementia, which is suggested to relate to a lack of resilience and repair. In addition, impaired physical and mental function reduce the possibility to exercise and engage in social activities (Livingstone, 2017).

### Ethnicity

Ethnicity also seems to play a role, interacting with age as a risk factor. A systematic literature review summarized eleven studies on Afro-Caribbean people (Adelman, Blanchard, & Livingston, 2009). All the studies found an excess of dementia in this population as compared to the indigenous white British population. In addition, a review of epidemiological data from USA also reported notable differences in risk of AD between African Americans and whites (Clark *et al.*, 2005). However, an association between sex, education or occupation, and AD or cognitive decline was detected in the old Afro-Caribbean population in the UK (Adelman *et al.*, 2011).

### **Age and ethnicity combined**

Differences across ethno-racial groups with regard to age, onset of AD, and cognitive and functional impairment are reported by a study in the USA. The Latino group had an earlier age of onset and more and more severe cognitive impairment than African Americans and white non-Latinos (Livney et al., 2011). Whereas people in the African American group had a slightly later age of onset than white non-Latinos did, levels of dementia severity and cognitive impairment were intermediate between white non-Latinos and Latinos.

### **Genetic factors**

Family history has been reported to be a strong risk factor for dementia, especially in carriers of the APOE epsilon4 allele (Huang, Qiu, von Strauss, Winblad, & Fratiglioni, 2004). Studies have reported a strong association between apolipoprotein E (APOE) and dementia (Christensen et al., 2008; Farrer et al., 1997; Huang et al., 2004). A study done among Chinese in Taiwan reported that APOE accelerated the progression from mild cognitive impairment to AD (Wang, Hong, Lin, Liu, & Chen, 2011). A Japanese study also reported APOE as a risk factor for AD (Zhou et al., 2012). However, a study from the USA investigating the association between early life factors and AD observed no effect modification or confounding by APOE epsilon4 (Moceri, Kukull, Emanuel, van Belle, & Larson, 2000). In a study from Netherlands, the authors found significantly higher prevalence of mild cognitive impairment and dementia in the majority of non-western immigrant groups. They hypothesize that one explanation can be genetic susceptibility that are unmasked as a result of environmental changes such as changing nutrition, obesity, physical inactivity (resulting in vascular diseases), acculturative stress, depression and other psychiatric disorders (Parlevliet et al., 2016).

### **Life style, BMI, physical activity and smoking**

In general, life style factors such as diabetes, hypertension and obesity at midlife (45-65 years) and smoking, depression, physical inactivity, social isolation and diabetes are potentially modifiable risk factors for dementia in later life (>65) across ethnic groups (Livingston *et al.* 2017). Data from the Honolulu-Asia Aging Study (HAAS), a community-based prospective cohort of Japanese American men between the age of 71–93, followed since 1965, showed that high BMI in midlife was most strongly associated with increased risk of overall dementia (OR, 1.87; 95% CI, 1.26–2.77; BMI > 25.0 vs. < 22.6 kg/m<sup>2</sup>; Gelber et al., 2012). Studies have reported that leisure-time physical activity, even of moderate level, protected against the development of dementia in later life (Gao et al., 2011; Gelber et al., 2012; Stewart et al., 2003). In people who report high levels of physical activity, the association between increasing age and cognitive decline, particularly verbal recall, is weak (Stewart et al., 2003). A study among Japanese American men in the USA reported that having a healthy lifestyle in midlife is associated with a lower risk of dementia in late life (Gelber et al., 2012). Physical activity could affect cognition through an increase in cerebral blood

flow, oxygen extraction, and glucose utilization, as well as activation of growth factors promoting structural brain changes, such as an increase in capillary density. An association between smoking and cognitive decline is also documented, and may be explained due to the link between smoking and cardiovascular pathology. However, cigarettes also contain neurotoxins, which heightens the risk (Livingstone, 2017).

### **Intellectual activity**

Several studies indicate that the knowledge of two languages helps delay the onset of AD (Bialystok, Craik, & Freedman, 2007; Costa, Hernandez, Costa-Faidella, & Sebastian-Galles, 2009). Another study in Montreal, Canada, also reported a protective effect of bilingualism in immigrants, with a delay in diagnosis of AD by almost 5 years as compared to less educated immigrants who remained monolingual (Chertkow et al., 2010). In contrast, in non-immigrants whose first language was English, no such effect was found. However at this point in time, these studies have been criticized for several methodological and statistical flaws, and it has been hard to replicate the findings in later more thorough studies. Many studies have however reported that the onset of dementia is delayed in highly educated people (Sharp and Gatz, 2011). Low education level is thought to result in vulnerability to cognitive decline because it results in less cognitive reserve. A high cognitive reserve enables people to (a higher extent) to maintain function despite brain pathology (Livingstone, 2017).

### **Other risk factors**

Early-onset dementia (< 65 years) is associated with a history of traumatic brain injury (but the epidemiological evidence is quite weak), alcohol, and human immunodeficiency virus (HIV), as compared to late-onset dementia. These factors was among others associated with early-onset dementia in a study from the USA (McMurtray, Clark, Christine, & Mendez, 2006).

Another risk factor reported (Annweiler, Llewellyn, & Beauchet, 2013; Littlejohns et al., 2014) to be responsible for substantially increasing the risk of dementia and AD in later ages is vitamin D deficiency. However, the results from other studies are conflicting. A review published in 2014 reported a weak but not established link between post-traumatic stress disorder and AD, but the evidence is weak, as only two studies were included (Greenberg et al., 2014).

In a recent Lancet review (2107), hearing loss as a risk factor for dementia is emphasized as a relatively new and important finding. Even mild levels of hearing loss increases the long-term risk of cognitive decline and dementia in individuals that are cognitively intact but hearing impaired at baseline. The causal mechanisms are not clear, but hearing loss might either add to the cognitive load of a vulnerable brain leading to increased changes in the brain, or lead to social disengagement or depression and accelerated atrophy (Livingstone, 2017). Depression and social isolation are also acknowledged as important risk factors. Cohort studies with longer

follow-up times show a link between number of depressive episodes and risk of dementia, which increases the assertion that depression is a risk factor for dementia. The authors of a recent Lancet review hypothesize that depression increases the risk of dementia because it affects stress hormones, neuronal growth factors, and hippocampal volume (Livingstone, 2017). As with depression, it is still not certain whether social isolation might be a prodrome (early symptom) or part of the dementia syndrome. However, evidence is growing that social isolation is a risk factor for dementia, and it increases the risk of hypertension, coronary heart disease, and depression. Social isolation may also lead to cognitive inactivity, which again is linked to faster cognitive decline and low mood (Livingstone, 2017).

## Summary & Conclusions

The high prevalence and incidence of dementia make it the most common condition affecting the elderly. It is a major public health challenge not only in high-income but also in low-income countries. More methodologically comparable studies on the incidence of dementia are needed if one is to understand the occurrence of the disease in different parts of the globe. In addition, it is still not clear whether the age distribution of the occurrence of dementia in women differs from that in men or if the correlation between age and occurrence of dementia varies with type of dementia.

In light of the studies reviewed and the risk or protective factors identified, it would be appropriate to state that certain factors stand out as stronger than others in the etiology of dementia and AD. Age, family history, and the APOE are strong risk factors for dementia. Age is the most significant risk factor for both dementia and AD (for AD, from age 65, prevalence doubles every 5 years, reaching 47% for people  $\geq 85$ ). Less education is an early life risk factor; hearing loss and life style factors such as hypertension and obesity are potentially modifiable risk factors at midlife (45-65 years), and smoking, depression, physical inactivity, social isolation and diabetes are potentially modifiable risk factors in later life (>65) (Livingston *et al.* 2017). There are few studies involving migrants and ethnic minorities, but some studies have found higher prevalence of mild cognitive impairment and dementia among immigrant groups, when compared with the native population, in western countries. This may be due to genetic susceptibility and/or be due to risk factors such as social isolation, depression, changes in life style leading to obesity, diabetes and vascular diseases – all factors that might be unmasked or triggered due to the migration process.

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# Chapter 5: Diagnosis and Management of Immigrants With Dementia

Esperanza Diaz and Samera Qureshi

## Introduction

The diagnosis of dementia relies on communication with patients and their caregivers. In addition, physical and psychiatric examinations, observation of behavior, cognitive tests, blood samples, imaging scan of the brain, and assessment of activities of daily living should be performed for a correct evaluation of the patient (Nielsen, Andersen et al., 2011). However, no pathognomonic test exists that can make a correct diagnosis without proper communication between the health personnel and the patient (Nielsen, Andersen et al., 2011).

Dementia is usually first recognized, diagnosed, and often treated in primary health care, and approximately one out of five patients with dementia are referred to a specialist in Scandinavia (Olafsdottir, Foldevi et al., 2001). A correct diagnosis allows people with dementia to plan ahead while they still have the capacity to decide about their future care, and to receive practical information, advice, pharmacological treatment, and support in time. However, patients and their caregivers often believe that nothing can be done for people with dementia, and the health personnel's ability to diagnose dementia vary across countries, making dementia generally underdiagnosed (Prince, Bryce et al., 2011), especially at the early stages (Eichler, Thyrian et al., 2014). Lack of diagnosis is even more widespread in low- and middle-income countries (Venketasubramanian, Sahadevan et al., 2010).

Immigrants represent an increasing proportion of the elderly population in European countries like Norway (Mørk, 2011). Despite the heterogeneity of this group, the diagnosis of cognitive impairment and dementia often proves additionally challenging given, among other things, differences in culture, language, education, and expectations from native populations. As a consequence, the proportion of immigrants in Norway, especially those from middle- and low-income countries, that receives a diagnosis of dementia or memory impairment in primary health care is significantly lower than that of native Norwegians (Diaz, Kumar et al., 2015). Similar differences in dementia diagnoses have been found between non-western immigrants and native Danes in Danish secondary health care (Nielsen, Vogel et al. 2011). In the following, we will present the research evidence for the knowledge regarding the diagnosis of and pharmacological treatment for dementia in immigrants and people belonging to ethnic minorities.

## **Dementia Symptomatology and Onset Across Immigrant Groups: What is Making the Differences?**

Dementia encompasses cognitive and non-cognitive domains. Complex migration histories, the degree of assimilation into and acculturation to the host culture, lifestyle changes, language, education, cultural values, and health-seeking behavior may influence the types and nature of signs and symptoms of mental illness at the time of clinical presentation (Haider & Shah, 2004; Shah, 2007). The same factors may also delay the contact between immigrants and ethnic minorities and health services until later stages of the disease (Cooper, Tandy et al., 2010).

Non-cognitive symptoms, also called behavioral and psychological symptoms of dementia (BPSD), are classified into disorders of behavior, mood, thought content, perception, and personality alteration (Shah, Dalvi et al., 2005). Several studies have shown differences in the prevalence of BPSD for some ethnic minorities. Haider et al. reported that patients with dementia from the Indian sub-continent in London had a lower prevalence of anxiety and phobias than white indigenous patients (Haider & Shah, 2004). Among patients with Alzheimer's disease (AD), Karim et al. compared Pakistanis living in Pakistan versus English living in Manchester and reported that the former were more depressed, had a different profile of personality change since the onset of illness, and had more severe changes in activities of daily living than the latter, whereas the latter became more short-tempered, excitable, and out of touch than the former. The Pakistanis were described as unhappy, calm, lifeless, reliant on others, rash, and unreasonable (Karim, Minhas et al., 2011). Chiu et al. reported very high rates of depression associated with other BPSD in Taiwanese patients with AD (Chiu, Steffens et al., 2012). Also, the prevalence of delusions and hallucinations, schizophreniform psychosis and paranoid psychosis, apathy, irritability and agitation, aggressivity, and activity disturbance in people from various ethnic minorities have been reported to be different from that in host populations in the last twenty years (Shah, Dalvi et al., 2005).

In a recent study from Brussels, European immigrants with memory loss presented a higher proportion of Parkinson-related cognitive disorders and Lewy-body disease, while non-European immigrants more often had a psychiatric diagnosis. Interestingly, the authors hypothesize that an alternative explanation to different symptoms among immigrants with AD could be a higher threshold among family and health personnel to pay attention to symptoms of AD in immigrants. Consequently, more florid non-cognitive symptoms (hallucinations, motor problems) and falls following extra-pyramidal symptoms might be needed for patients from some immigrant groups to be recognized as having dementia than for patients from the majority population. Nevertheless, also in this study, the strongest positive predictor of low Mini Mental State Examination (MMSE) scoring was being an immigrant (odds ratio 6.5; Segers, Benoit et al., 2013).

Studies from the USA are slightly different from European studies in that they often include ethnic minorities that have lived in the country for several generations. In the USA, Liveny et al. studied several ethnic minorities regarding their presentation of symptoms of dementia. Puerto Rican Latinos, who had a very low educational level, had an earlier onset of AD, more cognitive impairment, and greater severity of cognitive impairment. More depression was reported in the Latinos. Cardiovascular disorders, which have also been linked to the higher incidence of dementia for some ethnic groups, were more prevalent among ethnic minorities, but had no effect on age of onset of dementia. Last, the study confirmed previous findings considering more advanced stages of dementia in African Americans than in whites, but the severity was even higher for Puerto Ricans (Livney, Clark et al., 2011).

Discussions about race and dementia have been held for several decades, with numerous studies showing evidence that rates of dementia among African Americans and Latinos may be higher than among white non-Hispanics. Further, African Americans diagnosed with AD present more severe cognitive and neuropsychiatric impairment than white non-Hispanics (Griffith, Lichtenberg et al., 2006; Chin, Negash et al., 2012). However, although race and ethnicity are often linked to genetic differences, greater genetic variation exists within racial groups (85%) than between them (15%), and a similar race does not necessarily reflect a genetically homogeneous population (Faison, Schultz et al., 2007). Education is an important risk factor associated with race and ethnic minorities that has been shown to explain several, but not all, the differences between groups. Yet, education might be considered a proxy for many factors (poverty, nutrition, health-care access) that affect health as well as the expression of disease, particularly cognitive disorders (Livney, Clark et al., 2011). Indeed, the classical way of measuring education has recently been questioned, as years of education do not seem to reflect the same for all cultures. For example, quality of education expressed as the reading level, and not just quantity of education, seems to account for more differences in results from cognitive tests (psychometric performance) between African Americans and white non-Hispanics with AD (Chin, Negash et al., 2012; Pedraza, Clark et al., 2012).

Other factors that have been proposed as relevant in the presentation of symptoms but that have been less studied are whether differences in caregiver relationship according to ethnic background affect clinical outcomes and report of symptoms (Faison, Schultz et al., 2007; Portugal Mda, Coutinho et al., 2012). Also, the ability of clinicians to recognize typical symptoms of dementia in ethnic-minority patients not speaking the host language should be further studied (Borson, Scanlan et al., 2006).

Nevertheless, it should be taken into account that many of the referred studies were conducted in secondary or tertiary level of care, and do not represent the real incidences or prevalences of the disease in the population disregarding their minority background.

## Psychometric Tools in the Assessment of Dementia for Immigrants

### Cognitive tests

Several studies have been published during the last decades proving the influence of culture on many of the most used tests for dementia assessment. Some of these publications are descriptions of the unexpected situations the physicians experience when trying to apply these tests: A patient asks, “How could these questions test the great memories of my childhood in the valley?” (Roy, 2011), or the interpreter explains, “We have no words for those (animals) in Inuktitut” (Canada; Young, 2011).

The MMSE is the tool most often used in the assessment of dementia. It is easy to apply, and it takes approximately 10 minutes but has repeatedly been proven to be associated with education, social and cultural class, and ethnicity (Parker & Philp, 2004). This test has mostly been used on minorities in the USA, showing that one can still use MMSE to detect AD in ethnically diverse highly educated (16 or more years of age) individuals with a higher cut off score (27–28 out of 30) to maximize diagnostic accuracy. However, the optimal balance between sensitivity and specificity varies by ethnic grouping and language (Spering, Hobson et al., 2012), and for most African Americans, adjustments for age and education only attenuate the discrepancy of MMSE scores between them and non-Hispanic whites (Pedraza, Clark et al., 2012).

Three different mechanisms to account for minority-group differences in assessed cognition have been proposed. Firstly, differences in the measurement of the cultural relevancy of cognitive-assessment items, which is called item bias or differential item functioning, affect the scores. Secondly, the influence of socio-economic variables such as education or health behaviors can affect the scoring of a test. Lastly, heterogeneity in the relative importance of background variables for different ethnic or minority groups is postulated. This is explained as the effect of a given variable, for instance education, in a minority-group scoring for a test being different from the effect in the majority population scoring (Jones, 2003). These mechanisms were studied for the Telephone Interview of Cognitive Status (TICS), a brief cognitive-impairment-screening instrument. In an interesting study published in 2003, Jones tried to disentangle the racial bias (African American vs white) of the TICS. Nearly 60% of the group difference could be attributed to the first mechanism explained above (measurement or structural differences of the tests), 12% to the second mechanism (background variables), and an additional 7% to the third mechanism (differences in the importance of background variables across racial groups). Low education was more deleterious for African Americans, and high income conferred advantage only on whites. Current smokers had lower cognition among whites, but not among African Americans. Age differences were more pronounced among African Americans, suggesting a steeper cognitive decline with age relative to white participants. After adjusting for the above-mentioned factors, apparent racial-group differences in assessed cognition were very small and non-significant (Jones, 2003). Although this

type of study has not been conducted for other instruments, its key messages can probably be translated to other culturally biased psychometric tests. The TIC has also been compared to the racially sensitive Short Portable Mental Status Questionnaire (SPMSQ) and to the Dementia Questionnaire (DQ) and found to be a less accurate assessor of cognitive impairment among African Americans and other minorities (Kiddoe, Whitfield et al., 2008; Manly, Schupf et al., 2011).

In 2004, Parker et al. published a review of the cultural modifications and evidence of cross-cultural performance for several cognitive tests including the SPMSQ, the Short Orientation-Memory-Concentration Test, the Abbreviated Mental Test Score, the Clock Drawing Test (CDT), and the Mini-Cog (Parker and Philp, 2004). According to Parker's review, the evidence showed that short unadapted traditional tests performed as well as or even better than longer ones (Prince, Bryce et al., 2011) and were more consistent across cultural and educational groups. Cut-point adjustments had not universally been found successful in improving accuracy and did not address issues of acceptability (Parker and Philp, 2004). An increasing number of cognitive tests have more recently been evaluated and partially validated for different populations. There are, however, more promising results on tests like the CDT, the Mini-Cog (Borson, Scanlan et al., 2006), and, lately, the Rowland Universal Dementia Assessment Scale (RUDAS), all of which are seen as less threatening and requiring little language interpretation (Borson, Scanlan et al., 2006; Naqvi, Haider et al., 2015).

