

GRASPING FADING MEMORIES OF A MOTHERLAND: CAPTURING DYNAMIC CARE REALITIES OF OLDER LABOR MIGRANTS WITH DEMENTIA

PhD Thesis

Saloua Berdai Chaouni

Promotor: Prof. Liesbeth De Donder

VUB

**PSYCHOLOGY &
EDUCATIONAL SCIENCES**

Table of contents

Acknowledgments	4
Intermezzo 1	6
Chapter 1: Introduction	7
1. Background	9
2. Research Gaps & Questions	24
3. Methodological approach	26
4. Dissertation Outline	31
Intermezzo 2	39
Chapter 2: Invisible realities: caring for older Moroccan migrants with dementia in Belgium	41
1. Introduction	42
2. Methods	44
3. Results	47
4. Discussion	52
5. Study limitations and further research	54
6. Conclusion	54
Chapter 3: Caring for migrant older Moroccans with dementia in Belgium as a complex and dynamic transnational network of informal and professional care	59
1. Introduction	60
2. Methods	61
3. Results	65
4. Discussion	70
5. Study limitations	72
6. Conclusion	73
Chapter 4: The influence of religion on the experiences of family caregivers of older migrants with dementia	79
1. Introduction	80
2. Methods	82

3. Results	85
4. Discussion	89
5. Limitations	92
6. Conclusion	93
Intermezzo 3	98
Chapter 5: How to (qualitatively) involve older people with dementia and their informal carers with a migrations background in research? Insights from a longitudinal project in Brussels	99
1. Introduction	100
2. Methods	100
3. Results	101
4. Discussion	105
5. Conclusion	106
Chapter 6: Doing research on the intersection of ethnicity and old age: Key insights from decolonial frameworks	109
1. Introduction	110
2. “Ethnicity blind spots” challenge gerontological research about ethnicity and old age	110
3. Explored paths to move forward	112
4. Decoloniality as a new path to explore the intersection of ethnicity and old age	113
5. Key insights to be applied from decolonial perspectives	114
6. Conclusion: Potentials and limitations of decolonial perspectives	122
Chapter 7: General Discussion	129
1. Introduction	130
2. Discussion of the main findings in relation to the research questions	130
3. Implications for practice & policy	154
4. Limitations of the dissertation and directions for future research	161
5. General Conclusion	163
Summary	174
Samenvatting	176
List of publications	178

Acknowledgments

I imagined that writing acknowledgements would be the most exciting part of this dissertation as it means that I made it till the finish line. More so, it makes clear that this dissertation is a collective endeavor. I'm so blessed to be surrounded by many wonderful people during this journey. Alhamdulillah!

First, I want to thank everyone for letting me interview them. A special thanks to the family caregivers for sharing your knowledge and time with me. You were so generous to contribute to this dissertation, aspiring that this study will contribute to better conditions for those who will follow. I promise you that I will continue to fight for that. Also many thanks to everyone that helped me to find all the participants.

Second, many thanks to my wonderful promotor and person Liesbeth De Donder. Thank you for being the coach that I needed. Thank you for your enthusiasm, encouragement, open, critical and sharp mind, feedback, accessibility, care,...I can go on and on. I learned a lot from you as a professional and as a person. Thank you for renewing my belief in academia and academic work. I also want to thank the members of my PhD-committee: Iman Lechkar, An-Sofie Smetcoren and Eva Dierickx. What a blessing to be surrounded by such inspiring ladies. Thank you for your thought-provoking feedback and compassionate guidance. My thanks go also to the colleagues of Adult Educational Science department. Thank you for the warm, supporting and welcoming working environment even though I was not always around. Also thanks to my Rhea, Race & Research and Birmm colleagues for the inspiring working sessions and talks.

I combined writing this dissertation while I was working at two university colleges. I could only succeed in managing this endeavor with support of these colleagues. First, many thanks to Ann Claeys, my Diverse Elderly Care partner. I'm grateful that we could share this crazy PhD-journey as working mothers. Also thanks to my KDG-colleagues for their support during this period. A special thank you to Katrien Verlinden and Véronique Hendrickx. Thank you Katrien for literally making my work schedule flexible to make the combination feasible. Véronique, thank you for various forms of support to lighten up my burden (e.g. surprising me by already filling in the exam results,...), encouragements and loving thought provoking talks during the last years.

I'm also grateful to be surrounded by many intelligent, inspiring and caring females that I can call my friends. Some of them inspired me by their academic/activist/other work, by thought provoking talks, collaborations or just by sharing moments over a cup of tea. So thank you: Maryam, Mariam, Bouchra, Birsan, Karima, Tina, Anissa, Samira, Dorien, Iman, Dounia, Mariska, Eva, Hanna, Fatos, Jennifer, Liesbeth, Nadia...I felt safe enough to share my premature results for feedback to some of you: thank you for making this PhD better. Many thanks to Tina for your feedback, support and the working/relax weekends. A special thank you to Nadia Babazia who is close to my heart and my house. Thank you for being the friend I needed, to care for me and my girls and for making sure that I build in some self-care.

I also want to thank my family for their support. Thank you Nada for opening the door to your network in Morocco so I can learn about dementia care over there. I have always enjoyed our geek moments. Thank you for being the connection to my roots. Merci! Also thank you to Nahima and Guy for your unconditional and ongoing support by being the persons that I can always turn too with any question. Blessed to have you in my life.

Finally, I want to thank the most precious people in my life. Thank you to my parents for being present even though I had to miss you at young age. Thank you for planting in me the seed to resist boundaries, to see the world as an learning opportunity and the power to go that step further even when I can't. Also many thanks to my husband Abdelmajid. This PhD would not be possible without your continuous love and support (in all shapes and forms). I'm so grateful that I can call this dissertation as our family-dissertation. Parts of you and the girls are in this work, my fellow gerontologists. Thank you for the talks, to go visit with me aged care during our vacations, for the small love and caring gestures, for encouraging me not to quit when it became too heavy to bare,...So many thanks and love to my beautiful, intelligent and loving daughters. I started this journey when you were children and I watched you growing into wonderful teenagers. Thank you Yara and Isra for keeping me grounded to what matters in life. I know that I haven't always succeed to avoid that this dissertation took time that you were entitled to. Thank you for your generosity and understanding, I'm looking forward to our totally laptop-free weekends and holidays.

Saloua, 10/07/21

Passeport el Ghdar (The green passport)

We are in the stranger/unknown (el ghorba), and the stranger/migration (el ghorba) is long and hurt us between the eyes.

If we stay alive we will return to our home country and if we die others will burry us there.

I had my green passport and thought with it I will have a better life. I found a boat that was trilling and a haven full of flags

The day has come to say goodbye to my loved ones with hart full of sorrow (mehmoum). I left my mother in sadness saying 'my son has gone to Europe (roem)'.The distance gives you grey hair my dear, I will never forgot that day. She shared her tears and I, only Allah knows about my heart.

I took the boat with my friends, the night spent with the waves, the morning in Malaga,on Spanish ground.

The waitress saw me and asked me what I wanted: I said I wanted to have breakfast. She brought something that I ate. I asked her 'can you inform me of this food of you is Hallal'. She told me 'eat and shut up, what you are asking is impossible!'

I took a stroll to the market and discovered fruit in all colors, quices, peaches, apples and bananas. Hey blond lady, Spanish women inform me 'quando' (Spanish) in the price? I found no tongue to speak, they told me I needed a translator...I did not understand anything, nada nada (Spanish), lady!...

I left my home country far away and came to Paris to work, I thought I would be successful, buy a car so my loved ones can ride with me.

I worked Saturdays, Sundays, all holidays and New Year. I'm tiered, years passed on, and today the days feel long.

Oh my Allah, Oh my Allah, is this real or impossible, 12 years in the stranger 'el ghorba', and still counting

...

Own translation of song lyrics of "Passeport el Ghdar/Green passport" by Mohamed Younci, 1965

Chapter 1: Introduction

Abstract

The introductory chapter of this dissertation is divided into four parts. Part 1 describes the empirical and theoretical background of the dissertation. Part 2 summarizes the research gaps and formulates the research questions. Part 3 reflects on the methodology and methodological approach chosen. Lastly, Part 4 displays an outline of the dissertation.

Part 1, Background, starts by presenting the demographic and historical background of older labor migrants. Belgium, like the rest of Europe, has a growing ethnic diversity among its older population resulting from the increased migration in the 20th century, with a first wave of ageing labor migrants that came here in the 1960s and 1970s. This dissertation will focus mainly on Moroccan migrants as the largest group with a migration background in Belgium. An overview reveals the lessons learned about ageing-related issues faced by older migrants in Belgium. Dementia is subsequently discussed as an age-related condition with a high prevalence and different types and stages that challenge how to deal with it. As the quest for a dementia cure is far from being successful, a shift has been made to preventing and living well with it. Supporting living with dementia also inevitably entails caring for persons with dementia, as care needs progressively increase through the course of the dementia trajectory. Informal care generally constitutes an important part of the care for persons with dementia. However, inclusion of specialized professional care is needed to support and sometimes substitute informal dementia care. Person-centered care is presented as the most influential psychosocial care approach in professional dementia care. The main findings about the intersection of dementia and older migrants are also elaborated on. Although exact numbers on dementia prevalence among ethnic minority populations in Belgium is missing, there is a hypothesis that dementia is higher among this subpopulation. Furthermore, older migrants with dementia seem to follow a specific dementia care trajectory with diagnostic challenges, preference for family care and under-use of professional care. The emphasis on the specificity of older migrants with dementia is also reflected in culturally competent care as the dominant care approach put forward for this population. Next, this state of affairs about the intersection of dementia and older migrants is situated within a broader research context about older migrants as aging ethnic minorities in the West. Gerontological research on this topic seems to be biased, resulting in reproduction of narrow assumptions about this population and of societal inequality within and throughout research itself.

Against this background, in Part 2 three research gaps are identified: limited knowledge about dementia and older migrants in Belgium, culture as a dominant one-sided gaze on the situation of older migrants with dementia, and limited knowledge on how to conduct ethical research on dementia among older migrants. These gaps lead to the two main goals of this dissertation, namely to explore: a) a nuanced image of the dementia experience and dementia care provision among labor migrant families, and b) methodological pathways to contribute to more ethical research involving this population.

Part 3 discusses the methodological approach followed during this dissertation. The combination of constructivist grounded theory and critical gerontology shaped the main methodological gazes of the dissertation.

At the end of Part 2, the main dissertation goals are translated into four research questions that will be answered in the course of the five studies outlined in Part 4.

1. Background

Older migrants/Moroccans in Belgium

Demographics

Europe is facing increased ethnic diversity among its older population (Ciobanu, Fokkema & Nedelcu, 2017), resulting from the intensive migration of the 20th century (Van Mol & de Valk, 2016). Belgium, for example, has been a “net migration” country since the Second World War. This means that Belgium welcomes more migrants than Belgians migrate. The migrants’ profile has changed over the years (Martiniello, 2003). The postwar migrant population was composed of results of migration waves from certain countries, like labor migrants from Italy, Morocco and Turkey (Lafleur, Mardouk, Fadil, 2018; Morelli, 1988; Reniers, 1999). Today’s ethnic diversity among the Belgian population is a result of multiple, much more complex migration flows. It is difficult to estimate the current ethnic diversity among the Belgian population, as there are no measures by ethnicity.

Moved by the need of recent statistical data reflecting the ethnic diversity of the Belgian population, the Belgian statistical office Statbel (2021) estimated Belgians’ ethnic background by looking at the registered nationality of individuals and their parents. Based on this data, on 1 January 2020, 67.9% of the population was Belgian with a Belgian background, 19.7% was Belgian with a foreign background, and 12.4% did not have the Belgian nationality. In absolute figures, this concerns 7,806,078, 2,259,912 and 1,426,651 inhabitants, respectively (Statbel, 2021). In other words, in 2020, 32.1% of Belgian citizens were of foreign origin compared to 25.7% in 2010. Using “nationality of origin” as criterion, the same study showed that Moroccans were the largest group, ahead of Italians, French, Dutch and Turks. This top-five has remained stable over the past 10 years, with the difference that compared with 2010 the Italians switched positions with the Moroccans. The share of Belgian residents with a foreign origin, with and without the Belgian nationality, varies per region: 24.1% of the population in Flanders, 33.2% in Wallonia and 74.4% in Brussels (Statbel, 2021).