The RUDAS, a cognitive-assessment tool developed in 2004 for multicultural populations in Australia as an alternative to the MMSE, has received special attention. It has six items assessing body orientation, praxis, drawing, judgment, memory, and language, takes about 10 minutes to apply, is available in more than 30 languages, and is considered to be culturally and educationally fair (Naqvi, Haider et al., 2015). When applied to non-demented Turkish immigrants in Denmark, years of schooling explained 16% of the variance in tests scores on the RUDAS compared to 44% of the variance in scores on the MMSE (Nielsen, Vogel et al., 2012). Also in Denmark, the diagnostic accuracy of RUDAS was similar to that of MMSE in a multicultural population in memory clinics, but contrary to MMSE, RUDAS was unaffected by factors related to the patients' immigrant background (Nielsen, Andersen et al., 2013). In a recent systematic review and meta-analysis to assess the psychometric characteristics of the RUDAS, including eleven studies, its pooled sensitivity was 77% and its specificity 86%. Correlation with MMSE was relatively high (0.77), but RUDAS was less affected by language and education level than MMSE, and not affected by immigrant status (Naqvi, Haider et al., 2015). Thus, the RUDAS is a very promising test, and it can be used not only on minorities but also on the general population.

Other complementary neuropsychological tests evaluated in Denmark in healthy Turkish immigrants and Danish elderly by Nielsen et al. are the Recall of Pictures Test (RPT), the Clock Reading Test (CRT), and Supermarket Fluency (SF). Significant

differences were found between Turks and Danes in CRT and SF performance but not in RPT. The authors consider all tests to be important as supplements to RUDAS, particularly when one assesses dementia in elderly patients from ethnic-minority migrant populations (Nielsen, Vogel et al., 2012).

### **Instruments to measure behavioral and psychological symptoms of dementia (BPSD)**

Non-English instruments measuring BPSD have only recently emerged and are mainly developed with conventional translation and back-translation techniques and subsequent evaluation of psychometric properties. Some examples of these tests are the Rating Scales for Aggression in the Elderly, the Cornell Scale for Depression in Dementia, the Geriatric Depression Scale, the Behavioral Pathology in Alzheimer's Disease Rating Scale, the Neuropsychiatric Inventory, the Revised Memory or the Behavior Checklist, and the Geriatric Mental State Examination (Shah, Dalvi et al., 2005). Additionally, an increasing number of tests have been evaluated and validated during the last years, like the Parkinson Neuropsychometric Dementia Assessment in Switzerland (Gasser, Kalbe et al., 2011), the Revised Memory and Behavior Problems Checklist Scale (Salvia, Dawidowski et al., 2011) and the Spanish version of the Geriatric Depression Scale in persons in Argentina (Lucas-Carrasco, 2012), the Montgomery-Åsberg Rating Scale, and the Cornell Scale for Depression in Dementia in Brazil (Portugal Mda, Coutinho et al., 2012). This astonishing number of different tools makes Shah's conclusion in a review of the field in 2005 even more relevant: A consensus should be reached on the best instrument developed in languages other than English (Shah, Dalvi et al., 2005).

## **Cross-Cultural Diagnosis of Dementia**

### **Few culturally sensitive services**

The cross-cultural diagnosis of dementia poses further challenges at several levels. Apart from the barriers in health-care utilization described elsewhere (Liu, Hinton et al., 2008; Ruspini, 2009; Mukadam, Cooper et al., 2011; Mukadam, Cooper et al., 2011; Diamond & Woo, 2013; Diaz & Kumar, 2014; Diaz, Calderón-Larrañaga et al., 2015), once the immigrant patient is in contact with his or her GP, diagnostic evaluation of dementia can be particularly complicated. On the one hand, communication problems between patient and physician and prejudices on both sides not believing any treatment can be achieved for patients with dementia might influence their relationship and expectations challenging the diagnosis of dementia (Iype, Ajitha et al., 2006). On the other hand, lack of availability of cross-culturally validated cognitive instruments and dementia-rating scales, especially for immigrants with low levels of education, might represent a critical obstacle (Nielsen, Andersen et al., 2011, Nielsen, Vogel et al., 2011).

The same difficulties apply to secondary care, where the current practice of assessment of dementia in ethnic-minority patients in fifteen European countries was reported as suboptimal in 2011 (Nielsen, Vogel et al., 2011). Although ethnic-minority patients were seen in 69% of the centers, most countries performed cognitive assessment with instruments that were validated only for Western cultures and frequently relied on family members for interpretation (Nielsen, Vogel et al., 2011). In Denmark, only 23% of the ethnic-minority patients had an acceptable diagnostic workup documented, and just one out of three was assessed through cognitive testing (Nielsen, Andersen et al., 2011). Unfortunately, there is no reason to believe that the situation is different in either primary or secondary health-care services in other European countries given the scarcity of indicators of culturally sensitive dementia services (like information sheets and validated tools/rated scales) in the fifteen European countries. The authors concluded that there was a general need to increase health professionals' awareness of the implications of cross-cultural assessment of dementia and to develop appropriate assessment methods for patients from the ethnic-minority populations in Europe (Nielsen, Vogel et al., 2011).

#### **Over- and underdiagnosing and the risk of misclassification**

A registry-based study from Denmark established that dementia was underdiagnosed among Turks, Pakistanis, and ex-Yugoslavians aged 60 and above but overdiagnosed in those younger than 60 years (Nielsen, Vogel et al., 2011). The authors discussed the poor validity of the diagnoses especially among the younger ethnic-minority groups and wondered if they reflected underlying psychiatric disorders or could be related to legal or economic advantages of having a dementia diagnosis instead of representing cases of true dementia (Nielsen, Vogel et al., 2011).

Cognitive impairment is the key feature in the diagnosis of dementia and is usually assessed through cognitive tests. However, most psychometric tests, like the MMSE, have been developed in Western cultures. Typically, cognitive tests for dementia assess orientation using the Western calendar, indirectly test the patient for literacy, numeracy, and drawing skills learnt at school, or ask the patients about animals or objects that are most common in Western countries ("What animal does wool come from?"; Spering, Hobson et al., 2012). Also, unfamiliarity with test situations can make the experience of cognitive testing, especially in a foreign language and with unfamiliar questions, a threatening one, with a subsequent suboptimal performance (Shah, 2007). Thus, most cognitive tests underestimate the abilities of elderly immigrants, and their routine use poses a high risk of misclassification of patients with a minority background. As an example, the risk of overdiagnosis using the MMSE, which is the most commonly used cognitive test to assess dementia, was reported as 6% among non-impaired white and 42% among non-impaired black people (Parker & Philp, 2004).

As explained above, attempts to improve the accuracy and validity of the tests for ethnic minorities have included translation and adaptation of existing tools, with adjustment of cut-points and replacement of culture-specific items. Cognitive-screening instruments that are less affected by culture and language, literacy, and other skills developed during formal education (“culturally fair measures”) have also been developed (Parker & Philp, 2004). Nevertheless, comparisons between the diagnostic instruments used on immigrants and those used on the majority populations can additionally be challenged by the possibility of a different prevalence of dementia and different symptoms of the disease in some immigrant and ethnic-minority groups (Ramsey, Stevens et al., 2009; Venketasubramanian, Sahadevan et al., 2010).

Despite the validity of the tests, many elderly immigrants do not master the language in the host country well enough to communicate with their physicians. When available, some patients might choose general practitioners (GPs) from their own region of origin (Diaz, Raza et al., 2014). Otherwise, relying on interpreters, most often family members, often involves unstandardized and ad-hoc translations of tests, which may limit the validity of the assessment (Fratti, Bowden et al., 2011). Predictably, in specific tools providing information about patterns of language in different dementia syndromes, like the Barnes Language Assessment, elderly ethnic-minority groups for whom English is a second language perform poorer than participants with English as their first language. However, differences tend to reduce as education level rises (Ramsey, Stevens et al., 2009).

On the other hand, bilingualism among immigrants has been reported to delay the age of onset of first symptoms of dementia by almost five years (Chertkow, Whitehead et al., 2010), although not all studies agree on this point (Lawton, Gasquoine et al., 2015). For bilingual immigrants, not using interpreters might actually be an advantage. An Australian study showed that Italian-born Australians with English as a second language who scored poorly on a diagnostic memory test in English were more probable to have cognitive impairment than language problems. If, instead, we attribute poor performance to language competence, the risk of a false negative diagnosis may increase (Fratti, Bowden et al., 2011).

## **Pharmacological Treatment of Immigrant Patients with Dementia**

There are few studies specifically targeting management of immigrant patients with dementia, and mainly studies on pharmacological treatment for immigrants with dementia are summarized in this section. Although no curative treatment is available, there are a few drugs showing low to moderate effect on the maintenance of mental health in patients with dementia. The main types are called cholinesterase inhibitors, such as donepezil, galantamine, and rivastigmine. Memantine is another type of drug used to treat symptoms of Alzheimer’s disease, but may also help in mild to moderate vascular dementia (Qaseem, Snow et al., 2008).

A meta-analysis of ethnic differences found consistent evidence, mostly from the United States, that once ethnic minorities received a diagnosis, they were less likely to access anti-dementia medication and 24-hour care than the majority population (Cooper, Tandy et al., 2010). Also in the USA, Gilligan et al. reported that disparities in exposure to a cholinesterase inhibitor or memantine between ethnic minorities were just as prevalent, if not more so, than disparities between minorities and whites (Gilligan, Malone et al., 2012). A more recent study in Norway confirmed that anti-dementia medication was purchased 20–50% more often by Norwegians than by immigrants with dementia, although the differences remained significant only for immigrants from middle- and low-income countries after adjustment for demographic and socio-economic variables (Diaz, Kumar et al., 2015). Other studies, however, could not detect differences in prescription of drugs for dementia, but a small sample size and selection bias were probably part of the explanation (Haider & Shah, 2004).

There is a paucity of pharmacological studies on ethnic minorities, one exception being a multi-center, open-label twelve-week study published in 2006 to evaluate the efficacy and safety of donepezil in African Americans with mild to moderate AD. Unfortunately, the study did not have a control group, but the authors reported that there were improvements on test measures in the subjects treated and that donepezil was well tolerated, but half the patients experienced adverse effects (Griffith, Lichtenberg et al., 2006).

Although there is convincing evidence of ethnic and genetic variability in drug metabolism for some medications, the specific ways in which genetic differences might influence the response to treatment of AD is still a subject of debate, and it is unknown whether ethnicity affects treatment response to cholinesterase inhibitors in AD. In a review of randomized, controlled, industry-sponsored trials of drugs to treat dementia, non-Caucasian participants were underrepresented, so that there were insufficient data to assess any differences in treatment outcome among different ethnic groups (Faison, Schultz et al., 2007).

## Summary

The diagnosis of dementia mainly relies on communication and the use of tools to assess cognitive and non-cognitive behavior. For all patients, but especially for immigrants, an increase in the number of culturally sensitive services and culturally competent health-care professionals is needed so that the patients can trust these and can be given correct diagnoses.

Misclassification of patients can easily arise when one uses assessment tools that are not culturally relevant or that are tightly related to socio-economic class. Thus, culturally and linguistically validated and adapted tools are necessary for diagnosing dementia. The Rowland Universal Dementia Assessment Scale (RUDAS) and other

culturally fair measures seem to be promising tools for cognitive assessment, but consensus is needed with regard to adequate tools to measure non-cognitive symptoms.

The presentation of symptoms of dementia is largely similar between majority populations and immigrants. Although differences in the relative prevalence of cognitive and non-cognitive symptoms have been described across immigrant and ethnic-minority groups, it is still a subject of debate if such differences represent genetic differences, educational and socio-economic differences, or different thresholds among both health-care professionals and caregivers of immigrant patients for identifying the various symptoms.

There is a paucity of literature regarding the use and effect of pharmacological treatment for dementia for immigrants, reflecting the little importance attached to elderly immigrants in research to date.

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# Chapter 6: Perceptions and Experiences of Migrants and Ethnic Minorities with Dementia and Their Caregivers

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## Introduction

The intention of this chapter is to explore the variety of perceptions and understandings that prevails within different groups and in different contexts with regard to cognitive impairment/dementia. The chapter also aims to provide insight into the challenges and experiences of people living with dementia and their caregivers.

A variety of review studies suggest that the meaning of dementia and family caregiving to people with dementia should be understood in the light of “cultural” and social understandings, values, and norms (McClearly & Blain, 2013; Botsford et al., 2011; Mukadam et al., 2011). Given the increasing ethno-cultural diversity among elderly adult populations in many countries, understanding how cultural values and traditions as well as migration processes and socio-economic positions affect patterns of care and use of health services seems important.

When reviewing the literature, it is however challenging to differentiate between the effects of “cultural differences” and the effects of structural barriers, such as not speaking the majority language or not being able to pay direct or indirect costs of accessing relevant health services. Contextual factors such as values and norms, as well as education and health literacy, all influence how and whether people recognize that there is a problem, how they conceptualize and describe the problem, where they chose to—or have the opportunity to—seek help, and whether and how they consider preventive measures (Morhardt et al., 2010; Kleinman, 1980). Subsequently, this chapter will try to address both perspectives, but with an emphasis on what can be described as “socio-cultural factors.”

In the following chapter, the focus is partly on “migrant populations” in European countries, including second- and third-generation migrants, as it is these children and grandchildren of migrants who are facing the challenge of caring for their elderly parents. Since research is sparse on this topic in Scandinavia, only a few studies are from the Scandinavian context. The chapter also addresses dementia among “minority populations” in both Europe, North America, and Australia. As outlined in chapter 1, the dividing line between “minority” and “migrant” populations is not clear-cut. In some EU countries, migrant policies are integrated with broader policies on “ethnic minorities.” While the Norwegian Sami are clearly an ethnic minority, and

not a migrant group, Pakistanis living in Norway are both migrants and an ethnic minority.

Many studies on this particular topic are conducted in different South Asian communities, and consequently, a disproportionate number of the studies reflect this particular population. Many of the studies presented are, in other words, from countries where the health-care systems are quite different from that of Norway, and where the composition of minority and migrant groups will differ. However, when one reviews the synthesized findings in the presented review articles and the elaborated examples in the primary studies, one finds that there are many clear patterns of cross-cultural or cross-textual similarities that seem highly relevant to the Norwegian and Scandinavian setting.

The studies described in this chapter are systematic reviews, narrative reviews, meta-analyses, and a limited number of primary studies. Most of the reviews draw on qualitative studies. Consequently, this chapter is written in a style that mirrors the qualitative-research tradition, including the account of some important theoretical concepts and a detailed presentation of examples that seem highly relevant and transferable to many groups and contexts.

In the following text, the concepts of “cognitive impairment” and “dementia” are both used. The purpose of this is to illustrate that dementia is a biomedical concept that constitutes a diagnosis, while cognitive impairment is a concept that includes awareness and symptoms of early stages of dementia and that is used by communities and people that do not know or use the concept of dementia.

## **Interpretation of Symptoms of Cognitive Impairment**

The overall health-care experience of people with dementia and their caregivers can be seen as progressing through different phases, each with specific challenges for both the patients, their caregivers, and health personnel (Prorok et al., 2013). The first stage is characterized by the manifestation of initial cognitive changes and a variety of interpretations and health-seeking behaviors associated with the initial symptoms (Prorok et al., 2013). (Bio-medical) knowledge of cognitive impairment/dementia, knowledge of what it means, knowledge of what the causes are, and attribution of symptoms are highly interconnected, as will be illustrated in this chapter.

As pointed out in a meta-ethnographic analysis of qualitative studies, the general challenges during this phase include an overall lack of information about dementia in the society, associated social stigma, as well as difficulties on the part of persons with dementia in communicating their symptoms (Prorok et al., 2013). A systematic review of “ethnicity and pathways to care in dementia,” including both quantitative and qualitative studies in different countries and continents, documents significant barriers to help seeking for dementia among ethnic-minority groups (Mukadam et al.,

2010). One of these barriers relates to the recognition and attribution of initial dementia symptoms. Several ethnic-minority groups, for example Asians in the UK and the USA and Hispanic Americans and African Americans in the USA, show a tendency to categorize symptoms such as memory loss, disorientation, and loss of functional abilities as a part of normal aging (Mukadam et al., 2010; Johl et al., 2014; Uppal & Bonas, 2014; Botsford et al., 2011).

In a review of empirical studies on Chinese Americans exploring cross-ethnic differences in pathways to dementia diagnosis, it was found that in Chinese culture, Alzheimer's disease and dementia are seldom described as a brain dysfunction, as compared to in Western culture. Symptoms of cognitive decline are rather described as a consequence of "fate," "wrongdoings," "worrying too much," "craziness," or "contagiousness," reflecting what can be seen as "folk models" of causal explanations (Sun et al., 2012). This suggests that members of different ethnic minorities may have specific understandings of aging and that they do not necessarily recognize and categorize cognitive impairment in biomedical terms.

Studies also show that different interpretations link to different stages of the disease or the severity of symptoms. In a cross-cultural comparison of African Americans, Chinese and Latino family caregivers' perceptions of dementia, there were striking similarities of thought with regard to the normality of cognitive symptoms until the symptoms were so serious that control seemed lost (Mahoney et al., 2005). Initial symptoms of the elderly's memory loss or symptoms of disorientation were attributed to normal aging and deemed unimportant to address. Among African Americans, such symptoms were described as *old timer's disease*, whereas Latinos described symptoms of cognitive impairment with the term *el loco* (craziness) and the Chinese with the term *hu tu*, meaning becoming forgetful in old age (Mahoney et al., 2005).

In general, very few Asian participants in studies from the UK and the USA associate biomedical terms as "dementia" with symptoms indicating cognitive impairment observed in their relatives (Mukadam et al., 2010). For example, both qualitative and quantitative studies have reported that South Asians in general have significantly less biomedical knowledge of dementia (such as which part of the body is affected and if there is a cure) and knowledge related to epidemiology (types, prevalence) than Caucasians. A systematic review exploring constructions of dementia in South Asian communities confirms that there are no specific term for "dementia" in this region of the world (Uppal & Bonas, 2014). It is suggested that the absence of the word or use of the word in this region, is related to dementia being seen as something shameful and therefore to be hidden away (Botsford et al., 2011). A quantitative survey from Denmark, based on 100 native Danish, 47 Polish, 52 Turkish and 62 Pakistani immigrants, found that Turkish and Pakistani people were most likely to hold stigmatizing views of Alzheimer's disease. Level of education and acculturation had limited influence on the (bio) medical knowledge on dementia, and was accounting

for only 22 of the variance at most, and had little influence on perceptions of Alzheimer's disease (Nielsen & Waldemar, 2015).