In terms of older persons, Statbel (2021) estimates that in Belgium 12.7% of all persons aged 65 and older had a foreign background in 2020 (6.3% Belgian nationals, 6.4% non-nationals). This number was lower in 2010: 9.4% (3.2% Belgian nationals and 6.1% non-nationals) (Statbel, 2021). In Flanders, Wallonia and the Brussels region these numbers were 6.9%, 18% and 39.3%, respectively (Statbel, 2021). The number was much higher in those cities and regions that hosted the majority of migrants who came to Belgium in the 1960s and 1970s, such as Antwerp 15.5%, Charleroi 28.5%, and Brussels 39.3% in 2020 (Lodewijcks, 2014, 2017; Statbel, 2021). These numbers rose in the last decade: for example, in 2010 the share of older persons over 65 with a migration background was 26.7% in Brussels (Statbel, 2021). Looking at the current number of migrants, the share of older persons with diverse ethnic backgrounds is expected to continue to grow in the future. As mentioned, the Moroccan minority constitutes the largest group of non-European migrants in Belgium: in all Belgian regions, persons of Moroccan descent aged over 65 were always the largest non-European group, followed by Turks in the top-five of older persons of foreign origin (Statbel, 2021). This is also true for Flanders (Ouali, 2004; Timmermans et al., 2017), where 10% of older ethnic minorities are of Moroccan background. This percentage is higher in cities and regions with a strong migration history, like Antwerp and Brussels and the Dutch province of Limburg. In 2020, already 10% of all persons aged

over 65 living in Brussels were of Moroccan descent – the largest such group of older adults with a foreign background in the last decade (Statbel, 2021).

In summary, the older population in Belgium is ethnically diverse and includes a proportion of seniors with a migration background. Comparably to other older labor migrants like Italians and Turks, seniors of Moroccan descent represent an important share of older persons with migration backgrounds. In some regions and cities, like Brussels, this diversity is already visible because they form a significant part of the ageing population. This will continue in the future with increasing ethnic diversity: for example, in Brussels seniors of Congolese and Romanian descent will become an important group in the future. Nevertheless, older persons of Moroccan descent will remain an important group within this increasing diversity.

The history of migration of older Moroccan migrants

There has always been migration, also in Belgium. Before and during the Second World War, Belgium was primarily an emigration country, with Belgians mainly migrating to other countries or fleeing (during the world wars). During this time a limited number of migrants were also present in Belgium, like the labor workers recruited from Poland in the 1920s. This is also the start of the Moroccan presence in Belgium: Moroccans as French colony subjects were recruited to fight during the world wars together with other colonized Africans (Berriane, de Haas, Natter, 2015; Bousetta & Martiniello., 2003). Some of these early pioneers stayed but the majority died or returned to Morocco after the wars.

It was only after the Second World War that the presence of Moroccans grew as a result of the “industrial” recruitment of migrant workers during the labor migration wave in Western European countries. There was a postwar demand for cheap workers in Belgium and all over Western Europe to revive industry. The native population was not sufficient in numbers, it did not want to be employed in sectors where one had to work hard, under harsh conditions and with low pay. A solution was sought in active recruitment of cheap workforce from nearby countries like Italy (Morelli, 1988) and/or ex-colonies such as Algeria, in the case of France (Berriane, de Haas, Natter, 2015). Due to the Cold War, Western European countries could not recruit from Eastern Europe, shifting attention to the south. First migrants were recruited from southern European countries and afterwards North Africa and the Middle East (e.g. Turkey) (Van Mol & de Valk, 2016). In line with the other Western European countries, Belgium concluded bilateral agreements with Italy in 1947 and at a later stage with Morocco and Turkey in 1962. Northern Europe chose countries whose rural regions had high poverty and unemployment. The recruited workers were seen as temporary attendees, “guests” who were expected to return to their country of origin after the labor was completed. They therefore had few rights and limited to no access to the welfare system (Van Mol & de Valk, 2016).

In the 1960s both Morocco and Belgium perceived this bilateral agreement as positive. There was something to be gained for both countries. Morocco, still in transformation from its recent independence in 1956 (Berriane, de Haas, Natter, 2015) from European colonization (by France and Spain), could lower its number of young unemployed, helping to contain social and political unrest. For Belgium, in addition to cheap workers this labor migration meant a rejuvenation of the general population. Due to the criteria set by the recruiter (Belgium) and the prohibition of Moroccan females to travel alone, the first wave of Moroccan migrants was mainly male (Ouali, 2003). Later on, as a result

of the flexible family reunification policy a migration wave of women and children followed soon after the men's arrival (Bousetta & Martiniello, 2003).

The bilateral agreements were the start of the arrival of tens of thousands of Moroccans and Turks to regions in need of strong workers: the mining regions (Limburg and Wallonia basin) and cities in need of workers in industry and construction, such as Antwerp, Brussels, Liège and Charleroi. With the economic recession of the early 1970s, there was an "immigration stop" in Belgium in 1974. In practice, this stop marked the end of organized recruitment and transportation of labor migrants by the Belgian authorities. Further migration of Italians, Moroccans and Turks continued, albeit to a lesser extent, through family reunification, study migration, tourist visas and clandestine migration. From 1974 onwards, the discourse on migration also changed: it became the "migration problem" (Bousetta & Martiniello, 2003; Timmermans et al., 2017). This changed discourse was the start of a policy that made migration, especially that of low-skilled non-European citizens, more difficult.

The largest share of older migrants of Moroccan descent came here to work. Consistently with the demands of their future workplace, these labor migrants were recruited based primarily on their physical ability. This is why guest workers share a similar socioeconomic profile: they were mostly illiterate and from rural areas in Morocco where the way of life favored physical strength over education. This migration history has a big influence on their current socioeconomic position. For example, their low literacy has been confirmed by quantitative data of Lodewijcks (2014): 70% of Moroccan seniors aged 70 or older in Flanders had never had any type of formal schooling. The adverse socioeconomic status of older migrants is something that European labor migrants appear to share in old age (Liversage & Jacobson, 2016).

However, not every older person of Moroccan descent in Belgium was part of this labor migration wave. Seniors of Moroccan descent are socioeconomically, linguistically, ethnically, culturally and religiously diverse, regardless of which path of migration they have walked (Berriane, de Haas, Natter, 2015; Reniers, 1999). Furthermore, types of migration and underlying reasons have always varied and have seen increasing diversity through the last decades, leading to an assortment of life stories and profiles (Bousetta & Martiniello, 2003; Ouali, 2003; Reniers, 1999; Timmermans et al. 2017). To illustrate: for some Berber Moroccans the labor migration wave was an opportunity to escape from the oppressive political measures of post-colonial Morocco in the underprivileged northeastern region as a result of the colonial remains of the Berber-Arabic division (van Heelsum, 2003). Another example is that of migrants who came to Belgium at an older age. Berdai et al. (2011) estimates that in 2010 approximately 15% of Moroccan seniors in Antwerp were recent migrants, mostly women, brought by their children to be supported after becoming widowed. This small subgroup of Moroccan elders often find themselves in a weaker position resulting from their recent migration to Flanders.

Ageing with a Moroccan background in Belgium

Belgium initially expected that these labor migrants would work temporarily and then return to their home country. Reality proved different though. The migrants, sometimes contrary to their own original aspirations, ended up staying. They developed an emotional attachment to their host country (Buffel, 2015), especially by having children and grandchildren there, and having realized the value of a high-quality healthcare system (Albert, Ferring & Lang, 2016).

In the early 21st century, the first studies about the situation of ageing labor migrants mainly with a Moroccan background emerged in Belgium (Berdai, 2005; Cuyvers & Kavs, 2001; Janssens & Timmerman, 2003). These studies included a relatively young population. Inclusion age started at 50-55, mostly with no care needs. The findings therefore paint a picture of the situation of mainly healthy older persons before the development of age-related conditions that require extensive use of professional care. A first observation is that ageing in Belgium is an overwhelming experience for them. The temporality of their stay in Belgium remained in the minds of many migrants despite their having set roots in Belgian society after spending most of their adult life here. Many still cherish an emotional connection with Morocco through their childhood memories, the beautiful weather, etc., but at the same time have also developed an emotional connection with Belgium through their life here and the presence of their children and grandchildren. The concept of the “return dilemma” attempted to capture this feeling of an unrealized dream of returning to the country of origin (Berdai, 2005; Cuyvers & Kavs, 2001; Janssens & Timmerman, 2003). Those with good health and financial resources cope with the attraction of both countries and their multiple-location attachment by commuting between Morocco and Belgium. A second main finding is the care dilemma capturing a preoccupation that most of these older persons had about their future in Belgium: who will care for them, their family or professional care providers? Formulating an answer to this dilemma is also complicated by a third general finding: the professional care is not adapted to the wishes and needs of older migrants. The latter has been confirmed, among others, by the work of Ahaddour, van den Branden and Broeckaert (2016), who between 1965 and 2014 reviewed publications addressing issues concerning older migrants of Moroccan and Turkish background in Belgium. The authors drew the conclusion that mainstream elderly care is inaccessible to older migrants and that the “neutral” Belgian care policy fails to meet cultural and religious needs formulated by older Moroccan and Turkish migrants.

Dementia

Dementia in numbers

According to the World Health Organization (WHO, 2020), dementia is a syndrome in which memory, thinking, behavior and the ability to perform everyday activities deteriorate over time. It is therefore seen as a major cause of disability and dependency among older persons worldwide, with a physical, psychological, social and economic impact on individuals with dementia, their families and caregivers, and society at large (WHO, 2020). Dementia is also seen as an age-related condition. This means that it mainly affects older adults, but it is not a normal part of ageing. Put differently, the chances of someone developing dementia increase with age, but not everyone who is getting older develops dementia. For example, about 5 to 8% of the world population older than 60 develop dementia, according to the estimates of Prince et al. (2013, 2015). Approximately 10% of people over 65 have dementia compared to 20% of those over 80 and 40% of those over 90 (WHO, 2020). And yet there is also young onset dementia, constituting 9% of dementia cases developing in the population younger than 65 (WHO, 2020).

Worldwide, about 50 million people currently have dementia and nearly 10 million new diagnoses are added every year (WHO, 2020). Globally, the number of people affected by dementia is increasing: in 2010, 35.6 million had dementia, a number estimated to increase to 65.7 million in 2030 and 115.4

million in 2050. Countries with middle and low income will face the greatest increase of dementia cases (Prince et al., 2015), accounting for 71% of cases by 2050 according to WHO (2020) estimates. This increase results from a recent ageing wave associated with a general improvement of healthcare in these countries, leading to lower mortality caused by acute health issues. A moderate increase of dementia cases will also be seen at the European level and in Belgium. So far we do not have exact prevalence figures for dementia in Belgium (Steyaert, 2016; Vermeulen et al., 2020). Based on estimates, in 2020 (Expertise Centrum Dementie, 2020), 220,104 individuals lived with dementia in Belgium, 136,624 of them based in Flanders. This figure is expected to double by 2060. As discussed, the share of Belgians with a migration background is unknown in these estimations (Steyaert, 2016; Vermeulen et al., 2020).

Different types of dementia

Dementia is an overarching term for various underlying conditions affecting brain functioning, resulting in memory and other cognitive, behavioral and physical disturbances that over time interfere significantly with individuals' ability to keep up their activities of daily living (Prizer & Zimmerman, 2018; WHO, 2020). There are different types of dementia. Alzheimer's disease is the most common type and accounts for 60-70% of cases. Other major types include vascular dementia, Lewy Body dementia, and a group of diseases contributing to frontotemporal dementia. The boundaries between the different types are often indistinct, leading to mixed types of dementia. Each type of dementia has its own course in terms of manifestations and progress over time, yet all types share an impact on cognitive, behavioral, psychological and physical functions. Symptoms will therefore differ, depending on which brain area is affected, and be a mix (Lemey & van den Ameele, 2019; WHO, 2020). Impairments of the brain areas responsible for cognitive functions affect functions like memory, thinking, orientation, understanding, learning ability, language and judgement. Impairments of the psychoemotional brain areas can influence emotional control (e.g. crying, getting angry), motivation (e.g. apathetic impression) and miscalculation of socially acceptable behavior (e.g. socially disinhibited behavior like making sexually explicit remarks in formal company) (Cerejeira, Lagarto, & Mukaetova-Ladinska, 2012; Lemey & van den Ameele, 2019). Impairments at the level of brain areas controlling physiological functions can lead to various symptoms like apraxia as a manifestation of impaired coordination of muscles responsible for speech (Ahmed et al., 2016), difficulty in swallowing and incontinence.