Review articles from South Asian communities as well as other review studies have found a variety of other explanations and associated concepts used to explain cognitive impairment among elderly people. Review studies including both Asians and African Americans have shown that symptoms of dementia are thought to be caused by God's will, a supernatural intervention, or a curse. Studies including Chinese carers have found spiritual explanations to be prevalent, such as cognitive impairment being caused by "fate" or karmic retribution (Regan et al., 2012; Mukadam et al., 2010). Among Chinese Americans, cognitive impairment has been described as "contagious" and is highly stigmatized (Sun et al., 2012). Similarly, review studies including British South Asian carers found that some see the "evil eye" as a potential cause of cognitive impairment. However, within the same group, some participants conceptualized cognitive impairment as a direct consequence of a physical illness, such as diabetes, heart problems, and high blood pressure. Other studies have found that people see cognitive impairment as a possible reaction to medications (Mukadam et al., 2010; Morhardt et al., 2010; Uppal & Bonas, 2014). These findings all draw the attention to important cross-cultural similarities but also to the fact that there may be huge varieties in how dementia is perceived and managed within the same ethnic group.

Several studies have also documented that recent changes in circumstances, such as migration and "culture shock," are perceived as possible etiological factors (Mukadam et al., 2010; Morhardt et al., 2010). Psychological causes are also commonly described as part of people's explanatory models. For example, several studies in a variety of countries and continents have reported mental illness (often termed "craziness") as a perceived cause of cognitive impairment (Mukadam et al., 2010; Morhardt et al., 2010; Uppal & Bonas, 2014). Other studies have reported that participants attribute symptoms of cognitive impairment to worrying and stress, to trauma experienced by war, or to family problems. Broader social causes such as lack of stimulation, isolation, loneliness, lack of care, neglect, and abuse by family members—including poor diet and physical deterioration—have also been cited as causes of dementia or cognitive impairment (Mukadam et al., 2010; Morhardt et al., 2010; Uppal & Bonas, 2014).

Understandings of the condition are thus complex and varied, and people may be relating to more than one explanatory model. In a qualitative study of ninety-two carers from four different ethnic groups, representing African American, Anglo-European American, Asian American, and Latino, the authors identified three different explanatory models: the biomedical, the folk-model, and a mixed model (folk model/biomedical model). In their study they found that both educational level, gender, and ethnicity were significant for the adopted causal model. Both minority and non-minority caregivers often incorporated folk models into their understanding

of dementia; however, it was more common among minority caregivers and among those with less formal education (Hinton et al., 2005).

Overall, several review studies seem to conclude that cognitive impairment, such as memory loss and slight disorientation, is most of the time explained without people referring to a biomedical diagnosis or disease. Rather, it is common to see dementia as caused by normal aging or more normative factors such as psychological stress, family problems, the immigration experience, or spiritual factors such as God's will, "fate," or karmic retribution. Some also relate cognitive changes to medication or physical illness or see cognitive impairment more holistically as a general condition characterized by lack of care and isolation.

### **Interpretation of Dementia and Impact on Health-Seeking**

Interpretations of symptoms of cognitive impairment influence health-seeking behavior. As illustrated above, research indicates a diversity in interpretations and perceptions of cognitive impairment. Symptoms may be regarded as part of normal aging, they may be seen as chronic or reversible, and they may be perceived and experienced as highly stigmatizing. Consequently, both those afflicted and their relatives may be reluctant or be unaware of the need to seek help until the situation seems unbearable or out of control (Morhardt, 2010)

Shweder et al. (1997) have described general systems of understandings of health and illness, which they term "causal ontologies of suffering." They divided the explanatory models into biomedical, interpersonal, socio-political, psychological, astrophysical, ecological, and moral frameworks. Explanatory models of health and illness within contemporary Western societies are largely framed within a biomedical model, stemming from Cartesian dualism and the split between body and mind. However, during the 1980s there was a shift towards including an understanding of dementia that went beyond seeing it as a neurological impairment; to a biopsychosocial view of the condition (Botsford et al., 2011). A biopsychosocial view of dementia implies that health personnel need to understand people with dementia, and their health-seeking behavior, in the context of the person's personality, biography, general health and the socio-cultural circumstances surrounding the person. A person's ethnic background is one aspect of the person's identity and is therefore extremely relevant when one seeks to understand and support people with dementia and their caregivers (Botsford et al., 2011).

Many studies also point to the fact that viewing cognitive impairment or "dementia" in a broader or different causal framework creates different expectations with regard to the content of the conversation and the care offered by the health services to the afflicted family member (Morhardt et al., 2010). A systematic review on ethnicity and pathways to care found that those who believed that dementia had a psychological,

social, or spiritual origin did not perceive dementia as an illness to be treated within the frames of a (bio)medical model. Further, those who thought that dementia was a physical illness would seek help for what they considered the underlying causes and not for the cognitive impairment (Mukadam et al., 2011).

Several studies show that those who attribute the disease to psychological (e.g., “craziness”) social (e.g., isolation, lack of care), or moral factors (e.g., God’s will, evil eye, karmic retribution) often see dementia as a shameful disease to be hidden away. Groups adhering to explanatory models being stigmatizing or inspire feelings of guilt and shame tend to present to health services late or when they are in a crisis, or not at all (Botsford et al., 2011; Uppal & Bonas 2014; Prorok et al., 2013; Jutlla 2013; Botsford et al., Mukadam et al., 2011).

Studies point to initial periods of denial or disbelief among relatives and how a key incident, for example significant temporal disorientation or wandering at night, is necessary to change the interpretation of the condition and make people seek help (Mukadam et al., 2011).

Delayed or lack of initiative to seek help from outside sources may also be caused by cultural pressure to care for family members. Several studies among Asians as well as African Americans have found a tendency to perceive problems related to cognitive impairment as a personal and familial matter and not a condition that inspires seeking help from public sources (Mukadam et al., 2011). This may partly relate to the perceived cause, such as lack of care, social stimulation or family problems, and partly relate to what can be described through the concepts of *filial piety* or *familism*; a strong identification and solidarity with family members, both nuclear and extended (McClearly & Blain, 2013). Seeking help from the health services can be seen as disrespectful to the afflicted person’s autonomy, as a failure to fulfill familial responsibility or it may be avoided due to the shame and stigma associated with dementia (Mukadam et al., 2011).

However, several systematic reviews of empirical research findings underline that the most important barrier to identify dementia as a medical condition and to seek help is the perception of memory loss as a part of a normal process of aging (Botsford et al., 2011; Mukadam et al., 2011). Studies show that many relatives do not see why they should go to a doctor even if they do interpret symptoms of cognitive impairment as corresponding to a medical condition. This is because they believe that it is a normal process, that there is no treatment, and consequently that it is a waste of time (Morhardt et al., 2010).

Studies that have compared minority groups with the majority population in a variety of contexts, conclude that there is a tendency of a lower level of biomedically oriented awareness of dementia (as a neurological disorder) among ethnic-minority

groups, and consequently the stigma tends to be correspondingly higher (Moriarty et al., 2011). It is, however, important to be aware of factors such as socio-economic status and level of education (health literacy) and how these factors may influence people's health-seeking behaviors and "choice" of support and treatment. Review studies have noted less use of formal services by ethnic-minority caregivers (McClearly & Blain, 2013), and not only beliefs about or interpretations of dementia but also experiences with the health-care system represent barriers to treatment and care. Relatives have reported language barriers as one such concern in a variety of contexts where they are a minority (Mukadam et al., 2011; McClearly & Blain, 2013). Several studies from different contexts show that lack of awareness of services, barriers accessing them (direct or indirect costs, health literacy), and hesitancy to use services that are regarded as culturally inappropriate are often-cited reasons for underutilization (McClearly & Blain, 2013). One example of this is a study portraying Chinese caregivers' pathway to seeking help. They moved outside their own community to avoid "disclosure" of the stigmatized condition, but when faced with Western "professional objectivity," they felt a profound conflict with the core Chinese value of *guanxi* (the importance of developing a personal and trusting relationship between the doctor and the patient) (Mahoney et al., 2005). Several studies have noted that the Western values of patient autonomy and direct disclosure of a serious illness conflicts with the "protect-the-patient approach" exhibited in particular in studies from countries in Asia (Mahoney et al., 2005).

Structural barriers to care, such as economic constraints and concerns about immigration status, have mainly been cited in studies from the USA (Mukadam et al., 2011). However, an often-cited review study underlines that relatives with an ethnic-minority background may feel wary of using health-care services due to previous experiences of discrimination or racism (Mukadam et al., 2011). Uncertainty of how to access help and lack of clarity about the referral pathway are other cited reasons for underutilization of health services. There are also a number of studies reporting that relatives with an ethnic-minority background have experienced health-care professionals being dismissive of symptoms of cognitive impairment (Mukadam et al., 2011). One study from Boston found that also Chinese-speaking doctors attributed symptoms of cognitive impairment to normal aging and considered tests or specialist referrals to be unnecessary. Further, elderly Chinese patients were found to show their respect concerning their doctors' decision through "deferential silence" (Sun et al., 2012).

Other studies from other parts of the world have also suggested that people with dementia have been delayed in diagnosis due to what can be described as a culturally based or traditional reluctance to question the authority of the doctor (Mukadam et al., 2011). These findings are important in the sense that they create awareness of the fact that health personnel too may lack awareness of symptoms of dementia, and even adhere, or partly adhere, to folk-inspired explanatory models.

## Perceptions and Experiences of Dementia and Impact on Caregiving

Given the increasing ethno-cultural diversity among elderly adult populations, it seems important to understand how not only cultural values and traditions but also migration processes and socio-economic positions affect family caregiving. Some studies suggest that the meaning and consequently patterns of family caregiving are largely ethno-culturally based (McClearly & Blain, 2013). Other studies suggest that the factors are complex and that lack of awareness of services, barriers related to availability and accessibility, stigma, language barriers, and culturally inappropriate services are all important reasons for there being a tendency that ethnic minorities use formal health-care services in dementia care to a lesser extent (McClearly & Blain, 2013).

The most commonly examined aspects of cultural values and traditions are those of *familism* and *filial responsibility* or *filial piety* (McClearly & Blain, 2013). The concept of familism refers to a strong identification and solidarity with family members, both nuclear and extended. It involves strong normative feelings of dedication, attachment, responsibility, and reciprocity, and the concept is interpreted as a value contradicting the Western value of individualism (MacKenzie, 2006). In a review of cross-cultural comparisons of familism among families caring for people with dementia, the lowest levels of familism were found among white American samples, followed by African American, Japanese American, Korean American, Latino American and Korean samples (Knight et al., 2002).

Another relevant concept is that of filial piety, a fundamental value in Confucian (Chinese) ethics implying respect for parents and for elderly people and placing the families' needs over the individuals' needs. Filial piety is a key value in Asian cultures, but similar ethical values and norms are parts of many other cultures and religions (McClearly & Blain, 2013). In Western-oriented cultures, the concept of filial piety includes reverence for parents, feelings of gratitude and a wish to repay a debt to parents, and expression of friendship, love, and closeness to parents through care (McClearly & Blain, 2013). A meta-analysis of caregiving among different ethnic groups found filial piety to be more prominent among ethnic-minority groups (Pinquart & Sorensen, 2005).

In a review based on eight articles from different ethnic-minority communities in the UK, it was found that many participants viewed caring for their relative with dementia as a normal part of their life. Relatives often did not refer to themselves as "carers" but rather as persons fulfilling a natural and extended role in the family (Johl et al., 2014). In one of the reviewed studies, where experiences of white, Afro-Caribbean and South Asian carers were compared, caregivers with South Asian origin were those most likely to explain caring for their parents as part of a cultural norm and as a

possibility to reciprocate parental care. White British caregivers in this particular study (Lawrence et al., 2008) did not give these types of accounts. Caregivers holding what was termed “traditional caregiver ideologies” tended to see caring as something natural, virtuous, and expected, and holding strong religious beliefs seemed to strengthen this idea (Johl et al., 2014). In a systematic review of religion and dementia-care pathways, it was found that religion hindered access to biomedical health-care pathways since external religious institutions and its members tended to isolate the caregiver and the person cared for. The internal faith, on the other hand, seemed to be a positive contributor in accepting, reflecting on, and coping with the situation (Regan et al., 2013).

However, even though people represent other cultures—with associated values and norms—migration may affect both family structures and care-giving norms. Jutlla (2010), an influential author in this area, argues that migration influences people’s role as caregivers, and she describes migration as a “repositioning of existence.” Her study of the Sikh population in the UK suggests that caring for a family member with dementia creates a further upheaval in family life, as members face contradictions between new roles and responsibilities in the new country and older expectations of family roles and family support. Consequently, new roles and positions are formed in the meeting between the new culture and the often-held narratives of how the roles and the support would have been “back home.” When analyzing these narratives, Jutlla (2010) describes them as “idealized descriptions” of situations and perceptions pre and post migration; people tend to idealize their home countries with regard to the family network and support one would have received both through the extended family and through the community. Other studies on transnational migrants indicate that representatives of this group have many conflicting desires, often juxtaposing the advantages and disadvantages of living in the country they are in at the moment with the advantages and disadvantages of living in their country of origin (Jutlla, 2013).

In Jutlla’s own work she found that the feelings of ambivalence became even stronger when the family member was affected by dementia and in need of extensive care. This situation caused migrants to even further idealize the social-support network they used to have or still have in their home country (Jutlla, 2010). However, since many respondents also noted that community support in their home societies was becoming more fragile and that there was a lack of formal, biomedically oriented health services, most migrants accepted that (in this case) the UK was the best place to be.

Jutlla (2013) also underlines how gender and identity roles may change due to migration. In one of her studies, she shares a particularly interesting finding when it comes to men and their role as caregivers (Jutlla, 2010). Since most of the men in the study population had lived in the UK for some time before being reunited with their families, they had acquired a variety of domestic skills to be able to live

independently. These skills were highly transferable and useful when providing care for spouses not being able to care for themselves due to dementia. These findings may be transferable to many other migrant groups and represent a window of opportunity when planning care for people with dementia. However, in another review study, Jutlla underlines that cultural norms about gendered roles and traditions in general seem strengthened due to migration (Jutlla, 2013).

Further, other studies have documented that “felt obligation,” a theoretical concept similar to filial piety and defined as “expectations of appropriate behavior that are perceived within the context of specific personal relationships with kin across the life course,” is stronger among women than among men (Harper & Levin, 2005, p. 162). Decisions about who should take up the burden of caring for elderly people are still often made in accordance with a hierarchy of obligation, running from the (female) spouse being the first choice and the daughter being the second choice (Harper & Levin, 2005; Jutlla, 2013). Women in particular may feel trapped and powerless due to the gendered roles and expectations in their respective communities (Jutlla, 2013). For example, those who have migrated for social reasons may find it difficult to get help from formal or informal networks on the outside, having spent much of their time at home after migration (Jutlla, 2011).

In addition to a potential change in gender and generational roles, social capital in the sense of class identity both before and after migration can represent an advantage or disadvantage in negotiating formal support to provide the best possible care for the family member (Jutlla, 2013). Those who have migrated with a middle-class background clearly have the advantage of being educated as well as having English skills. The same relates to those who have been able to find work or educate themselves after the migration process. Those with a middle-class background or with the above-mentioned skills are found to be better able to access services and receive adjusted help than those who for example migrated for social reasons (Jutlla 2013).

Different studies point to the importance of knowing people’s routes of migration and the reason that people migrated because such reasons will influence the availability of both socio-economic and cultural resources in the process of achieving care for the one affected with dementia (Jutlla 2011, 2013). People who migrate due to employment or educational reasons will have a very different migration history from those who migrate due to social reasons, such as family reunification or arranged marriage, and those who escape from war.

## **Changing Family Structures and Roles and the Influence on Caregiving**

Changing demographics is another factor influencing families and their ability to provide care. The shift from a high-mortality/high-fertility society to a low-

mortality/low-fertility society causes an increase in the number of living generations and a decrease in the number of relatives that live together with their extended-family members (Harper & Levin, 2005).

Within the Western world in particular, we see former extended-family structures being replaced by long, vertical, multigenerational families. Delayed family transitions, such as delayed birth of first child, may also lead to long intergenerational spacings and a delayed transition to both parenthood and grandparenthood. However, such changes in family structures, which are well documented (Harper & Levin, 2005), do not necessarily mean that the role of the family in supporting the elderly family members is less important. On the contrary, some longitudinal studies suggest that the role of the family is more important than ever but that there have emerged many new roles as well as competing demands attached to the roles for different family members in different settings (Harper & Levin, 2005).

Comprehensive European studies conducted approximately ten years ago (Harper & Levin, 2005) have underlined the multifaceted role of social and familial networks in caring for elderly people in general. These studies emphasize that the socio-cultural context of caregiving changes over time because the family structure and inter-family relationship change over time. As emphasized by Harper et al. (2005), static and stereotyped descriptions of ethnic-minority communities and their needs related to care ignore not only changes in family structures but also the vast diversity of attitudes and behaviors within these groups.

Further, structural influences, such as the fact that migrant families are often divided in the migration process, resulting in changes in the family structure and in the geographical location of kin, can make it difficult to provide “traditional” care for the extended family. Therefore, even though people representing ethnic-minority communities want to provide the type of care that ordinarily would have been provided through extended families or community network, they may have to make use of public services even though these may not seem desirable or appropriate.

As highlighted in a review study on dementia care, it is important to be aware that even though there are structural barriers or geographical distance between relatives, felt obligatory and reciprocal relationships may still exist between parents and children (Jutilla, 2013). Due to families becoming more fragmented and nuclear, the responsibility of care can be negotiated based on strengthened cultural norms (e.g., gender roles), or the negotiation can take new forms and be based on an assessment of each person’s position, geographical location, and skills. Either way, the pressure exerted on single individuals can be large, as these persons might feel obliged to conform to the traditional caregiver role but without the support from a wider extended family and in the context of other pressing duties (Jutilla, 2013).

In the Nordic countries, few elderly members from ethnic-minority groups live in care facilities (Plejert, 2014). A qualitative study from Sweden, exploring Iranian immigrant caregivers' experience of taking care of a family member with dementia, found that family members, especially married partners, would like to continue the care for their partner with dementia (Mazaheri et al., 2011). This corresponds to other studies (that do not focus on dementia in particular) from Scandinavia, that document that ethnic-minority families of the second and third generation often do want to play a full practical role in caring for and supporting the elderly family members (Harper & Levin, 2005; Thyli et al., 2014).