Different stages of dementia

The course of dementia is progressive and chronic. This means that a number of functions will deteriorate over time. How this manifests and what impact it has on the person with dementia varies per individual. Regardless, the course of dementia can generally be divided into three stages: early, middle and late (Regier et al., 2017; WHO, 2020). This division is an attempt to highlight common symptoms or dysfunction per stage, deterioration over time, and the correlated need for care and support. This categorization is based on the Global Deterioration Scale of Reisberg et al. (1982), describing clinical manifestations of Alzheimer's disease. As the symptoms of dementia appear gradually, the start of the early stage is difficult to pinpoint (Steyaert, 2016, Lemey & van den Ameele, 2019). Common symptoms during this stage include forgetfulness, confusion, getting lost in familiar places, being more emotional than usual. During this stage the person generally functions well (Lemey & van den Ameele, 2019; WHO, 2020). In the middle stage the symptoms become increasingly clear.

This may include forgetting recent events and acquaintances, disturbed sleep, difficulty in communicating, wandering off. The need for support in the execution of daily tasks such as cooking, shopping, transportation and communication also increases (Prizer & Zimmerman, 2018). In the late stage, persons with dementia lose more and more vital functions like the ability to swallow, go to the toilet and eat, which makes them increasingly dependent on their surroundings for daily tasks such as personal grooming, eating and getting dressed (Prizer & Zimmerman, 2018; Sampson et al., 2018). It is important to emphasize that this description may give an idea about the progression of dementia and the related needs of a person with dementia that mainly reflect the course of Alzheimer's disease, but is not inclusive of all the varieties of dementia (Prizer & Zimmerman, 2018). People with frontotemporal dementia, for example, will require a great deal of care and support already at the early stage (Caceres et al., 2016).

No cure: shift focus toward support and prevention

There is currently no treatment to cure or change the progression of dementia. In the West, cholinesterase inhibitors (e.g. Donepezil, Reminyl) are used to moderate symptoms of Alzheimer's disease and Lewy Body dementia. However, these drugs' effectivity on the course of dementia is not always certain. Current drug treatment is therefore limited to the accompanying cognitive, neuropsychiatric and physical symptoms (Lemey & van den Ameele 2019). An exception is the recently found Aduncanumab: the first drug targeting the physiopathology of Alzheimer's disease by reducing the proteins (amyloid beta) plaques associated with development of Alzheimer's. However, this drug has been only approved in USA and the promising results are still to be confirmed on a larger scale (FDA, 2021). The search for medicated solutions for dementia continues unabated.

Meanwhile, psychosocial interventions to support persons with dementia, such as environmental adaptation, group cognitive stimulation, physical exercise and occupational therapy, are gaining attention (Mooniz-Cook et al., 2011, WHO, 2015). These approaches centralize improvement of the quality of life of persons with dementia in interaction with their caregivers. Although work remains to be done methodologically for evidence-based effectivity of the various interventions (McDermott et al., 2019; Vernooij-Dassen & Moniz-Cook, 2014), psychosocial interventions have already proven to have positive outcomes on cognition, quality of life and cost effectiveness by lowering rates of institutionalization and enhancing positive interactions between persons with dementia and their caregivers (McDermott et al., 2019; Mooniz-Cook et al., 2011).

Another recent strategy to address dementia while waiting for a curative medicated breakthrough is a focus on strategies to reduce the risk of dementia (WHO, 2017). Recent studies show that by adjusting our lifestyle, eating healthy, exercising, and not using tobacco and alcohol we can have a positive impact on reducing the risk of developing dementia (Livingston et al., 2017). It is estimated that 40% of the dementia risk and protective factors are modifiable (Wolters et al., 2020). Investing on primary prevention of dementia by promoting a healthy lifestyle seems to reduce incidence: a 70-year-old now seems to have 13% less risk of developing dementia than in 2010. Actions to moderate these risk factors are therefore promoted by the WHO (2017) global dementia plan 2017-2025. Wolters et al. (2020) do draw to our attention that this beneficial effect has only been proven in the USA and the EU, where the data did not take into account the ethnic diversity of their population. Moreover, a few aspects remain unclear, like the impact of socioeconomic and environmental aspects on dementia and its increasing incidence in other parts of the world, like Japan, China and Nigeria.

Caring for persons with dementia

The importance of informal caregiving

Globally, the majority of persons with dementia are cared for at home by informal caregivers (Erol, Brooker & Peel, 2015). This also the case in Europe (Bremer et al., 2017), as well as for 70% of persons with dementia in Belgium (Expertise Centrum Dementie, 2020 b). This tendency towards de-institutionalization or “socialization” of care is also supported and stimulated by policymakers as a way to reduce formal dementia care costs (Bremer et al., 2017). Receiving informal care seems indeed to be beneficial and cost-effective for persons with dementia. Such informal care, especially when provided by a live-in informal caregiver, has been estimated to reduce hospitalization stays from 15 to 5 days in Belgium (Cès et al., 2016). The results of a European study (Bremer et al., 2017) align with the Belgian findings: a higher amount of informal caregiving for persons with dementia seems to go along with a lower demand for home care services and nurse visits. Other benefits are better fall prevention, better nutrition and timely medical intervention (Cès et al., 2016).

On the other hand, an exclusive focus on informal caregiving has pitfalls. Informal caregivers of persons with dementia, especially those with a live-in arrangement, spend the most time providing care for older persons with dementia compared with other care-needing home-dwelling seniors – according to Cès et al. (2016), more than 10 hours compared with an average of 4.2 hours for other home-dwelling older persons. The same Belgian study warns us of a reduced potential of informal care as strategy for dementia care policy. People are less willing to choose for informal care. Informal caregivers of older persons with and without dementia complain about the lack of supportive actions, like accessible points of information, supportive professionals to guide them in the informal care process, respite care, better work leave measures and coherent financial incentives to make it feasible to provide care (Cès et al., 2016; Lopez-Hartmann, 2020). Cès et al. (2016) therefore argue that policymakers should enforce measures to enhance the capacity of informal caregivers who choose to provide informal care, to enhance the time span that they are able to provide care. A first step can be ensuring the accessibility of existing supportive services for informal caregivers of home-dwelling older persons. Under-utilization of available supportive measures and services by these informal caregivers seems to be an ongoing problem identified and confirmed by several studies (Lopez-Hartmann, 2020).