A qualitative study from Norway, which included 9 representatives aged 63–85 from Iran, Iraq, Vietnam, and Bosnia-Herzegovina, showed that elderly immigrants' expectations and experiences of care were strongly connected to social values in their native country and to expectations that the young generation would care for elderly family members. The most important issues when growing old in a foreign country was to be surrounded by and taken care of by one's own family, also when more extensive help was needed. Except for visiting the physician, all participants rejected any contact with the community health-care program. Feelings of fear and distrust towards unknown people, preference for the known and familiar, as well as language barriers were the most common reasons for old people's preferences for family-based care. Another finding was the acknowledgement by elderly immigrants of the considerable responsibility the young generation actually took in their care, a responsibility which made it difficult for the young to fully partake in society in the form of studying and working full time outside the home (Thyli et al., 2014). Even though this study does not focus on dementia in particular, it provides important information about the possible conflicting needs and expectations of new and old roles and of the older and the younger generation.

A review article on dementia care among ethnic minorities from the UK concludes that particularly adult daughters or daughters-in-law frequently combine extensive caring responsibilities with paid employment, even though they do not necessarily live close to the person affected with dementia (Moriarty, 2011). A recently published study on cognitive impairment/dementia in Norway shows that the centrality of what is seen as the "traditional family" has significant influence on how Norwegian-Pakistanis relate to the Norwegian health-care culture and on how signs and symptoms of cognitive impairment are interpreted and responded to (Næss & Moen, 2015). The study shows how Norwegian-Pakistani families "negotiate dementia" in the space between their own imported, culturally defined system of cure and care and the Norwegian health-care culture. This negotiation is characterized by an inclination to use public care and biomedical intervention. In other words, even though few elderly members from ethnic-minority groups live in care facilities today, minority groups that have stayed in Norway for several decades may gradually move towards more use of public services.

Either way, migration processes may lead to a number of conflicting roles and ambivalent choices. A number of studies actually suggest that caregivers holding a “traditional ideology” of care face less stress and less contradictory role expectations and have better coping mechanism when caring for people with dementia (Botsford et al., 2011; Dilworth-Anderson & Gibson, 2002; McClearly & Blain, 2013; Sun et al., 2012). The importance of family structures and values underlines that social and cultural contexts are fundamental in mediating understandings of dementia. As Næss and Moen argue (2015), this important fact “tends to be lost behind the individual-centered focus of biomedicine and psychiatry.”

However, it seems important to be aware that family structures and cultural traditions are constantly changing and pressure may be exerted from different and fluxed ideologies, in negotiation with highly individual realities (McClearly & Blain, 2013).

In order to fully understand the contribution and needs of family care within ethnic-minority communities, it seems important that one consider not only the availability of household and kin members but also the present understanding of obligation and reciprocity underlying the perception of care. It is also important to be aware that the role of family members does not have to be either—or. Rather, many relatives may *want to*—or *have to*—both play the role as a caring and participating relative and work and otherwise partake in Norwegian society. Consequently, health personnel should be wary of stereotyping and generalizing groups and rather try to understand and adjust to the present set of needs.

## Summary

The intention of this chapter has been to explore the variety of perceptions and understandings that prevails within different groups and in different contexts with regard to cognitive impairment/dementia. The chapter also aimed at providing insight into the challenges and experiences of people living with dementia and their caregivers.

Studies conclude that cognitive impairment, such as memory loss and slight disorientation, is often interpreted as a consequence of normal aging or of factors such as psychological stress, family problems, the immigration experience, or more spiritual factors such as God’s will, “fate,” or karmic retribution. Some also relate cognitive changes to medication or physical illness or see cognitive impairment more holistically as a general condition characterized by lack of care and isolation.

Research emphasizes that to understand people with dementia and their health-seeking behavior, we therefore need to get an overview that includes personality, biography, general health, and the socio-cultural circumstances surrounding the

person. Families and individuals that believe that dementia has a psychological, social, or spiritual origin may not see the relevance of seeking help within the frames of a (bio)medical model and/or delay seeking help due to associated stigma. Similarly, those who believe that dementia is caused by a physical illness will most likely seek help for what they consider the underlying condition and not for the cognitive impairment.

Research does underline, however, that factors such as socio-economic status, level of education, and experiences with the health-care system may also influence people's health-seeking behaviors and "choice" of support and treatment. In other words, not only beliefs or interpretations about dementia but also structural barriers such as language difficulties, economic constraints, lack of awareness of services, barriers to accessing them, and hesitancy to use such services due to cultural inappropriateness or previous negative experiences may come into play.

Studies show that transnational migrants may have conflicting desires, often juxtaposing the advantages and disadvantages of living in the country they are in at the moment with the advantages and disadvantages of living in their country of origin. Research underlines the importance of being aware that family structures, cultural traditions, and gender roles are constantly changing and pressure may be exerted from different and fluxed ideologies, in negotiation with highly individual realities. In addition to a potential change in gender and generational roles, social capital in the sense of class identity both before and after migration can also represent an advantage or disadvantage in negotiating formal support to provide the best possible care for family members.

Static and stereotyped descriptions of ethnic-minority communities and their needs related to care ignore not only changes in family structures but also the vast diversity in attitudes and behaviors within these groups.

Since research is sparse on this topic in Scandinavia, this chapter has largely summarized research conducted in other European countries, as well as USA and Australia. Further, many studies on this particular topic are conducted in a variety of South Asian communities, and a disproportionate number of the studies reflect this particular population. Many of the studies presented are therefore from countries where the health-care systems are different from that of Norway, and where the composition of minority and migrant groups differs. Even though this chapter provides many clear patterns of cross-cultural and cross-textual similarities highly relevant to the Norwegian and Scandinavian setting, there is a need for more research from Scandinavia on this topic.

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# Chapter 7: Dementia-Care Services for Migrants and Ethnic Minorities

Ragnhild Storstein Spilker

## Introduction

Several factors could influence migrants' and ethnic minorities' access to and use of dementia-care services, and the aim of this chapter is to describe research findings when it comes to pathways to care and use of services as well as the way in which one could develop and adapt services to reduce barriers and improve equity.

In the following, findings mostly from review articles but also from some primary studies will be presented under different thematic categories identified in the included literature.

Eight review articles that all are concerned with ethnic minorities and dementia-care services are included together with several primary studies. The articles concentrate on different parts and aspects of dementia care for ethnic minorities and migrants. This includes disparities in access to and use of services, barriers and facilitators in care pathways, and service needs and service adaption. The articles differ when it comes to review methodology and they have all been published in international scientific journals concerned with aging, geriatrics, and mental health, except for two of the reviews, which have been published as research reports.

Most of studies included in these reviews have been conducted in the USA, and most of the other studies are from English-speaking countries, mostly the UK but also Australia and Canada. The minority-ethnic (ME) groups studied reflect primarily the ethnic composition of the USA but also the UK, Australia and Canada. Despite this and the fact that the health-care systems in these countries differ in various degree from Norwegian health care, there seem to be many common challenges for Western societies when it comes to developing and adapting dementia services, and consequently these research findings may also be relevant in a Norwegian context.

The terminology used on different groups of people and parts of health-care services reflects the one used in the review article or primary study discussed and will therefore differ throughout this chapter.

## Access to and Use of Services

Equitable health-care services is a pronounced health-policy aim both on supranational and national levels in Europe (Madlovsky, 2011) and is also formulated

in the health legislation in Norway (Lovdata, 2015). Elderly migrants and ethnic-minority groups are heterogeneous and diverse when it comes to important factors such as culture, education level, socio-economic conditions, health status, and migration trajectory, and these different factors can influence access and use of dementia-care services.

Cooper et al. (2010) carried out a systematic review and meta-analysis with the objective of comparing “the use of dementia treatment, care and research between different ethnic groups.” Thirty-three studies were included in their review, and twenty-nine of these were carried out in the United States, while two studies took place in Australia and two in the United Kingdom. Most of the studies from the US compared people of African American, Hispanic, and white non-Hispanic ethnicities, while the two studies from the UK compared people of white UK or white European background with people mainly of black Afro-Caribbean and South Asian origin. In the Australian studies, people from English-speaking backgrounds or those who were Australian born were compared with other ethnic groups, of which a majority were of Italian origin. The authors found consistent evidence that persons with an ethnic-minority background accessed diagnostic services at a later stage of dementia, and when diagnosed they were less likely to receive anti-dementia medication. They were less likely to be included in research trials and to access twenty-four-hour care in long-term-care (LTC) facilities (Cooper et al., 2010).

### **Dementia diagnostics and medication**

In their review, Cooper et al. (2010) found five studies examining access to dementia diagnostic and treatment services. The studies compared either the compositions of different ethnic groups attending memory clinics to the local population of older adults or the mean duration of memory loss or level of cognitive impairment in different groups at the time of accessing services. There were conflicting results in the studies comparing the ethnic compositions of patients at memory clinics with the local population of older adults. However, they found good evidence that people of ethnic-minority background were more cognitively impaired than people with a majority background when accessing services. There was no overall significant difference in the duration of memory loss at diagnosis between different ethnic groups. However, in a sub analysis people with a Hispanic background reported experiencing memory loss for a longer period than white non-Hispanics, on average three months longer. According to the authors, the evidence suggested that the differences found were due to later presentation to services rather than differences in education or cultural bias of cognitive tests (Cooper et al., 2010).

Several studies also showed ethnic differences in both prescription and discontinuation of antidementia medication, and in a large national US sample taken from Alzheimer’s disease (AD) research centers, Medicare and Veterans Health Administration, black patients were only half as likely to be prescribed cholinesterase

inhibitors (drugs for treatment of Alzheimer's disease) as white non-Hispanic. When prescribed antimentia medication, black patients were less likely to be taking it six months later. The authors also found evidence that minority ethnic (ME) groups were underrepresented in Alzheimer's disease drug trials (Cooper et al., 2010).

A register-based study from Norway with the aim of describing and comparing the use of primary health care of older immigrants and that of ethnic Norwegians showed that immigrants above 66 years of age used primary health-care services less than Norwegians in the same age group (Diaz & Kumar, 2014). Data from the same registers showed that immigrants from other than high-income countries were significantly less likely to have a dementia diagnosis or declared memory impairment than Norwegians. Among those with such a diagnosis, Norwegians purchased anti-dementia medication 20–50% more often than immigrants did (Diaz et al., 2015). A register-based study from Denmark, mapping dementia diagnosis, found that there was a higher prevalence of dementia among immigrants younger than 60 and a markedly lower prevalence among immigrants older than 60, compared to the general population (Nielsen et al., 2010).

#### **Use of services in the community**

Cooper et al. (2010) found seven studies that compared service use among people with a dementia diagnosis from different ethnic groups. Three studies in the US concerning use of social services (e.g., use of support groups, information and referral programs, and adult day care) found no significant difference between ethnic groups after controlling for socio-economic factors and dementia severity. One study examining the use of in-home respite and adult day care in a US program designed to be adapted to the needs of ME groups, the Alzheimer's Disease Demonstration Grants to States Program (ADDGS), found that African American and Hispanic families used in-home respite more than white families. African American families also used adult day care more than white families. The differences remained after controlling for the caregiver's income and the degree of functional impairment of the person with dementia. According to Cooper et al. (2010), these results suggest that the tailored program was achieving its aim. This program (ADDGS) was characterized by its focus on outreach and educational activities, client advocacy, community commitment, and flexibility in implementation (Montgomery et al., 2002). Cooper et al. (2010) also found evidence that people with dementia of a ME background used more inpatient and emergency services than people of a non-ME background did (Cooper et al., 2010).

#### **Use of long-term-care facilities**

Cooper et al. (2010) identified twelve studies which looked at ethnicity as a predictor of entering a long-term-care (LTC) facility and found that people of a ME background with dementia were 40% less likely to be institutionalized. In the only non-US study,

from the UK, there was no significant difference in entering rates between ME and non-ME groups.

In a systematic review of *prediction of institutionalization in dementia*, the authors point to various demographic factors influencing institutionalization (Luppa et al., 2008). According to the authors, several studies have shown an increased risk of a shorter period until nursing-home placement (NHP) for older patients and caregivers, for unmarried (single, widowed, or divorced) patients, and for patients living alone. The studies from the US that focused on the ethnicity of patients found an extended period until NHP for African Americans and for Hispanics compared to white Americans. Differences in appraisal of dementia-related problem behavior was documented, with a less stressful appraisal observed in African American caregivers compared to white Americans. A possible explanation suggested is the existence of a cultural norm in the African American community regarding caregiving as an expected experience of adult life (Luppa et al., 2008).

In addition to sociodemographic factors influencing risk of institutionalization, there are patient-related risk factors; severity of cognitive decline and problem behavior, and caregiver-related risk factors; self-rated health, burden of caregiving, use of services and resources available (Scott et al., 1997). Community Long-Term Care (CLTC) can be an alternative to institutionalization for older people in need of extensive care and relieve caregivers of their burden. Scott et al. (1997) undertook a study to identify factors increasing risk of institutionalization among CLTC clients with dementia. The study included 786 clients, of which 492 were African American and 294 were white. 18 months later in a follow-up, only 8% of all the clients studied had entered a nursing home even though the study sample was highly impaired in IADL (instrumental activities of daily living) at baseline with a mean score of 11.5. The results showed that increased risk of institutionalization was associated with an increase in impairment of ADL (activities of daily living), with being cared for by a child or living alone, or being cared for by a non-relative. White clients were twice as likely as African American clients to be institutionalized. All clients in this study were Medicaid-eligible, and according to the authors, the ethnic differences were not likely due to socio-economic differences, but instead they point to cultural differences in nursing-home use (Scott et al., 1997).

In a US study of “racial differences in the prevalence of dementia among patients admitted to nursing homes,” Weintraub et al. (2000) found that the rate of dementia on admission to nursing homes was significantly higher among black residents (77%) than among white residents (57%). A possible explanation of this ethnic difference was suggested to be psychosocial factors operating differently in the two groups and influencing time of admission to a nursing home. According to the authors, both limited financial resources and greater psychosocial support might explain why cognitively impaired blacks are more likely to remain in the community than whites

are. Older whites are more likely to live with a spouse, while older blacks are less likely to live alone and more likely to live with children or extended family (Weintraub et al., 2000).

In another study of ethnicity and time to institutionalization of dementia patients (Mausbach et al., 2004), the objective was to compare the rates of institutionalization of dementia patients cared for by Latina and Caucasian female caregiver and to examine the caregivers' and care-recipients' characteristics that predicted institutionalization. 110 Latina and 154 Caucasian women participated in an intervention program designed to reduce caregiver stress. Over an eighteen-month period, the number of days between a baseline interview and institutionalization was measured. In addition, views on caregiving were measured by using a scale with nine statements about positive aspects of caregiving. Latina participants also completed an acculturation rating scale where they were asked several questions about how frequently they engaged in activities related to Latino or Anglo culture. The results showed that Latinas were significantly less likely to institutionalize their relatives with dementia, and according to the authors, further analysis revealed a relationship between a more positive view of caregiving and less acculturation, and delay in decision to institutionalize. Latina caregivers were significantly younger than Caucasian caregivers and were more likely to be married, and had less education (Mausbach et al., 2004).

Mold et al. (2005) undertook a review of the literature concerned with ME older adults in care homes. According to the authors, the increasing heterogeneity of the aging populations in Western countries highlights the necessity of offering services that meet diverse needs when it comes to language, culture, and religion. Twenty-eight scientific articles, and some grey literature like policy documents and other similar reports, were included. Sixteen of the studies was carried out in the US, three in Taiwan, three in China, two in Canada, and one in Australia. Three of the studies were from the UK and were presented under a specific *UK perspective* heading (Mold et al., 2005).

Studies from the US reported disparities in access to care homes among ME groups and pointed at differences in financial resources as an important explanation. In addition, there were differing views on provision of care within the family and differences in health status. Research also suggested variation in the distribution and resources of care homes serving different ME groups (Mold et al., 2005).

Mold et al. (2005) identified the following key themes: barriers to care provision, the promotion and maintenance of independence, and the challenge of meeting cultural needs. According to the authors, the recurring themes in all the literature reviewed were differences in access and admission to care homes among ME older persons and the impact of financial resources and views on caregiving on the perceived need and

use of services. The challenge of language barriers and the effects on communication and participation in decision-making and the importance of recognizing ethnic diversity and different religious as well as cultural and communicative needs were highlighted. The authors underlined the absence of statistics and a paucity of research on ME older persons in care homes in the UK. They also underlined that knowledge about where and who the ME elders are, what their needs are, how to meet these needs, and how to improve their quality of life is needed. Further, to gain insight into these issues, ME residents and employees in care homes must be involved through research methods that satisfactorily explore their views (Mold et al., 2005).

### **Ethnic differences in provisions of end-of-life care for people with dementia**

A systematic review of twenty studies (Connolly et al., 2012) examined the relationship between ethnic-minority status and the provision of end-of-life care for persons with dementia. The review had a focus on involvement in the care process and attitudes towards end-of-life care. All studies, nineteen quantitative and one qualitative, were carried out in the US, comparing African Americans, Hispanics, Asians and Pacific Islanders, and Americans Indian and Alaskan Natives with the white/Caucasian majority group. Nursing homes or long-term-care facilities (LTC) were the setting for eleven of the studies, three studies took place in hospitals, three in outpatient clinics and three in the wider community. Eight of the studies looked at use of and recommendations for artificial nutrition. Other studies covered other aspects of end-of-life care, like use of life-sustaining treatments, hospice enrolment, pain management, differences in end-of-life decision-making and advance-planning. Two studies investigated caregiver experiences (Connolly et al., 2012).

Several studies found higher rates of artificial nutrition in all ethnic-minority groups than in Caucasians. One study exploring physicians' recommendations for artificial nutrition found that African American and Asian physicians were more likely to recommend artificial nutrition for their patients than Caucasian physicians were. Use of artificial nutrition was also more likely to occur in nursing homes with a higher proportion of residents with an ethnic-minority background. Only one qualitative study attempted to explore differences in attitudes between African Americans and Caucasians towards artificial nutrition and the reasons behind the observed differences in use, but with inconclusive results. Connolly et al. (2012) conclude that the reasons for the higher rates of artificial nutrition in ethnic-minority groups, like patient and family attitudes and physicians' role, are not clear. One study also found that there were higher rates of other life-sustaining interventions in individuals with advanced dementia from ethnic-minority groups, such as blood transfusions, mechanical ventilation, and care in an intensive-care unit (Connolly et al., 2012).

Findings from three studies of hospice use showed conflicting results. In one study of nursing-home residents with advanced dementia, African Americans were more likely to be referred to hospice than Caucasian residents, while in a larger study of

individuals with both advanced and mild to moderate dementia, the use of hospice care was lower among African Americans than among whites. No differences were found for other ethnic groups, but data were limited (Connolly et al., 2012).

In a study of hypothetical decisions as caregivers of a relative with dementia, African American participants were more likely to initiate cardiopulmonary resuscitation (CPR) and artificial nutrition than Caucasians. In another study included in this same review, African American surrogates of nursing-home residents with dementia were more likely to have decided to provide intensive care (hospital admission, surgery) than white surrogates. African American and Hispanic nursing-home residents with severe dementia were also found to be less likely to have a “do-not-hospitalize-order” than Caucasian residents (Connolly et al., 2012).

There is evidence from the US of differences in end-of-life care for people with dementia when comparing ethnic-minority groups to Caucasians. The reason for this is however unknown, and whether the findings from the US are applicable to other multi-ethnic countries is questionable. According to Connolly et al. (2012), it is therefore a need both for research from other countries and for research that focuses on the underlying reasons for the observed differences: patient and caregiver attitudes, possible barriers within the health system, the role of physicians, and the way in which dementia is perceived (Connolly et al., 2012).

### **Determinants Influencing Access and Pathways to Care**

In a research briefing from the UK (Moriarty et al., 2011) on access to support and services for black and minority-ethnic (BME) people with dementia, the importance of early intervention and the potential for prevention is highlighted. According to the authors, there is a potential for reducing the risk of vascular disease and possibly vascular dementia in certain BME groups. The importance of access to memory assessment to receive a diagnosis and thereby get access to prescribed drug treatment and dementia-specific services is also emphasized. Moriarty et al. (2011) also points to the evidence that people of a BME background are less likely to receive a diagnosis and present to health-care services at a later stage of the disease. Lower levels of knowledge of dementia and the likelihood of seeing the condition as normal aging make raising awareness of dementia an important first step in making services more accessible for BME populations, according to the authors (Moriarty et al., 2011).

Boneham et al. (1997) found in their study of older people from ethnic minorities in Liverpool (UK) a low level of service use despite considerable unmet needs. Their findings represented the outcome of Phase II of the Health and Ethnicity Project (HEP) and included interviews with 71 ethnic-minority elders above 65 years of age who had been diagnosed as suffering from dementia or depression. Using Yeatts et al.’s typology (1992) “lack of knowledge” barriers and “lack of intent” barriers, they found

that respondents either did not know of existing services or perceived them as culturally inappropriate (Boneham et al., 1997).

Moriarty et al. (2011) also points in their research briefing at the possibility of black and minority-ethnic (BME) people not using services because of feelings that practitioners lack competence to cope with language and cultural differences. Another discouraging factor to service use can be practitioners' stereotyped views about BME people with dementia and particularly the role and extent of family support. Experiences of isolation in services where there is little ethnic diversity among service users and staff and few attempts to provide culturally sensitive care can lead BME people to refuse services (Moriarty et al., 2011).

Mukadam et al. (2010) conducted a systematic review of ethnicity and pathways to care in dementia with the objective of exploring why people from ME groups with dementia present later to specialist dementia services. They included both qualitative and quantitative research exploring pathways to care and determinants influencing access. Thirteen studies (ten qualitative and three quantitative) were included. Ten of these studies were conducted in the US and the remaining three in the UK. In the studies from the US, three studies looked at African Americans, four at Asian Americans, and two at Latino/Hispanic Americans; in addition, one study compared Chinese, blacks, and Anglo-Americans. Two of the British studies recruited participants of South Asian origin, and one study compared people of Black, Asian and white ethnic groups (Mukadam et al., 2010).

According to Mukadam et al. (2010), knowledge about dementia is a key to facilitating help seeking. Several factors influencing whether patients present to health-care services were identified in the included studies. In the following, only a short overview will be given as most of these factors are discussed in more detail in chapter 6.

### **Perception and recognition of dementia and associated symptoms**

Studies included by Mukadam et al. (2010) show that people of ME background recognized dementia symptoms but did not conceptualize these as illness, believing that cognitive decline was part of normal aging. Other studies showed that, for many, dementia was not a familiar term and not connected with symptoms observed in the families. The studies also reported many other explanations of cognitive decline, like spiritual, psychological, physiological, and social. How dementia symptoms are recognized will influence help-seeking behavior, and when one perceives dementia as part of normal aging or attributes it to psychological, spiritual, and social factors, medical help may not be sought. If dementia is understood as a consequence of physical illness, such as diabetes, help will be sought for the underlying condition but not for the symptoms of dementia itself (Mukadam et al., 2010).

Apart from normalization of symptoms and a perception that there is nothing that can be done, the included studies also showed that denial of problems and adaptation to changing situations can prevent people from seeking help. The likelihood of seeking help can also be influenced by the shame and stigma associated with mental illness and dementia symptoms as well as expectations of caring as a personal and/or familial responsibility and a belief that involvement of health-care services is a violation of a person's autonomy (Mukadam et al., 2010).

Some of the studies looked at the stage of dementia when one accessed services together with the reasons for presentation. There was a wide range of symptoms that could lead to active help seeking, from early symptoms like forgetfulness to later neuropsychiatric symptoms such as wandering, aggression, and paranoia. In the studies reviewed, ME carers were more likely to seek help at a time of acute crisis or when they could no longer cope with the situation (Mukadam et al., 2010).

### **Religion as a determinant for access to services**

In a systematic review of religion and dementia-care pathways in black and minority-ethnic populations (Regan et al., 2013), findings from two US studies indicate that religion might influence use of dementia care in two different ways: religion may hinder access to health-care services, and religion may assist in positive coping. Religious obligations and fear of culturally insensitive practices in provision of care can prevent use of services. When a decision is made to use services, there is evidence of prior consultation with religious institutions. Strength of faith has shown to correlate negatively with use of in-home services, which can suggest that religious beliefs and prayer reduce stress levels and the need for formal support (Regan et al., 2013). This relationship should however be treated with caution because attending services takes up time and provides community links that can support in caregiving. Collaborations between health-care providers and religious institutions can aid in information dissemination, improve referral, and relieve caregiver burden according to this review (Regan et al., 2013).

### **Experiences with and views on the health-care services**

Experiences with and views on the health-care services can also influence help seeking. According to Mukadam et al. (2010), studies show that people with ME background are often uncertain of how to access services. Language barriers is one main concern, but lack of information from health-care providers about referral and pathways of care is also mentioned by participants. Participants in several studies also pointed to negative encounters with health-care providers, who were dismissive of symptoms, and experiences of discrimination and racism from health professionals. In a study from the US exploring perceived needs of African American caregivers of elders with dementia, respondents expressed frustration with health-care and service providers and shared experiences with rudeness from employees and perceptions of

covert racism (Lampley-Dallas et al., 2001). Such experiences can be a potential barrier to seeking help (Mukadam 2010).

In the US, the Institute of Medicine (IOM) was asked by Congress to assess the extent of racial and ethnic differences in the quality of health care received by patients. They concluded that “racial and ethnic disparities in health care exists even when insurance status, income, age, and severity of conditions are comparable” and that “bias, stereotyping, prejudice, and clinical uncertainty on the part of health care providers may contribute to racial and ethnic disparities in health care” (Nelson 2002).

Blanchard and Lurie (2004) found in their nationwide (US) survey of 6,722 adults that a significantly higher proportion of minorities (blacks, Hispanics, Asians) reported having been treated unfairly and with disrespect in the patient-provider relationship compared with whites. Persons who did not have English as their first language were also more likely to report being treated with disrespect. These negative perceptions influenced health-care utilization, and these respondents were significantly less likely to receive optimal care and more likely to report not following the doctor’s advice or putting off needed care (Blanchard & Lurie, 2004).

### **Service Needs, Service Provision, and Models of Good Practice**

Daker-White et al. (2002) undertook an extensive review of literature describing service needs, service provision, and models of good practice concerning ME groups in dementia care. Service needs of ME groups might be unidentified and therefore unmet and a reason for underutilization. In the literature reviewed, Daker-White et al. (2002) found different factors influencing use of services. As also pointed out by Mukadam et al. (2010), lack of knowledge about dementia, differing perceptions of signs and symptoms, stigma and negative experiences, and reluctance to use services could be reasons for underutilization. According to Daker-White et al. (2002), there can also be other more pressing concerns than prioritizing dementia as a health problem among some ME groups, like underemployment, poverty, and inadequate housing. Language barriers during the diagnostic process and overall service delivery is particularly highlighted as a challenge in meeting the service needs of ME groups. In addition, comes the specific challenges when using instruments to assess cognitive function in people who do not speak the majority language (Daker-White et al., 2002). This topic is further elaborated in chapter 5.

### **Adaption of services**

When it comes to special adaption of services to better meet the needs of ME groups, most of the literature reviewed by Daker-White et al. (2002) do not address the question, and there are differing views and perspectives in those few articles which do. In a study from the UK of Afro-Caribbean carers, the respondents were not expecting or demanding specially adapted services. However, staff and services that

could meet needs in terms of diet, gender of carers, and hair and skin care were important for good-quality care (Adamson, 1999).

Research from the US suggest that matching clients with staff based on ethnicity and language improved patient outcomes. Braun and Browne (1998) put forward three possible approaches to increasing service attractiveness in their article on “perceptions of dementia, caregiving and help seeking among Asian and Pacific Islander Americans” (API). One approach is to develop parallel services specifically for the target group, where outreach, education, and diagnostic and treatment services are offered in the same language and cultural context and by providers of the same ethnic background as the group served. This might be very effective for some groups but also very costly. A second approach is adding bilingual health-care workers to mainstream services, and this should be facilitated by policies supporting individuals from ME groups in pursuing degrees in health and social welfare. The third approach is training workers in mainstream services in cultural awareness and sensitivity (Braun & Browne, 1998). According to Daker-White et al. (2002), some ME groups express concerns for being marginalized and do not want separate services, while other groups do.

According to Moriarty et al. (2011), it has been suggested that different ethnic groups have different opinions on whether they prefer culturally specific or “mixed” dementia services. It was, however, important also for those preferring “mixed” services that care was culturally acceptable in the form of food and activities and had an atmosphere where people could feel at home. Moriarty et al. (2011) mention that many practitioners feel they need more training to support BME people with dementia—they need to improve their own knowledge both about dementia and about different cultural and religious practices among BME groups. Access to such training is however variable (Moriarty et al., 2011).

### **Approaches to good practices**

To mitigate the problem of ME groups being under-represented in dementia services, Daker-White et al. (2002), based on their review, suggest different approaches to good practices. Services that reach out to people are important, and the authors highlight some strategies to be successful in outreach work. Firstly, there must be support and involvement of service leaders and managers so they can secure sufficient funding and staff resources. Secondly, information materials and diagnostic tools for the target groups must be developed and available. Thirdly, there should be employment of ethnic-minority staff across services but only as one part of an overall strategy. All dementia staff in all services should get cultural-awareness and sensitivity training to meet the needs of patients and families from diverse cultural background. It is also suggested that some interpreters get special training in assessment of cognitive function. Finally, services should be adapted to the local conditions and communities (Daker-White et al., 2002).

One key article referred to in Daker-White et al.'s review (2002) was "Strategies for increasing participation of ethnic minorities in Alzheimer's disease diagnostic centers: A multifaceted approach in California" (Hart et al., 1996). In California, nine Alzheimer's Disease Diagnostic and Treatment Centers (ADDTCs), founded by the California Department of Health Services (DHS), faced the challenge of identifying and reaching specific minority populations. The DHS therefore established an *Outreach Committee* with at least one representative from each center. The main tasks of the committee were to coordinate and develop outreach policies and activities for the ADDTCs, and all different outreach efforts were reviewed and discussed by the committee.

According to the authors (Hart et al., 1996), the establishment and the activities of this committee were essential in three different ways. Initially, the focus of the committee on the fact that the percentage of minorities enrolled at the ADDTCs was not adding up to their representation in the population was important. Secondly, by identifying shared challenges in developing and conducting outreach and prioritizing matters and making recommendations, the committee had an influence on a structural policy level in the statewide program. Finally, committee members were in key positions at their centers to direct and influence outreach activities and could provide motivation and support to individual programs (Hart et al., 1996). Apart from the importance of leadership support, commitment of time and effort, and specific and sufficient funding, the Outreach Committee identified hiring of qualified bilingual/bicultural staff as a key element to success. They were perceived as "important cultural liaisons," and access to communication pathways may be much harder to pin down without the additional knowledge of minority-ethnic staff members (Hart et al., 1996).

Jutlla (2013) highlights some key points for practices in her research review from the UK on ethnicity and cultural diversity in dementia care. She warns about making assumptions based on generalized and stereotyped views from existing research on black and minority-ethnic (BME) communities. There are differences both between and within groups and individuals, and according to Jutlla, health-care workers should practice a person-centered approach in dementia care of BME people recognizing the diversity between and within groups. Cultural competency, according to the author, refers to a comprehension of such diversity and is characterized by a value-based perspective that acknowledges individuality. Understanding the life histories, experiences of migration, culture and community norms, and their possible impact is crucial in aiding BME families to live well with dementia (Jutlla, 2013).

### **Addressing diversity in monocultural institutions**

According to the literature review conducted by Mold et al. (2005), good communication and quality in care homes are challenged when residents in a care home have diverse ethnic backgrounds. Several problems arise when older persons

with ethnic-minority background are institutionalized in a “monocultural” care home. The problems can concern foods served, language spoken, customs celebrated, social activities, and religious practices (Jones & Jones, 1986). According to the authors, institutions need to consider how to provide the best possible care to all residents regardless of background. Jones and Jones (1986) suggest different approaches to improving communication and quality of care, like recruitment of a diverse workforce, development of translation services, and offering residents “culture-specific activities” in collaboration with voluntary organizations. In addition, both in-service training of staff and improved curricula in nursing schools is necessary (Jones & Jones, 1986).

Studies show that for people to preserve a sense of identity and to adjust to the new life situation when entering a care home, support from family and relatives is crucial and important for the experience of quality of life (Mold et al., 2005). A nursing-home placement can be a dramatic and stressful change in a person’s life. According to a study of Chinese older people in Hong Kong (Lee et al., 2002), adjusting to nursing-home life can be seen as a process with different stages towards regaining some form of normality in a new life. This involves regaining routines and relationships within the limitations of nursing-home living. Nursing homes should assist the residents in maintaining patterns of their former everyday living and meet their sociocultural needs. The adoption of a biographical approach to needs assessment and care planning is suggested to be done through a shift from the institutional focus on care practice to a more flexible practice directed at the distinct and individual life stories of the residents (Lee et al., 2002).

All older persons entering a long-term-care facility face considerable changes in their lives which can create great stress and which require significant adjustment and coping (MacLean & Bonar, 1986). In their article on ethnic older people in long-term-care facilities, MacLean and Bonar (1986) suggest that the support of everyone who is involved in this process is important—the person’s family, community or friends and relatives, and staff and administration in the institution. When entering a long-term-care facility, this support is even more critical for a person of ethnic-minority background, according to MacLean and Bonar (1986). Ethnic-minority older people face, as members of a minority group, additional challenges when adjusting to institutional living in the dominant culture. These challenges can be related to a feeling both of loss of family, loss of culture, and loss of community (MacLean & Bonar, 1986).

Many ethnic older people are living within extended-family networks, and the families will often provide for older persons’ need for care (MacLean & Bonar, 1986). However, economic and social pressure in many Western countries influence the families’ abilities to take care of older family members. If the need for care exceeds the resources of the family, the ethnic older person may be placed in a long-term-care

facility. Since institutionalizing older family members in many ethnic groups is not common, the person may have to cope with considerable feelings of shame, disrespect, and dishonor in addition to the normal feelings of anxiety when entering a long-term-care facility (MacLean & Bonar, 1986).

When entering an institution of a dominant culture, older people with a different ethnic background are likely to experience a loss of culture. Their daily existence is probably more than at any time before organized in and by representatives of another culture. Food and drinks may not be familiar; in addition, comes a potential loss of music, literature, and folklore that can contribute to a great sense of isolation for the older person. Another major cultural loss is that of not being able to communicate in the mother tongue. The communication with staff may be limited, and misunderstandings, misinterpretations, and inability to communicate in their own language may cause older persons to become more passive and dependent, with deteriorating physical and mental health as a consequence (Maclean & Bonar, 1986).

Ethnic-minority older people moving to an institution also suffer a loss of community. For ethnic-minority older persons there are many advantages of belonging to a specific ethnic community, like interaction and support. This is often lost when entering another community, an institution of the dominant culture. In this new setting, there are different rules and behaviors, and opportunities of being together with people with a common cultural background are few (MacLean & Bonar, 1986).

MacLean and Bonar (1986) point at implications for both practice and education. Voluntary organizations and volunteers can play an important role in supporting residents' identity, sense of community, and quality of life. According to the authors, care institutions should engage with different ethnic groups to recruit volunteers, both young and adults. They can provide valuable contact and communication to ethnic-minority residents and can be important collaborators when adapting the care services and arranging special events and celebrations. There is also a need for educational content for staff on how to improve the quality of life of ethnic-minority older people in long-term-care facilities (MacLean & Bonar, 1986).

### **A multicultural workforce**

In recent years, there has been an increasing demand for personnel in health and care services in Norway. International recruitment of nurses and doctors has been one way to meet this challenge. Another solution has been to recruit and qualify immigrants already living in Norway to work in nursing homes and home-care services (Seeberg, 2012). Today 34,400, or 9%, of those who work as health and care personnel in Norway are foreign born, and this number increased by 7,5% from the year 2013 to 2014 (Statistics Norway, 2015).

In the reviewed literature on care homes, Mold et al. (2005) found another important theme, which was ethnic-minority staff's experiences of racism from residents, their families, and colleagues. This could be in the form of harassment and inappropriate language use, a type of racism especially affecting unqualified workers. In the US, many nursing homes are complex multicultural institutions with predominately white residents and a heterogeneous staff of minority workers, both US- and foreign-born. Cultural diversity in a care home can create ethnocentric attitudes if this diversity is seen as something negative and not as a strength (Clermont et al., 1993).

In a study from the US (Berdes & Eckert, 2001) exploring the effects of racial and ethnic differences between residents and nurse's aides in nursing homes, three-quarters of the interviewed nurse's aides had experienced racism. Most common was the experience of racism from residents, but several respondents also reported experiences of racism from fellow staff and from residents' relatives. The incidents of racism were not frequent but happened occasionally, and a few respondents reported that it made them stressful. However, many stated that racism was worse inside the institution than in their life on the outside. The experience of racism from residents was different from that of family or staff. Racism from residents was often more overt, but of an "anachronistic" form using words and language no longer acceptable, or the comments were made by residents judged to be mentally impaired. Racism experienced from residents' families or other staff was subtler and bothered the respondents more. According to the authors, these findings warrant investigation of race relations in nursing homes and strategies for tackling racism (Berdes & Eckert, 2001).