Person-centered care as the most influential care approach in professional care for persons with dementia

At a certain point during the dementia trajectory, specialized medical, home and residential dementia care is an inevitable source of care for individuals with dementia, complementing or replacing informal care. In the provision of professional care for persons with dementia several paths (e.g. relationship-centered care (Morhardt & Spira, 2013), environmental care (Ludden et al., 2019; Verbraek & van der Plaats, 2016) and embodied selfhood (Kontos, 2005)) were explored to develop suitable care approaches. A care approach that gained influence in recent years is the person-centered care of Tom Kitwood (Fazio et al., 2018; Mitchell & Agnelli, 2015). The notion of person-centered care originates from Carl Rogers’ work in the 1960s, which places individuals and their experience at the center of their own care (Fazio et al., 2018; Mitchel & Angelli, 2015). Inspired by this concept, Kitwood (1997, 2019) adapted it to the context of caring for persons with dementia as a reaction to the dominance of the biomedical approach to dementia care. In Kitwood’s person-centered care, essential psychological

needs should be considered when caring for a person with dementia. These are comfort, attachment, inclusion, occupation and identity, and come together in the central need for love (Figure 1) (Kitwood, 1997, 2019). Kitwood sees these needs as universal, but they tend to be more on the foreground among individuals with dementia because they are usually more vulnerable and less likely to be able to take action to satisfy these needs (Mitchell & Angelli, 2015).



Figure 1: The psychological needs of persons with dementia (Kitwood, 1997, 2019)

Meeting these needs contributes to the maintenance of “personhood” of the person with dementia. Personhood is defined as “a standing or status that is bestowed upon one human being, by others, in the context of relationship and social being” (Kitwood, 2019, p. 7). Kitwood emphasized the responsibility of the social environment, mainly professional caregivers, in meeting the essential psychological needs and maintenance of the personhood of persons with dementia. Meeting these needs would enable persons with dementia to better cope with stress associated with dementia and therefore improve their quality of life (Brooker, 2019 a). Kitwood believed in the direct impact of psychosocial factors on the brain’s functioning. It is the reason he emphasized the psychological wellbeing of professional caregivers and a positive organizational environment as key to better care for people with dementia (Fazio et al., 2018).

Kitwood’s initial attempts to search for interventions to customize dementia care to meet the goals of person-centered care have been furthered by other researchers after his death. The concretization of person-centered care has led to supportive interventions such as validation, inclusion of sensory-therapy like music and art, and reminiscence. Inspired by Kitwood’s work, Brooker (2019 b) developed the Dementia Care Mapping method, an approach to monitor the quality of professional dementia care mainly in residential care facilities. This method includes the feedback of persons with dementia as care receivers. Additionally, care provision by staff and organizational matters are also observed by trained Dementia Care Mapping practitioners. This method is well-known and used globally, in Belgium too (Brooker, 2019b).

Not all person-centered care-inspired interventions have been proven effective, nor have all confirmed Kitwood’s framework. The difficulty of methodological approaches to capture the impact of interventions and of comparing customized practices and interventions have been put forward as possible reasons for the limited evidence for person-centered care-inspired practices and interventions (Fazio et al., 2018; Kitwood, 2019). According to Mitchell & Agnelli (2015: p. 50), the inconsistent proof of the effectiveness of person-centered care practices should not hold us back from

seeing the biggest achievement of Kitwood's person-centered care: providing "a template that is easy to relate to, defining what can be good – or inadvertently bad – about practices". This "template" has shifted the views on dementia from being exclusively a biological problem to dementia as a feature of a depersonalizing and disabling environment (Brooker, 2019a). It has led to a movement advocated for a care culture that centralizes the voices of persons with dementia while being attentive to the support of their care providers (with limited attention to informal caregivers). Brooker (2019 a) sees this template as something that remains needed in a world that keeps functioning on reductionist paradigms about dementia in policy, research and care practice. Although evidence to support person-centered care models and interventions is not wholly conclusive, there is a consensus on the following six building blocks of person-centered care practice that lead to positive outcomes (Fazio et al., 2018): knowing the person living with dementia, recognizing and accepting the person's reality; identification and support of meaningful engagement of the person with dementia; investment in authentic, caring relationships; creation and maintenance of a supportive community for individuals, families, and staff; continuous evaluation of care practices leading to appropriate changes.

Person-centered care, together with the "social approach" of Anne-Mei The – which emphasizes the support of psychological and social needs of persons with dementia and their family caregivers, also during the initial stages of dementia (Tao of Care, 2020) – inspired the Flemish "reference framework for quality of life, housing and care for people with dementia" (Dely, Verschaegen & Steyaert, 2018). This reference framework is composed as a model for quality of housing and professional care aiming to inspire everyone who is involved in caring for a person with dementia (Dely, Verschaegen & Steyaert, 2018); it places the care relationship as a central component of quality care. This care relationship should be built on six foundations, all of which need to be present in order to deliver "good care": 1) Perception, whereby the person behind the condition always comes first; 2) The normalization principle, whereby "keeping things as normal as possible" is the basic concept and social participation is key; 3) Independence in security, whereby the person with dementia is supported in her independence but has a sense of security when needed; 4) Personalized care, whereby the formal and informal carers together with the person with dementia explore what quality of life and a sense of purpose means to them; 5) Good support and cooperation with family carers and relatives; 6) Professional carers and volunteers who can use their knowledge and skills to offer quality care in all areas of life (Dely, Verschaegen & Steyaert, 2018, p. 15). With personalized care the reference framework refers to its inspirational source of person-centered care for persons with dementia. The authors assess that providing personalized care as a variant of person-centered care is not a simple task, regardless of the setting it is offered in, be it home or a care facility. They underscore that personalized care is only achieved when the care organization has a strong vision about dementia care and an intrinsically motivated staff who are supported in their task (Dely, Verschaegen & Steyaert, 2018). This aligns with Kitwood's importance of a well-functioning organization and staff as preconditions for person-centered care (Kitwood, 1997, 2019). Dely, Verschaegen & Steyaert (2018) state that personalized care is not an achieved form of dementia care in Flanders, but something that facilities are "striving for" (p 26). Falling back into routine actions with limited room for flexibility, stereotypes about dementia, prioritization of efficiency and task orientation in care, an association of person-centered care with additional costs was identified by the authors as barriers to the provision of personalized dementia care (Dely, Verschaegen & Steyaert, 2018).

Caring for older migrants with dementia

Prevalence of dementia among migrant groups

Recent estimates counted 136,624 persons with dementia in Flanders (Vermeulen et al., 2020). The same study predicted that the prevalence of dementia would double by 2060, although accurate figures for dementia prevalence rates among the population of older migrants are scarce and difficult to identify. Canevelli et al. (2019) estimate that nearly 6.5% of overall cases of dementia in Europe involve foreign-born populations. A recent attempt calculated that approximately 7 % of older migrants above 65 in Belgium have dementia (Monsees et al., 2021). In general, the risk of dementia is estimated to be higher among non-Western populations (Gove et al., 2018; Nielsen et al., 2011b). Uysal-Bozkir (2016) demonstrated for the Netherlands that Mild Cognitive Impairment was two to four times more prevalent in the Turkish, Moroccan and Surinamese-Hindustani groups, compared to the native Dutch. Parlevliet et al. (2016) estimated that dementia affects non-Western Dutch populations, such as those of Moroccan and Turkish backgrounds, three to four times more than autochthonous Dutch. Also, earlier studies address the higher susceptibility of Moroccan older migrants to dementia-related risk factors like diabetes, high blood pressure, poverty, lower education, social exclusion and depression (Gove et al., 2018; Riffi, Devroey and Van De Vijver 2012).

Demographic data estimated higher numbers of the “oldest-old” aged 80+ among older migrants compared to their autochthonous Belgian counterparts (Lodewijcks, 2014). Recent work of Nielsen, Antelius and Waldemar (2019) does draw attention to dementia-protective factors for specific groups within this population: bilingual Turkish adults and older migrants seem to have cognitive advantages over monolingual Turkish adults and older migrants in Denmark. The latter shows that we should exercise caution when drawing general conclusions about older migrants as a homogeneous group. Based on demographic projections for older persons with a migration background, the estimated higher risk of dementia and dementia-related risk factors, and the established increase of dementia incidence with age (Prince et al., 2015), we can assume that the number of older Moroccan migrants with dementia will grow in Belgium.

Dementia and older migrants: a specific trajectory

Diagnostic challenges

Although diagnosing dementia is always subject to challenges, the process involves extra complexities among ethnic minorities in the West, leading to inadequate diagnoses. Nielsen et al. (2011a) found that in ethnic minorities dementia is underdiagnosed among those 60 and older, in contrast to overdiagnosed youngsters. Whereas 41-80% of newly referred majority patients are diagnosed with dementia in 36 European diagnostic centers, only 20% of newly referred non-European patients are (Nielsen et al., 2011b). Additionally, Danish-based studies show that most older migrants received a substandard diagnostic evaluation with an incomplete workup (which should consist of solid subsequent follow-up or treatment (Nielsen et al., 2011 c)) compared to the native population.

Multiple factors contribute to the misdiagnosis of dementia in older migrants. Besides communication problems due to language barriers, low education and cultural factors, diagnostic tests are not sensitive to literacy and do not take into account the educational system of the country of origin (Goudsmit et al., 2017; Nielsen et al., 2011 a&b; Segers et al., 2013). Several studies therefore question

the validity and reliability of diagnostic tests. MMSE (Mini Mental State Exam), a widely used diagnostic test, also in Belgium, has proven inadequate for lower-educated older migrants by several studies even when translated into the migrants' native language (Gove et al., 2018). For example, MMSE has questionable reliability because non-European patients systematically score lower on the test due to their illiteracy. Those who did have some type of schooling appear less "test-wise" because of their non-Western educational background (Segers et al., 2013). Although progress has been made in the search for reliable tests, there is as yet no tool or set of tools that is perfectly suited and completely adapted to the needs of individuals from minority ethnic groups. Some scholars evaluated and adapted the use of existing tests like the Rowland Universal Dementia Assessment Scale (RUDAS) and the Clock Drawing Test (Nielsen et al., 2018 a&b). For example, RUDAS came out as a better alternative for MMSE in diagnosing ethnic minorities in Europe, in Belgium too (Nielsen et al., 2018 a). Others developed new tests like the Cross-Cultural Dementia Screening (CCD) in the Netherlands (Goudsmit et al., 2017). This is a promising test but still has an education bias and has to be validated on a larger scale. All the above-mentioned authors advocate caution when using and interpreting diagnostics among older migrants.

Preference for family care

Providing dementia care to older non-Western migrants seems a task predominantly taken up by female family caregivers (De Graaf, 2012; Sagbakken, Spilker & Ingebresten, 2018; van Wezel et al., 2016). Ethnic minority groups appear to perceive family care as a more natural care option, as it is a task imposed by cultural and religious values (Ahmad et al., 2020; van Wezel et al., 2016). Cultural aspects appear to play a major role in defining how family care should be fulfilled. For example, ethnic minorities expect more from women (wives, daughters, daughters-in-law) (Johl, Patterson & Pearson, 2016) and adult children as caregivers (Moriarty, 2014). This is confirmed by Van Wezel et al. (2016), who examined non-European migrants in the Netherlands. Family care is seen as a task imposed by culture and religion and one ascribed primarily to women (Moriarty, Sharif & Robinson, 2014; van Wezel et al. 2016). Another recent Dutch-based study including non-European family caregivers of older migrants with dementia proposed that two moral rules are the driving force behind this gendered family care and reluctance to use professional care: reciprocal love and filial responsibility (Ahmad et al., 2020). The authors argue that these moral rules are informed by religious and cultural values, and justify an unequal care division and moral superiority toward family members who do not engage in family care.

The studies discussed above tend to paint a picture of the gendered (female) provision of family care as an exclusive issue among non-European, religious (mainly Muslim) migrant families. This assumption is debatable though. Informal dementia care is most often provided by women, even in Western countries like Belgium (Cès et al., 2016). The gendered provision of dementia care, both informal and formal, is a global issue, as argued by Erol, Brooker and Peel (2015).