## Summary

The aim of this chapter has been to provide an overview of research concerned with migrants' and ethnic minorities' access to and use of dementia-care services, and to provide insight into how to develop and adapt services in order to reduce barriers and improve equity.

There is research evidence of ethnic differences in use of dementia-care services. Ethnic minorities have delayed access to diagnostic services, less prescription and use of anti-dementia medication, and less likelihood of entering a long-term-care facility. Contrasts in provision of end-of-life care have also been found. Several possible factors contributing to these disparities are suggested in the reviewed literature. Some studies point at cultural differences regarding caregiving and family network. Other identified factors influencing access to and use of dementia-care services are knowledge, perception and recognition of dementia and associated symptoms, negative experiences with health-care services, language barriers, and ability to use services. More pressing concerns in life, like underemployment, poverty and housing, can make accessing services difficult. It is also pointed out in the literature that

service needs of several ME groups are unidentified and therefore unmet and could represent another explanation for underutilization of services.

There is a paucity of research on how to develop and adapt the services to meet the needs of older people with ME background. Several approaches are however discussed: offering special services adapted to language and culture, adding bilingual staff to mainstream services, and training workers in mainstream services in cultural awareness and sensitivity. Outreach work is particularly highlighted as important, and special strategies for succeeding in increasing use of services in minority groups are put forward. A key to success seems to be employment of bilingual/bicultural staff.

A special review of literature concerned with minority-ethnic elderly people in care homes underlined how good communication and good quality of care are challenged when residents have diverse ethnic backgrounds in a “monocultural” care home. Ethnic-minority older people face additional challenges when adjusting to institutional living in the dominant culture. To improve communication and quality of care, it seems necessary that one provide both in-service training of staff and improve curricula in nursing schools and other health educations. One highlighted recommendation is to recruit a diverse workforce and collaborate with voluntary organizations and different ethnic groups. It is also important to acknowledge the possibility of ethnic-minority staff experiencing racism from residents and their families and from colleagues, and one should therefore be aware of race relations in nursing homes and develop strategies for tackling racism.

The importance of a shift from the institutional focus in care practice and the adoption of a biographical approach to needs assessment and care planning is emphasized. The research focusing on various aspects of ethnic differences in dementia care implies a danger of making stereotyped assumptions about ethnic-minority older people based on broad categories. There is diversity both between and within ethnic groups, and health professionals must acknowledge this diversity and should practice a person-centered approach and understand the life histories, migration experiences, and cultural and communal norms and their possible impact on individuals with dementia and their families.

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# Chapter 8: Tailoring of Information on Dementia for Migrants and Ethnic Minorities

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## Introduction

The aim of this chapter is to examine outreach-intervention methods and information materials that can be used to inform about dementia among elderly migrants and minorities and their families. To shed light on this matter, it is important to uncover the barriers to information about dementia and services available to the target populations. It is also important to shed light on how we can overcome these barriers and, furthermore, what methods and information materials are suitable to inform about dementia. These are important questions to answer to find out how dementia information messages and materials can be tailored to suit the needs of elderly migrants and minorities and their families in Norway.

This chapter explores different resources that describe suitable outreach intervention methods for migrants in general and elderly populations explicitly. These resources are qualitative and quantitative studies published in international scientific journals as well as reports and surveys. Most of the resources are from the United States (US), Australia (AU) and the United Kingdom (UK), with some resources from other European countries and Norway.

In the searches conducted, we found few articles focusing specifically on the tailoring of information-outreach strategies and materials to raise awareness of dementia among different migrant and minority groups. A systematic review of literature pertaining to the status of black, Asian, and minority ethnic communities and dementia in the UK supports the argument that there is limited research done on this subject matter, especially on how to overcome stigma, understand needs, and find relevant support initiatives (Truswell, 2014). Much of the literature within the field of gerontology concerning elderly migrants and minorities focuses on either cultural understandings of dementia, risk factors, epidemiology, diagnostics, or mental health, whereas within the field of patient education and counseling, there is a large body of literature documenting what methods and materials can be used to raise awareness of disease, treatments, and services among specific audiences. However, in this field, few studies have also focused on tailoring information to elderly migrants with dementia explicitly.

Understanding the needs of elderly migrants with dementia and their families is key prior to designing health messages and materials. Few studies have in general explored the link between knowledge, design, and content of health information.

Tailoring and availability of information is key to raising awareness of dementia and to facilitating help-seeking behavior at an early stage (Weih et al., 2008; Boughtwood et al., 2012). Early interventions can contribute to reducing costs related to late transfers to residential care and unscheduled admissions to hospitals for elderly migrants with dementia (Truswell, 2014).

Elderly migrants in Norway constitute a heterogeneous group representing 222 nationalities and are very different in terms of health status, educational level, migration background, and socio-economic living conditions (Statistisk Sentralbyrå, 2015). In Norway and worldwide, the number of elderly people with dementia, and elderly migrants with dementia, is increasing (Braun, Takamura, Forman, Sasaki, & Meininger, 1995; Jolley et al., 2009; Halpem & Crotty, 2011; Berkman, Sheridan, Donahue, Halpem, & Crotty, 2011; Boughtwood et al., 2012; Jutlla, 2013). Even though the studies included here represent sociopolitical and cultural contexts that are different from that of Norway, they are all from countries with a longer migration history than Norway. Hence, many of the studies can also be relevant in a Norwegian context.

Literature available on how to tailor dementia information to elderly migrants and minorities and their families is scarce. Much of the insight will be drawn from patient education and health-literacy studies. This literature looks at different barriers various groups in society can experience to accessing health-care services. It also looks at ways to make health information more understandable for the users of health-care services. In addition, reports documenting tools for tailoring health-information messages and materials and surveys examining elderly adults' literacy and digital skills in general will also be reviewed.

### **Health literacy skills**

To understand the significance of tailoring written health information to raise awareness of dementia and services available, it is important to understand the term "health literacy" (HL). A systematic review of seventeen different definitions of HL has synthesized these into one over-arching definition:

Health Literacy is linked to literacy and entails people's knowledge, motivation and competences to access, understand, appraise and apply health information in order to make judgments and take decisions in everyday life concerning healthcare, disease prevention and health promotion to maintain or improve quality of life during the life course. (Sørensen et al., 2012, p. 3)

This is the same definition as the one used by the World Health Organization (World Health Organization, 2013). HL is thus the ability to access, understand, appraise, and use health information and is influenced by the interaction between system factors and individual factors (Sørensen et al., 2012; Wizowski, Harper, & Hutchings, 2014). System factors are the health-care provider's communication skills, time pressure on health-care providers, accessibility and complexity of health information, the physical

setting of the interaction between patient and health-care providers, and system demands and expectations (Wizowski, Harper, & Hutchings, 2014). Individual factors are most commonly categorized into (1) functional HL, which is “the basic skills in reading and writing that are necessary to function effectively in everyday situations,” (2) interactive HL, which is “more advanced cognitive and literacy skills which, together with social skills, can be used to actively participate in everyday situations, extract information and derive meaning from different forms of communication, and apply this to changing circumstances,” and (3) critical HL, which is “more advanced cognitive skills, which together with social skills, can be applied to critically analyze information and use this to exert greater control over life events and situations.” This typology represents levels of knowledge and skills that can influence the degree of autonomy and personal empowerment in health-related decision-making (Sørensen et al., 2012, p. 4).

The main antecedents to HL are often divided into demographic, psychosocial, and cultural variables, as well as individual characteristics and general literacy (Sørensen, et al., 2012). Demographic and social variables can be socio-economic status, occupation, employment, income, social support, culture and language, environment, politics, and media. Peers and parents can for example be influential for adolescents. Individual characteristics are age, race, gender, language, and cultural background, as well as health abilities such as vision, hearing, verbal ability, memory and reasoning, physical ability, and social skills. General literacy refers to meta-cognitive skills such as reading, comprehension, and numeracy, which are related to the ability to understand written information materials in order to function in society (Sørensen, et al., 2012). Nutbeam argues that HL may also be a result of overall health promotion actions such as education, social mobilization, and advocacy (Nutbeam, 2000).

Low HL is often associated with overall poorer mental and physical health. In addition, low HL can be associated with chronic illnesses, poorer ability to interpret health messages and labels, more frequent hospitalizations, greater use of emergency care, lower receipt of mammography screening and influenza vaccines, poorer ability to demonstrate taking medications, and, among elderly persons, poorer overall health status and higher mortality rates (Berkman, Sheridan, Donahue, Halpem, & Crotty, 2011; Bostock & Steptoe, 2012; Wizowski, Harper, & Hutchings, 2014). Strengthening HL is increasingly recognized as a public health goal and a determinant of health (Sørensen et al., 2012; World Health Organization, 2013).

Limited HL is most common among adults over the age of 65, members of ethnic minorities, recent immigrants, adults who have low income or who are unemployed, people with low education, those with low proficiency in a national language, and people dependent on social support (World Health Organization, 2013; Wizowski, Harper, & Hutchings, 2014). Skills and competencies in HL are linked to lifelong learning and are contextual. This means that HL must be understood as those

competencies and skills a person needs to navigate the health-care environment in which he or she currently lives (Sørensen et al., 2012; Wizowski, Harper, & Hutchings, 2014). A person can have HL skills that are adequate to understand the need for a vaccine or a cold but may not have the skills to manage diabetes. This means that anyone can experience low HL at any given time in life (Wizowski, Harper, & Hutchings, 2014).

A person's HL may increase through interaction with peers or health-care workers and systems but may decrease due to a general decline in cognitive skills throughout life. Low HL can have particularly harmful consequences in old age because of the complexities related to managing chronic diseases and experiencing cognitive decline (Bostock & Steptoe, 2012). When one knows that low HL is also associated with being a member of a migrant and minority group, the combination of old age and a migrant background may require a parallel process of raising HL skills among elderly migrants in general while simultaneously tailoring health information suitable to their HL skills.

There are many dimensions of HL we need to understand in order to uncover which barriers elderly migrants and minorities and their families may experience to accessing dementia information. To limit the scope of this chapter, we will focus mainly on those relating to understanding written health information, often referred to as functional HL, and how health-care workers and systems can adapt to make information more accessible.

### **Communication, language, and reading skills**

If a person is to understand written health information, it is imperative that the author of the information consider the language and reading skills of that person and how those skills can influence the person's capacity to understand and interpret the information. Findings from a recent survey in Norway measured to what extent Norwegian adults understand written health information. The weakest health-related literacy was found in the oldest age group, among immigrants, in adults with low education, and among unemployed persons<sup>1</sup> (Gabrielsen & Lundetræ, 2014). 5,400 persons participated in the survey, and the researchers uncovered that 15% of the adult population who considered their health to be poor also had lower literacy skills than those who considered their health to be good (Gabrielsen & Lundetræ, 2014). The oldest group, those between 55 and 65 years of age, had the lowest HL, and the higher the educational level, the higher the HL level. Good HL skills are important for reading, understanding, and processing health information that can help maintain personal and family health as well as navigate complex health-care systems. The results of the study demonstrate that when preparing written health information, one must also adapt it to poor readers. The authors argue that written information should

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<sup>1</sup> This is in descending order.

preferably be complemented by verbal information and instructions (Gabrielsen & Lundetræ, 2014).

Low levels of HL have also been found among elderly adults in the UK (Bostock & Steptoe, 2012). 7,857 adults aged 52 or above participated in a longitudinal cohort study to see if low functional HL was associated with higher mortality rates. Researchers found that one third of the participants had difficulties reading and understanding basic health-related written information, and this was associated with higher mortality. Differences in age, socio-economic position, baseline health status, and health behaviors explained less than half of the increased risk. Low HL was a significant predictor of mortality, even after adjusting for measure of cognitive function (Bostock & Steptoe, 2012). The fact that the study was carried out in the UK and not in the US makes the results more applicable as the health system in the UK is more similar to that in Norway.<sup>2</sup> It is also the first study examining the association between HL and health outcomes in England among elderly adults. A weakness of the study is the potential for non-response bias, meaning that people with limited reading skills may try to hide this and not respond. In addition, elderly, non-white, less qualified adults were under-represented, so the prevalence of low HL is likely to be an underestimate (Bostock & Steptoe, 2012).

In line with Gabrielsen and Lundetræ (2014), Bostock and Steptoe (2012) contend that health-care personnel have a tendency to overestimate patients' reading abilities, which can lead to confusion and anxiety in the patients when they are given written health information. Suggested solutions to overcoming these challenges is for health-care personnel to complement written information with verbal information (Gabrielsen & Lundetræ, 2014). Use of visual aids and "teach-back" communication techniques<sup>3</sup> is also advisable (Bostock & Steptoe, 2012). Design of health information and messages, be they health campaigns, prescriptions, labels, or general information sheets, must take into consideration the poorest readers and adopt a simple and understandable language (Weih et al., 2008; Bostock & Steptoe, 2012; Gabrielsen & Lundetræ, 2014; Wizowski, Harper, & Hutchings, 2014).

Not only can low HL be associated with overall poorer health and increased mortality among elderly adults, but it may also increase the risk of dementia. A quantitative study from the US found that especially elderly migrants with low literacy skills have greater decline in memory, language, and executive functioning than those with high levels of literacy (Kaup, et al., 2013). This suggests that limited functional HL can be an important risk factor for dementia (Kaup, et al., 2013).

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<sup>2</sup> Healthcare in the United States is usually private, and patients must pay for services (Bostock & Steptoe, 2012).

<sup>3</sup> For a guide to how to use "teach-back" communication methods for health-care personnel, please visit: <http://www.ahrq.gov/sites/default/files/wysiwyg/professionals/quality-patient-safety/quality-resources/tools/literacy-toolkit/healthliteracytoolkit.pdf>.

2,458 black and white elderly persons aged 71–82 participated in an epidemiological study lasting 8 years, where their HL skills were tested using the REALM<sup>4</sup> scale. Over 23% of the participants had literacy levels below 9<sup>th</sup> grade, which is often insufficient to interpret written health-information materials commonly used (Doak, Doak, & Root, 1996). People with low HL were likely to be male and black, have less education, lower income, hypertension, and diabetes, be obese, smoke, and be APOEε4<sup>5</sup> carriers, and they were less likely to consume alcohol. The researchers also found that the lower HL levels a person had, the higher was his or her risk of dementia (Kaup, et al., 2013). Particularly among APOEε4 negative elderly people, limited literacy predicted the development of likely dementia, independent of other factors such as educational level and comorbidities like hypertension, myocardial infarction, diabetes, stroke, or transient ischemic attack. A weakness of the study is that socio-economic disadvantages early in life and lifelong learning disorders, which can be associated with low HL and are risk factors for dementia, were not controlled for. The authors still contend that low HL can predict the development of dementia, independent of education and comorbidities. Thus, low HL is an important public health concern and must be addressed (Kaup, et al., 2013).

Contrary to the study by Kaup et al. (2013), Nguyen and Reardon (2013) included different socio-economic variables to determine the effect of race and English proficiency on the health of elderly migrants. Through quantitative and survey methodology, Nguyen and Reardon (2013) explored the effect of race and English proficiency among elderly Latinos<sup>6</sup>, Asians<sup>7</sup>, and non-Hispanic whites<sup>8</sup> living in California. The results revealed that limited HL, and especially lack of English proficiency, had a negative effect on health (Nguyen & Reardon, 2013). 1,196 immigrants over 65 years of age participated in a survey in which they were asked about their health with the Health-Related Quality of Life (HRQOL) measurement developed by the Centers for Disease Control and Prevention (CDC). The HRQOL measures a person's perceived physical and mental health over time, thus identifying health disparities and providing insight into the burden of disease among subgroups of a population. It is especially useful in measuring the perceived health among elderly migrants as it takes into account their diverse and unique needs (Nguyen & Reardon, 2013). When examining the way in which HRQOL affected health, the researchers applied the Commission on Social Determinants of Health (CSDH) framework. CSDH synthesizes different social determinants of health, such as structural and intermediary determinants. These determinants are related to socio-economic and political environments, socio-economic position and class, as well as

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<sup>4</sup> REALM (Rapid Estimate of Adult Literacy in Medicine). REALM is an instrument used to measure a person's reading and understanding of common health-related words. Another similar test that is often used is the TOFHLA (Test of Functional Health Literacy in Adults).

<sup>5</sup> Apolipoprotein E genotype, which is a known risk factor for dementia. For more information, please see chapter 4 on epidemiology.

<sup>6</sup> 29,6% of the sample.

<sup>7</sup> 42,13% of the sample.

<sup>8</sup> 29,27% of the sample.

material circumstances and biological and psychosocial factors (Nguyen & Reardon, 2013).

Through regression analysis, researchers tested the effects of race/ethnicity and English proficiency. Health status varied among the different migrant groups, but migrants with a higher level of English proficiency reported better health. Limited English proficiency, as well as social discrimination, had profound effects on the health of the participants. Experiences of discrimination in medical settings may contribute to exacerbating existing health and psychosocial needs as well as affect health-seeking behavior, the latter resulting in not seeking help. Especially people with limited English skills, like those included in this study, were likely to face discrimination due to their limited language abilities (Nguyen & Reardon, 2013). However, the results from this study may not be representative outside the research location. This is because of the relatively low response rate, the inclusion of only Californian residents, as well the inability to draw longitudinal conclusions due to the use of cross-sectional data. Nonetheless, Nguyen and Reardon (2013) stress that health-promotion efforts for immigrants must have a multifaceted approach and address language barriers since limited language skills can affect health in many ways later in life.

### **Barriers to accessing information**

In the previous sections, different studies have found that low functional HL, i.e., the ability to read and understand written health information, can have a negative impact on health. Furthermore, limited reading and language skills can act as barriers to accessing, understanding, and assessing health-related information and consequently hamper the ability to make good decisions regarding one's own or one's family's health.

Whether oral or written, language used in health information should be largely based on "plain language" principles (Wizowski, Harper, & Hutchings, 2014). In Norway, plain language is defined as correct, clear and tailored language adjusted to the target group (Språkrådet, 2011). Norwegian plain-language policy contend that plain language promotes democracy, creates trust, saves public time and spendings, and promotes improved communication (Språkrådet, 2011). In the context of provision of dementia information and care, applying plain language can potentially make information about dementia and services easier to understand for elderly migrants and their families.

In recent years, gerontology have begun to focus its research on "cultural understandings" of dementia, looking at how beliefs, traditions, and stigma can act as barriers to access, similar to some of the studies reviewed from the UK and AU in this chapter. This is in line with findings from a Swedish study which has looked at the representation of elderly migrants in research and policy documents in Sweden

(Torres, 2015). Torres found that gerontology's often essentialist understanding of ethnicity has led to the establishment of an explanation model where barriers to access and difficulties elderly migrants experience in accessing services can be explained with culture (Torres, 2015). Research from health literacy and patient education and counseling can aid in moving away from barriers being understood merely as "cultural differences" or help clarify what concretely is meant by it.

Information about an illness and services available is crucial for the person concerned and his or her family, as it allows for planning ahead if the health situation should deteriorate. Elderly migrants and minorities with dementia, and their families, may lack information about dementia and services available. One primary study that has tried addressing these concerns has researched dementia-related information needs, access, and delivery issues among Arabic, Chinese, Italian and Spanish-speaking communities in south-western Sydney, Australia (Boughtwood, et al., 2012). The qualitative study consists of two parts, one part reviewing the literature available in Medline and Psych Info databases, the other collecting data through focus groups and interviews. 121 family carers, 24 bilingual and bicultural health workers<sup>9</sup>, 16 bilingual general practitioners (GPs) and 20 geriatricians participated in the study. Content and thematic analyses<sup>10</sup> were undertaken to uncover patterns and themes emerging from the responses (Boughtwood, et al., 2012).

Informants mentioned were four major barriers to accessing information: Firstly, elderly migrants and minorities, and their families, were often unaware of the concept of dementia and services available. Secondly, they were unable to use technology, which in turn hampered access to online information. Thirdly, they had low literacy levels and were unable to understand the English language. Lastly, information was often unattainable and scattered (Boughtwood, et al., 2012). These findings are also supported by different reports from the UK which have explored various strategies for raising awareness of dementia-related diseases among black and ethnic-minority (BME) elderly people (Jackson, 2008; Westminster Advocacy Service for Senior Residents/Dementia Advocacy Network, 2009; Cornelia, 2012; Jutlla, 2013).

Language skills, lack of knowledge about dementia and the health-care system, as well as stigma and shame are reasons people do not seek help. Furthermore, the content of dementia information, where it is offered, and the format of the information may not fit the needs of elderly migrants and families (Braun, Takamura, Forman, Sasaki, & Meininger, 1995; Mundt, Kaplan, & Greist, 2001; Houts, Doak, Doak, & Loscalzo, 2006; Valle, Yamada, & Matiella, 2006; Jackson, 2008; Weih et al.,

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<sup>9</sup> This is a generic term used to cover several positions in Australia's health and welfare sector. The aim of these positions is to increase access to services by people from culturally and linguistically diverse (CALD) communities. Bilingual/bicultural workers provide health education and promotion, community development, and information and support groups and to a limited extent carry out casework and provide counseling (Boughtwood, et al., 2012).

<sup>10</sup> The researchers transcribed the interviews and used the NVivo 7 software program to analyze the results.

2008; Jolley et al., 2009). A weakness in all of these studies is that elderly migrants at risk of dementia, or those who may already experience cognitive decline, have not been consulted about what their needs are. Their needs are assumed to be communicated by third parties such as family members, health professionals, or other community workers interacting with them. Although these parties may have a good grasp of their needs, the voices of elderly migrants themselves, with or without dementia, should also be taken into consideration. Findings from a recent study in Norway among different migrant and minority groups show that the need for information about dementia and services available vary greatly (Ingebretsen, Spilker, & Sagbakken, 2015). In each of the studies included here, researchers have tried addressing barriers by looking at different sources of information and methods that can be used to overcome them. The proposed measures to improve information outreach will be presented in the following sections.

## Sources of and Access to Information

A great variety of information sources and methods can be used to inform about dementia and services available. This section will first present written sources, followed by the Internet, telephone, audiovisual sources, mass media, community services, health-care institutions, and social networks as potential means of disseminating dementia information.

### Written health-information material

Elderly people with cognitive decline or mild dementia are likely to have low levels of education and reduced literacy skills (Weih, et al., 2008). This consequently reduces their ability to understand medical procedures and available treatments. Therefore, it is important that information given is clear and accessible (Weih et al., 2008). In a primary study, readability levels of written health information about dementia and related diseases given to patients and families were evaluated (Weih et al., 2008). By using the SMOG<sup>11</sup> readability index grade, the researchers assessed 118 brochures in both English (25) and German (93). The brochures were selected based on the following criteria: (1) they were freely available, (2) they were targeted at the general population, elderly people, and patients or their carers, (3) the medical content pertained to symptoms, diagnostic procedures, and treatment, and (4) the material was at least three standard pages in length.

The SMOG test revealed that 82% of the brochures had readability levels above 12<sup>th</sup> grade. The recommended readability level of written health material should not be higher than 5<sup>th</sup>–10<sup>th</sup> grade. Material at higher levels are unlikely to be understood or read at all (Weih et al., 2008). There was no difference in readability levels between material produced by private actors or others, and there was no difference in

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<sup>11</sup> Simple Measure of Gobbledygook (SMOG), derived from the Gunning's Fog Index, estimates the number of years of education required in order for a patient/person to understand a text passage (Weih et al. 2008, p. 1117).

readability between recent and older brochures. Shorter brochures, brochures in English, and those containing medical information were easier to read. Brochures in German and those addressing psychosocial-care issues were harder to read. The reason for the difference in readability level between English and German is suggested to be that German is more polysyllabic than English. This illustrates the methodological problem of comparisons between languages (Weih, et al., 2008). Sentences often surpassed 20 words, and only 25% of the brochures had a font size of 12 or more. Guidelines and recommendations for writing health information for patients and families with low health literacy and reading skills recommend sentences with less than 20 words, preferably less than 15, and font sizes above 12 (Doak, Doak, & Root, 1996; Wizowski, Harper, & Hutchings, 2014).

This study highlights the importance of ensuring that written health information for persons who are elderly, who may suffer from cognitive impairment, and their families must be easy to read. Readability levels of written material should always be tested and carefully designed prior to finalization. One of the shortcomings of the study is that they did not measure and account for pictures and illustrations used in the brochures they tested. Weih et al. (2008) admit that it is possible that the brochures scored lower because the SMOG index takes into account only written language.

Readability levels of written health information material is important, but using simple language may not always be sufficient for patients and families to understand a health message. A study from the US has looked at the role of pictures in health communication. In a systematic review of articles from peer-reviewed journals, the researchers selected studies from health education literature that compared written text alone with written text plus pictures. The findings pointed at a clear tendency that the effectiveness of health communication could be significantly improved by the inclusion of pictures in health education materials, especially for people with low HL (Houts, Doak, Doak, & Loscalzo, 2006). When pictures were used with spoken or written text, the attention to the health message was increased (in comparison to text alone), which helped patients remember the information better (Houts, Doak, Doak, & Loscalzo, 2006). Pictures can help people with low literacy skills to comprehend both spoken and written messages from health providers. The researchers emphasize that the pictures used must be culturally relevant for the target audience and should be chosen and developed with the involvement of the target audience (Houts, Doak, Doak, & Loscalzo, 2006).

### **The Internet**

A recent survey from the International Longevity Center (ILC) in the UK found that one in seven survey respondents over 65 years of age thinks it is difficult to find health information online (ILC-UK, 2015). For this group, health professionals are still considered the most trusted source of health information. ILC suggests that elderly

people may risk losing access to important health information if this information is only available online (ILC-UK, 2015). Barriers that may hamper access to the Internet for elderly people may be lack of access to PC, laptop, iPads/tablets, and Internet connections, costs for subscription and installation, physical disabilities, in combination with lack of interest and skills to use it (ILC-UK, 2011). A survey from Norway found that 90% of people with a migrant and minority background use Internet every day (Thoresen & Andersen, 2013). This is a high number, but the survey does not account for the age group. Furthermore, the respondents' Internet use was mainly related to using social media and reading news from their countries of origin and not navigating online health-information sources. We know little about the use of technology and Internet among elderly migrants in Norway. Findings from the UK showed that elderly people thought that online health information was neither relevant to their needs nor particularly user-friendly. The survey uncovered that the trust in and use of web-based health-information sources is stronger among younger people than among the elderly (ILC-UK, 2015).

Many of the experiences described above are similar to those expressed by participants in Boughtwood et al.'s (2012) study in Australia among culturally and linguistically diverse (CALD) communities. Those who used the Internet to access information about dementia tended to be younger and proficient in English. It was usually younger family members who found the information and passed it on to the older generations. A few participants used the Internet to clarify their thoughts before or while simultaneously consulting health professionals about a relative (Boughtwood, et al., 2012). Similar to the findings from the UK, the participants mentioned cost, illiteracy, and lack of familiarity with new technologies as barriers to accessing information online.

To bridge the "digital gap" between generations, it seems important that one explore alternative sources to online health information to raise awareness of dementia. The next section describes a pilot study using a toll-free telephone service for this purpose.

### **Telephone services**

Currently, information about dementia and Alzheimer's disease is increasingly made available online (ILC-UK, 2011; Boughtwood et al., 2012; ILC-UK, 2015). In a pilot study from the US, researchers wanted to find out if using an interactive voice-response (IVR) telephone system<sup>12</sup> could be an alternative source of online dementia information for elderly persons and their carers. Many elderly persons use their telephones comfortably and effectively compared to the Internet (Mundt, Kaplan, & Greist, 2001).

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<sup>12</sup> IVR technology provides computer-based processing and retrieval of information through touchtone telephones (Mundt, Kaplan, & Greist, 2001).

The aim of the pilot was to assess the interest, need, and willingness to use a toll-free IVR system to access educational information about dementia. The callers were able to select from a menu of options, such as (1) dementia information and treatment options, (2) prevalence and risk factors, (3) local resources and caregiver support, and (4) system exit and feedback. Within the options, the callers could choose to access increasingly detailed information or return to the main menu of options. The IVR system could also transfer the caller directly to a resource office, but few chose this option. The content of the menu was developed using scientific and medical literature and government websites. A local Alzheimer's association assisted in developing the scripts. The toll-free number was advertised through local newspapers, and newsletters and flyers were distributed in churches, senior centers, and other public locations. Health-care personnel also distributed the flyers during Alzheimer's association events.

During one month, the IVR dementia information and resource service received 193 calls, a ten-fold increase compared to average calls to the local Alzheimer's association during a month. The toll-free number was available twenty-four hours. Although most of the calls were received during regular business hours, people called round the clock. Over half of the callers called because they were concerned about another person, the rest because of personal concerns or those of another individual. 86% of the callers selected option 1. Most callers spent over fifteen minutes interacting with the system, underlining the need and desire for convenient and anonymous access to critical information about such a sensitive topic (Mundt, Kaplan, & Greist, 2001).

An IVR toll-free educational and treatment-referral system can be cost-effective and immediately reduce and bridge the digital divide for elderly, lower socio-economic groups in a population (Mundt, Kaplan, & Greist, 2001). However, should such a solution be used for elderly migrants, it will require the use of "plain language"<sup>13</sup> and the option to get the information in other languages. Furthermore, the scripts must be developed with the involvement of users, health-care professionals, and relevant organizations. Using a telephone can be an easier option than the Internet as it requires fewer technical and reading skills and is more familiar for elderly migrants and minorities.

### **Audiovisual sources**

Audiovisual sources can be a suitable tool to raise awareness of dementia in elderly migrants and families. A pilot study from the US tested Asian and Pacific Islander American (APIA) groups' knowledge and perceptions of dementia prior to introducing culturally and linguistically tailored videos and brochures about dementia and measured the effect after the intervention (Braun, Takamura, Forman, Sasaki, &

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<sup>13</sup> To learn more about plain-language policy, please visit the Centers for Disease Control and Prevention (CDC) website: <http://www.cdc.gov/healthliteracy/developmaterials/PlainLanguage.html>.

Meininger, 1995). The APIA term covers 30 different ethnic groups in the US, of which the largest are Japanese, Chinese, Filipinos, Vietnamese, and Koreans. The largest Pacific Islander groups are native Hawaiians and Samoans.

Local Alzheimer's associations helped conduct a survey and recruit people to focus groups. 141 people participated in the testing. The most predominant finding was that video was the most effective tool to trigger discussions and questions compared to other stand-alone interventions. The brochures, however, aided the participants in reviewing and retaining information introduced in the video (Braun, Takamura, Forman, Sasaki, & Meininger, 1995). This is in line with the results from Houts, Doak, Doak, and Loscalzo's (2006) study from the US about the role of pictures in improving health communication. Another interesting and important finding was that the participants struggled to complete the survey form itself. This was because the methodology was unfamiliar to them and because they had limited English skills. In these cases, bilingual facilitators had to work one-on-one with the participants to help them complete the forms. However, the participants communicated that they enjoyed the focus-group setting, which allowed them to speak freely about the topic and material shown to them. Whereas the researchers concluded that the intervention had a positive effect on the knowledge about dementia, they also contended that there should be more focus on developing suitable methods to include people with migrant and minority backgrounds in developing and testing information materials (Braun, Takamura, Forman, Sasaki, & Meininger, 1995). Given the positive feedback on the focus-group setting, it is possible that this methodology itself should be developed as a method for dissemination of dementia information in migrant communities.

Another study from the US on educational interventions has used *fotonovelas*<sup>14</sup> as a tool for raising awareness of dementia among Spanish-speaking Latino/Hispanic<sup>15</sup> communities in the US (Valle, Yamada, & Matiella, 2006). Both young, old, male, and female segments of the Latino population read fotonovelas, although low-income middle-aged women are the largest audience. Fotonovelas are read and discussed within the communities, and their existence persists long after publication as they are often loaned, rented or resold to others, especially in the poorer neighborhoods. In the US, non-governmental and charity organizations and governmental agencies have often used fotonovelas to communicate their messages, especially targeting lowly literate and working-class Latinos. Health-education fotonovelas provide health messages using popular culture, suspenseful storylines, visual effects and little text with the aim to inform, educate, and empower their audiences. Two Spanish-language Alzheimer's fotonovelas were produced targeting lowly and moderately literate adults. Both were designed to counter common myths about Alzheimer's

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<sup>14</sup> Fotonovelas are "soap opera"-type stories told in pictorial formats with reduced levels of text. They are a popular cultural communicational and entertainment medium within the Latino/Hispanic communities (Valle, Yamada, & Matiella, 2006).

<sup>15</sup> Here we will use the term Latino in the text as done by the authors.

disease existing within the communities. 111 Latinos aged 55–90 participated, all recruited through either nutrition programs, senior housing complexes, or social clubs they frequented, the majority being of Mexican origin.

Contrary to the study done on APIA populations (Braun, Takamura, Forman, Sasaki, & Meininger, 1995), Valle et al. (2006) chose not to pretest their informants' knowledge of Alzheimer's prior to giving them the fotonovelas. Their rationale was that a testing-situation methodology would be unfamiliar to the respondents. Hence, the test situation would not be appropriate for pretesting. Valle, Yamada and Matiella (2006) used an exploratory design and mixed methods for data collection in their study among the Latino/Hispanic populations in San Diego County, US. The data was mainly gathered through questionnaires and supplemented by respondents' discussions and further analyzed with the use of SPSS<sup>16</sup>. The questionnaires contained sets of questions testing respondents knowledge of Alzheimer's (KAD), and each of them contained three-point Likert scale<sup>17</sup> options ranging from "strongly agree" to "disagree" supplemented by smiley faces for those with low HL.

About 50% of the respondents were bilingual. All respondents self-reported to be literate in Spanish, but during the sessions, researchers observed minor reading problems, such as "slow" readers or readers not being able to keep up the pace or losing their place throughout the sessions. The younger portion of the adults thought the fotonovelas were more informative than the elderly groups, and females liked them better than men. Over 60% reported that they had talked to others about the fotonovelas, and 40% had passed it on to someone else.

Given that Latino populations in the US are less likely than Euro-Americans to seek professional help, especially in early stages of dementia, an unconventional tool such as fotonovelas can curb the double-barreled effect of using strictly conventional education tools (Valle, Yamada, & Matiella, 2006). Valle et al. (2006) found that the fotonovelas had greater impact when accompanied by discussions and supportive educational techniques among participants. However, the findings are limited to one sample within one Latino community in the US. Furthermore, those in most need of the fotonovelas would probably be those already caring for a person with a dementia-related illness and most likely not have time to participate in the arenas from which the respondents in this study were recruited. The researchers did not have the opportunity to examine the educational and socio-economic backgrounds of the respondents thoroughly and do not know how ethnicity and socio-structural variables interplayed with cultural understandings of dementia-related illnesses. Fotonovelas

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<sup>16</sup> Statistical Package for the Social Sciences.

<sup>17</sup> The Likert-type scale is a psychometric scale commonly involved in research that employs collective questionnaires and is named after psychologist Rensis Likert. A Likert scale is the sum of responses on several Likert items, which are statements that the respondent is asked to evaluate by giving them a quantitative value on any kind of subjective or objective dimension, with level of agreement/disagreement being the dimension most commonly used. Responses are usually given by circling the preferred response (Wikipedia, 2015).

can be a cost-effective tool, both supplementary to other interventions and as stand-alone interventions, to educate elderly migrants and families about dementia. The tool can also be useful for educating and informing segments of a population that can be hard to reach (Valle, Yamada, & Matiella, 2006).

### **Mass media**

Most of the studies included in this review advocate individual-, family-, and community-oriented approaches to raising awareness of dementia (Cornelia, 2012; Jutlla, 2013; Truswell, 2014). Findings from the primary study by Boughtwood et al. (2012) showed that mass media can be perceived as a good source of general information about dementia, albeit tailored to suit the needs and sociolinguistic backgrounds of minority and migrant groups.

Boughtwood et al. (2012) found that bicultural workers and general practitioners (GP) considered ethnic-minority radio, television, and newspapers to be good sources for information dissemination about dementia. Particularly radio and television were seen as suitable sources of information for groups with low levels of literacy in both their mother tongue and English. These sources were also viewed as easy to update and fairly accessible by the participants (Boughtwood et al., 2012). The participants argued that government departments and organizations running general information campaigns about dementia should include CALD outlets and communities to ensure the messages would be culturally tailored, relevant, and made available in relevant locations. Evidence from the studies reviewed in section 1.2 stresses the importance of using “plain language” and tailoring messages and language to suit the needs of people with low HL and limited reading skills.

### **Organizations and community initiatives**

Many studies reviewed in this chapter emphasize that cooperation between different stakeholders in raising awareness of dementia is a key factor. Particularly cooperation between local migrant and minority community organizations, local government agencies, health-care personnel, and dementia/Alzheimer’s organizations working on informing about dementia is considered important if one is to succeed (Braun, Takamura, Forman, Sasaki, & Meininger, 1995; Mundt, Kaplan, & Greist, 2001; Jackson, 2008; Jolley et al., 2009; Westminster Advocacy Service for Senior Residents/Dementia Advocacy Network, 2009; Boughtwood et al., 2012; Cornelia, 2012; Jutlla, 2013; Truswell, 2014).

Seminars and education sessions about dementia and related services can also be sources of information, as noted in Boughtwood et al.’s study from Australia (2012). In this respect, Alzheimer’s Australia (AAU) was viewed as a potential source of information. In events arranged by AAU, information was provided verbally by a professional but supplemented by written information. These community-based

seminars and forums were seen as opportunities to raise community awareness, clarify misconceptions, and attain publicity for services. Similar experiences have also been noted in an UK based initiative called “Friends with Dementia” (Cornelia, 2012).

In the South West London initiative, health-care personnel from St. George’s Mental Health NHS Trust collaborated with the local community to organize open meetings for BME elderly people (Jackson, 2008). Nurses collaborated with translators, held the meetings in a multicultural day center, and used health-care specialists who spoke the native language of the BME group to inform about dementia. Based on advice from the Tamil community they were trying to reach, they did not use the word “dementia” in the advertisements as they felt this would alienate those who did not know what dementia was. The “Friends with Dementia” initiative in Surrey also shared the challenge of informing about dementia in the South Asian Community when there was not any word for dementia in the South Asian languages and people were not familiar with the condition (Cornelia, 2012). The health team at St. George’s that organized the open meetings in London argued that these types of meetings are low-cost initiatives that can help to correct the misconception that the BME community cares for its own. Their experiences were that if BME communities knew what help was available and information sessions were better tailored, they would participate (Jackson, 2008).

Two separate projects from the UK can serve as examples of how collaboration with local communities and government agencies can be successful in raising awareness of dementia. One is the “Twice a Child” project (Jolley, et al., 2009), and the other is the “Work on Ethnic Minorities Dementia Advocacy Project (Emdap)” (Westminster Advocacy Service for Senior Residents/Dementia Advocacy Network, 2009). Both projects found lack of knowledge and understanding of and stigma attached to dementia in their communities, and both projects recommended stronger collaborative efforts to raise awareness of dementia (Jolley et al., 2009; Westminster Advocacy Service for Senior Residents/Dementia Advocacy Network, 2009).

In the nine-year period the “Twice a Child” project lasted, they found that health-care personnel and GPs themselves had low levels of knowledge of dementia and dementia-related care. This led to poor provision of advice, misdiagnosis, and delay in reaching specialist care (Jolley, et al., 2009). Furthermore, members of the BME community expressed a need for more information about what can be considered normal aging versus symptoms of dementia and other mental-health problems later in life and how to access help. Community members also emphasized that communication between carers and social services was not always effective or reliable (Jolley, et al., 2009).

The Emdap project had a two-fold purpose: firstly to raise awareness of dementia, services available and the importance of dementia advocacy in BME communities, as

well as supporting them to provide information to their members; secondly to raise awareness among existing advocacy services to make their services and information more accessible to the BME communities, and support them by providing expertise and training. The project succeeded in educating both target groups about each other's needs. The advocacy organizations understood better how they could reach out with dementia information to BME elderly people, and the BME communities learned how to voice their needs and concerns. The evaluation of the project identified many gaps, which cannot be described in detail here. However, the project report offers a good platform for and guide to bridging gaps in future dementia research and outreach work among migrant and minority communities (Westminster Advocacy Service for Senior Residents/Dementia Advocacy Network, 2009).

Collaboration between local stakeholders and representatives from the communities one is trying to reach is also key in the development of dissemination methods and awareness-raising tools. This is in line with the experiences of Braun et al. (1995), Valle, Yamada, and Matiella (2006), and Boughtwood et al. (2012). Participants in Boughtwood et al.'s study from Australia had mixed feelings about AAU as a source of information (2012). AAU provides fact sheets on dementia translated into several languages as well as educational courses and support groups. Most bilingual and bicultural workers had a positive attitude to AAU and thought the material covered relevant topics related to dementia, and described it as sufficiently detailed and free of medical jargon. However, some bilingual workers pointed out that in comparison with information given to Anglo communities, AAU had little CALD-specific information. Family carers who used AAU all spoke fluent English. Some felt they did not understand the services provided, and others had benefitted better by interacting personally with the organization (Boughtwood, et al., 2012). However, one important finding from Boughtwood et al. was that the bilingual and bicultural workers within communities represented a good source of information about dementia in the CALD communities. According to the workers, their interaction with the communities would ensure that information was personalized, accurate, and up to date (Boughtwood, et al., 2012).

### **Primary- and specialist-care institutions**

Primary care is often the first point of contact with services for many elderly people with a migrant and minority background (Jolley et al., 2009; Boughtwood et al., 2012). GPs can play an important role as a source of information about dementia, as they have the advantage of following a person over a longer period of time (Boughtwood, et al., 2012). A report from a project looking at ways of educating BME elderly people in Wolverhampton, UK, about dementia revealed that GPs often had variable knowledge about dementia and ways to assess the disease in people with different ethnic backgrounds (Jolley, et al., 2009). Because GPs often play an important role in the elderly person's life, it is essential that GPs be equipped with the tools and competency to inform about dementia, to diagnose dementia, and to provide

guidance on services available to a person and the family (Jolley et al., 2009; Boughtwood et al., 2012).

To educate primary-service providers about dementia, to overcome their language barriers, and to provide them with “cultural competence” is as important as educating minorities and migrants about dementia and services available (Jolley, et al., 2009). Building primary-service providers’ cultural competence can for example entail making them aware of their own cultural values and how these influence the way they see and treat other people as well as teaching them about and making them sensitive to their patients’ migration histories, beliefs, traditions, and literacy skills.

Hospitals can also be a source of information. The example from AU show that patients can be admitted for different reasons, but a dementia diagnosis can sometimes occur during the patient’s stay in the hospital. In Australia, Boughtwood et al. (2012) found that geriatricians would often provide verbal information prior to or in combination with written information. Out of all the sources of information, hospitals were considered to provide the most detailed information about dementia, perhaps due to its readily available multidisciplinary teams and geriatric clinicians (Boughtwood et al., 2012).

### **Social networks**

Studies from both the US, AU, and the UK have unveiled that informal social networks, such as friends and family, and more formal networks, for example senior centers or mosques, can be important sources of information about dementia (Valle, Yamada, & Matiella, 2006; Boughtwood et al., 2012; Cornelia, 2012). Sharing information in this manner can aid in reducing the stigma associated with dementia. On the other hand, information shared in this way can potentially be inaccurate or incomplete if the conveyor of the message has not fully understood the ramifications of dementia-related illnesses (Boughtwood, et al., 2012). Family carers in the study from AU experienced that sharing information could simultaneously be a source of support and provoke discomfort, through listening to other peoples’ stories about similar situations (Boughtwood, et al., 2012). Other family carers, however, said that sharing information could help them identify dementia, which is in line with findings among the APIA community in the US (Braun, Takamura, Forman, Sasaki, & Meininger, 1995; Boughtwood et al., 2012).

### **Barriers to Dissemination of Information**

To reach out with information about dementia to elderly migrants and minorities and their families, one must consider literacy issues, the sources of information, and the content and delivery of information. This section will summarize the knowledge presented in the previous section and recap some of the emerging patterns.

## Literacy issues

HL encompasses a person's knowledge of health, body, mind, health systems, and language. The literature suggests that limited or low HL levels can be associated with lack of ability to self-manage health, access health services, understand written health information, and make informed health-related decisions. Furthermore, limited HL can also be associated with poor health outcomes and can be a risk factor for dementia (Kaup et al., 2013; World Health Organization, 2013).

Gabrielsen and Lundetræ's study (2014) from Norway examining the population's health-related literacy concludes that when one prepares written health information, it must always be adapted to the poorer readers and complemented by both verbal information and instructions. Low HL skills can influence elderly migrant and minority groups' health-seeking behavior in particular. It can lead to either underuse or overuse of services. Research from Norway and Denmark shows that elderly migrants are often under-represented in use of primary health-care services and dementia care (Kumar & Diaz, 2014; Nielsen & Waldemar, 2015). Although these recent studies do not provide any causal explanation to the underuse of services, it is likely that low HL in combination with lack of access to information and lack of properly tailored information can be part of the explanation. Addressing HL should therefore be built into information strategies. The information should be tailored to the knowledge and needs of a group and also address language barriers (Jackson, 2008; Jolley et al., 2009; Westminster Advocacy Service for Senior Residents/Dementia Advocacy Network, 2009; Boughtwood et al., 2012;). Nguyen and Reardon (2013) suggest that limited language skills and social discrimination could have profound effects on elderly migrant's health in general. This is most likely due to their overall cognitive decline with age (Bostock & Steptoe, 2012). As such, low HL and language barriers can be prominent barriers to accessing information about dementia and services available.

## Sources of information

Several potential sources of dementia information have been mentioned in the various studies examined here: written health information material both with and without illustrations, the Internet, telephone services, audiovisual sources, mass media, organizations and community initiatives, health-care institutions and professionals, and social networks. The number of sources available is vast, but what all studies contend is that the source chosen must be relevant, be used by, and be understood by the group one is trying to reach.

Health-care institutions and professionals can sometimes be the first point of contact and perceived as the most trustworthy source of dementia information (Jolley et al., 2009, ILC-UK, 2011; Boughtwood et al., 2012). However, the studies included here show a tendency for health professionals, especially GPs, not to have sufficient competency about dementia, diagnosing, treatment, and services available. In addition, communication barriers often hamper provision of information. Experiences

from the UK recommend educating service providers themselves about dementia and providing them with cultural competence and skills to overcome language barriers. This can improve information dissemination and contribute to increasing awareness of dementia among elderly migrants and their families (Jolley, et al., 2009). Furthermore, knowing that there is underuse of health-care services among elderly migrants and minorities (Kumar & Diaz, 2014; Nielsen & Waldemar, 2015), it is vital that GPs as potential sources of information are part of a larger multi-component information strategy to raise awareness, and not the sole sources of information.

Evidence from the US and Australia suggests that choosing unconventional and multi-component interventions to convey a health message about dementia can be viable paths to raising awareness of the condition and services available. This may entail using fotonovelas, DVDs, or a combination of several written and audiovisual sources, as well as information sessions, seminars, and health-care workers with relevant language skills to complement and communicate dementia-related information (Braun, Takamura, Forman, Sasaki, & Meininger, 1995; Valle, Yamada, & Matiella, 2006; Jackson, 2008).

Some of the articles and reports included here mention the importance of bridging the “digital gap” between younger and older generations. This entails providing alternatives to the Internet as a source of dementia-related information. The older generations may not have the trust, skills, resources, or interest necessary to use the Internet as a source of information and can potentially be “excluded” from gaining knowledge about dementia and services only available online (Mundt, Kaplan, & Greist, 2001; ILC-UK, 2011; Boughtwood et al., 2012; ILC-UK, 2015). Sources such as telephone services, tailored mass-media campaigns, radio and TV, and competent GPs and health professionals can possibly aid in bridging this gap.

Organizations and community initiatives can also be sources of dementia information. A few examples from Australia and the US were included here to demonstrate different ways of using these as sources of dementia-related information. These studies emphasize the importance of cooperation between multiple stakeholders, such as local migrant- and minority-community organizations, local government agencies, health-care personnel and dementia/Alzheimer’s organizations. The “Twice a Child” project and Emdap from the UK showed that dialogue between these stakeholders about their needs and building confidence among migrant and minority communities to voice their concerns are key if one is to succeed.

### **Content and delivery of information**

When informing about dementia and raising awareness, it is vital to choose the source(s) of information most relevant to the migrants and minorities one is trying to reach. Regardless of the source(s) of information chosen, dementia-related information must be tailored to answer the questions communities may have and

designed with their involvement and ultimately be disseminated in places they frequent and/or by people who are trusted in their communities. As emphasized in several studies, the information must be easily available.

From the literature reviewed here, we know that elderly migrants and minorities can sometimes have low HL and limited knowledge of the host language, which are barriers to understanding both written and oral health information about dementia. In written information it is important to ensure that brochures use simple and plain language, use words that resonate with the migrant and minority groups, and contain relevant pictures. The information should ideally answer all the questions the group may have or at least provide information about where to find this information (Jackson, 2008; Jolley et al., 2009; Westminster Advocacy Service for Senior Residents/Dementia Advocacy Network, 2009; Cornelia, 2012).

Examples from the UK and AU demonstrate the importance of teaming up with key persons within communities, health-care professionals, and dementia organizations to arrange information sessions in the local community. Valle, Yamada, and Matiella's study (2006) and Braun, Takamura, Forman, Sasaki, and Meininger (1995) both revealed two important points: firstly that even though migrants may perceive themselves to be fluent in their mother tongue, this may not be the case as it depends on years of schooling; and secondly that ordinary survey methods that requires a certain level of readability skills may not be a suitable for assessing knowledge about dementia and collecting feedback on information material. In accordance with Boughtwood's experiences (2012), the informants responded positively to focus-group settings, suggesting that this type of methodology may be more suitable when one includes elderly people with a migrant and minority background in the design of information material and other interventions.

Educating the general public about dementia can be one way of reducing stigma associated with the conditions, and reach out to "hard to reach" populations and aid in creating understanding of dementia among younger generations in society (Mundt, Kaplan, & Greist, 2001; Boughtwood et al., 2012). Using mass-media campaigns and teaming up with local migrant and minority organizations and dementia/Alzheimer's organizations can be viable options in this respect.

### **Interpersonal aspects**

Boughtwood's study from Australia (2012) underscores the importance of dementia-related information being explained by someone credible, tailored to individual circumstances, done in a non-confronting manner, and linguistically and culturally adapted to migrant and minority groups.

As mentioned earlier, GPs have the advantage of accompanying a patient over time as well as being the first point of contact in some cases. In this regard, GPs can play a unique role in a person's life and may be the right person to provide information about dementia. Bicultural and bilingual health professionals can also provide good

information, as well as health professionals working in different dementia organizations and associations, but not all countries use these types of professionals.

Regardless of who provides information, many of the findings advise that information given should be adapted to the particular situation of a person with dementia and the family. Experiences from the UK shows that smaller sessions with key persons who have a health background and speak the same language as the target group can also be relevant sources of information.

## Summary

The literature available on the tailoring of information for elderly migrants with dementia and their families is fragmented and scarce. Therefore, it is hard to draw any absolute conclusions based on the resources reviewed here. Nonetheless, the empirical examples included in this chapter do provide important insights into potential sources of information and methods for dissemination.

It is essential to keep in mind several aspects when designing intervention programs and projects with the aim of raising awareness of dementia among elderly migrants and minorities and their families. Most importantly, interventions must build on sound empirical and systematic assessments of the target groups' knowledge of dementia and their information needs.

HL literature can broaden our understanding of barriers elderly migrants and minorities and their families can face to accessing information about dementia and services available, especially of the significance of language and communication. This literature can help us understand how low HL and limited reading and comprehension of health-related information can influence help-seeking behavior. Furthermore, it can show us how to overcome barriers especially related to low functional HL.

Difficulties in reading and understanding basic health information can influence a person's health and health-seeking behavior and is associated with an elevated risk of dementia. As shown in this review, if one is to change people's health-seeking behavior, it is imperative that information is given early, is perceived as relevant, is clear, is easy to understand, and applies to a person's life situation.

Findings from the studies reviewed here reveal that material developed for elderly adults with dementia and migrants in general is too difficult to understand. Health-care personnel often overestimate the reading skills of elderly migrants and their families. In addition, inclusion of relevant pictures in written health communication can help readers with low HL remember and understand written health information better. Also, patients and carers often find dementia information hard to obtain and scattered. Given these tendencies, it may be advisable that government agencies or

organizations use plain-language principles in the design of written health information, be it online or in brochures. Especially in larger mass-media campaigns, the use of plain language and relevant visual effects can be vital in getting a message across. Relevant visual effects and pictures must be chosen based on the involvement of the target group. Lastly, it may be advisable that information be found in one central and accessible place.

Whereas the Internet can be a great source of dementia information, experiences from the US, the UK and AU may suggest that this is a more suitable platform for younger generations than for older ones. Due to trust and familiarity with technology, the Internet can be a good method to use when one targets younger family members and caregivers but not necessarily when one tries to reach older generations of migrants. Several studies offer potential alternative sources that can bridge the “digital gap” between generations, such as telephone services, which may be a technology elderly people are more familiar with. Fiction, photo based narratives (fotonovelas), films, and DVDs can also be good sources of information about dementia among elderly migrants. These sources can be suitable options when one tries to reach communities that are hard to reach and have low education and where written language is not necessarily a trusted source of health information.

Community meetings and networks, often organized through the cooperation of multiple stakeholders, can potentially be successful platforms for reaching out with information about dementia. Experiences from the UK and AU show, however, that the success requires that one cooperate with key persons within the group one is trying to reach, that meetings be arranged within the local community, and that competent translators and health-care providers who know the community well be used. In the studies applying focus-group methods, most informants communicated that they enjoyed the focus-group setting itself, as it afforded them the chance to share information with others and talk about their concerns. This observation may indicate that focus-group methodology should be further explored as a platform for informing about dementia and services available.

Primary health-care institutions and hospitals can also be sources of dementia information, albeit for those who can actually make use of them. In Norway, GPs can play an important role in informing about dementia. In order to do this, GPs and other primary health-care providers must have competencies in migration health, HL challenges, and dementia. GPs as sources of information should however form part of a larger multi-component information strategy to raise awareness and not be the sole source of information since we know there is underuse of services among elderly migrants with dementia.

Whatever source of information or methods for dissemination chosen, they must be carefully selected based on the information needs and involvement of the target

groups. Migrants in Norway are a heterogeneous group. Hence, information interventions necessitate a multi-faceted and multi-component approach in terms of tailoring methods and materials.

All of the sources and outreach methods presented here are examples of how one can inform about dementia. Experiences from the US and AU underline that interventions are most effective when they consist of several components, for example films, brochures, community meetings, and mass media, and are developed in cooperation with the target groups themselves. As a part of the exploration of different methods of tailoring and disseminating dementia information, it could also be interesting to explore the ways in which this is done in migrants' and minorities' countries of origin as well.

Ultimately, there may be a need to shift focus from producing more information material about dementia towards understanding and overcoming the barriers to dissemination of already-existing information. A part of overcoming these barriers is to understand the interpersonal aspect of communication, to take into account health literacy and illiteracy factors as well as the information needs of the target groups in information strategies, and lastly to recognize the important roles community and direct-care workers can play in informing about dementia. In this regard, developing and systematically testing suitable methods to include elderly migrants and their families in the development and design of health information about dementia seems important.

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