Non-reliance on professional health care services and the pressures of being responsible for the care of older family members can lead to a heavy care burden (Ahmad et al., 2020 Moriarty, Sharif & Robinson, 2014; van Wezel et al., 2016). At the same time, respect and appreciation from the community appear to contribute to care satisfaction among informal caregivers (van Wezel et al., 2016). However, there are several reasons and developments for why older migrants will opt for professional healthcare services, including decreased family proximity and shifting views about family care (Ahaddour, van den Branden & Broeckeaert, 2016).

Under-use of professional dementia care

A broader image of dementia care provision among migrant families is starting to get attention from the limited studies looking at dementia care provision practices among migrant families. A Swedish-based study including 12 family caregivers of older migrants from eight non-European countries argues that there are different family patterns of dementia care provision that sometimes merge with the use of professional care (Sagbakken, Spilker & Ingebretsen, 2018). The study emphasizes the importance of examining a complexity of factors underlying migrant families' limited use of professional dementia care. This is rooted in cultural values and traditions, communication and language barriers, as well as in immigration processes, changing socioeconomic positions and lack of culturally appropriate services. The authors therefore argue that further research is needed to understand this complex picture of family care preference over professional care.

According to Mukadam, Cooper and Livingston (2013), ethnic minority groups face three critical barriers in seeking professional help when confronted with dementia. The first concerns how dementia is perceived. As compared to the majority population, ethnic minorities appear to perceive dementia as a normal consequence of aging. They do not recognize it as an illness and they attribute associated behavioral changes, such as forgetfulness, to normal ageing-related behavior (Mukadam et al., 2011; Mukadam, Cooper & Livingston, 2013; Van Wezel et al., 2016). In addition, this first generation of ageing non-European migrants with dementia in Belgium is "pioneering" in experiencing and dealing with dementia (Segers et al., 2013). Because of this, the illness and its consequences do not fit within the reference frame of these older adults and their relatives (Segers et al., 2013). This lack of conceptualization and knowledge about dementia can therefore be an underlying factor for the hampered access to dementia care (Mukadam, Cooper & Livingston, 2013; Nielsen & Waldemar 2015; Segers et al., 2013). The second barrier concerns society- and community-related factors. Care for relatives is perceived as an engagement that family members will perform until it becomes unmanageable or otherwise unfeasible. The third barrier refers to the healthcare system and the experience with healthcare professionals. European healthcare systems present structural barriers toward ethnic minorities, leading to inequity in accessing this care. Such barriers result from national policies of lesser entitlement to healthcare for ethnic minorities in combination with the "one size fits all" approaches practiced by healthcare facilities (Ingelby, 2012). These structural barriers are enforced by personal and cultural barriers, thereby leading to underuse of dementia care by ethnic minorities (Mukadam, Cooper & Livingston, 2013). The pressure to care for one's parents, the sense of stigma felt when using the services, together with the experienced or perceived lack of culturally suitable care for older people, reinforce the hesitation to make use of these services (Sagbakken, Spilker & Ingebretsen, 2018). All the above studies underscore the need for culturally appropriate dementia services through which ethnic minority older individuals and their relatives can receive support that is both effective and positive.

Culturally competent care as professional care approach for older migrants with dementia

Considering the different cultural background of older migrants in care seems to be the general thread in recommendations for professional care approaches toward older migrants, and more specifically those with dementia (Gove et al., 2018). Although policymakers claim to follow the logic of these recommendations, their actual dementia plans and dementia care strategies show otherwise. A recent

comparison of national dementia plans and strategies for dementia care targeting older migrants with dementia reveals that the focus on cultural background plays a subordinate role in the compared European (EU and EFTA (European Free Trade Association)) countries (Schmachtenberg et al., 2020). The same study shows the unclarity about who is considered a migrant or an older migrant: the label seems to include a broad group ethnic or religious minorities, asylum seekers and refugees, mostly from non-EU countries. Furthermore, the limited plans for dementia care for older migrants with dementia emphasize addressing the different cultural needs of this group. The Flemish ambition on this matter illustrates this aspect: “Flanders has set the goal of developing culturally sensitive care services. For this purpose, Flanders would like to use the knowledge on culturally sensitive care for migrants from Erasmus Hogeschool’s research and implement it in specific projects such as dementia-skilled training and the consultation platform of dementia.” (Schmachtenberg et al., 2020, pp. 4-5).

To address the different care needs associated with older migrants from a different cultural background, several terms are used: culturally sensitive care, intercultural care, culturally competent care (Gove et al., 2018). Cultural sensitivity is generally used to refer to the sensitivity manifested toward people’s cultural backgrounds (Gove et al., 2018). The term tends to be employed in a White, Western context, in relation to the “cultural other” with an unclear definition of what is considered culture, which is confusing and in some cases even meaningless (Torres, 2019). Conversely, attention to having “a different cultural background” is barely addressed in the general dementia care approaches discussed above. No reference is made to cultural diversity in Kitwood’s person-centered care, and limited attention to cultural diversity is found in the Flemish framework for dementia care (Dely, Verschaegen & Steyaert, 2018; Kitwood, 1997, 2019). Kitwood’s person-centered care generally does not refer to culture as an influential factor in care: providing care is seen as a relationship between individuals (Dewing, 2019). According to Dewing (2019) the emphasis on individuality in person-centered care makes it a Westernized concept. On the other hand, the Flemish reference framework refers to the cultural diversity of persons of dementia solely as a result of non-EU migration, viewing culturally sensitive care as the answer to culturally informed specific needs. Culturally sensitive care is seen as an application of the framework, categorized together with other possible applications of the framework like architecture, in the field of “environment” (Dely, Verschaegen & Steyaert, 2018).

Culturally competent care is seen as a competency involving a set of knowledge, skills and attitudes to achieve cultural sensitivity in practice (Gove et al., 2018). Or, to quote Weech-Maldonado et al. (2012, p. 2), culturally competent care “is achieved through policy tools, learning processes, and structures through which organizations and individuals develop attitudes, behaviors, and systems that are necessary for effective cross-cultural interactions”. Gaining cultural competence as professional caregivers is considered a complex process of skills and attitude development (Olaussen & Renzaho, 2016). Such a process of growth is illustrated in the “cultural competence continuum” of Cross et al. (1989) with six stages of cultural competence: 1) Cultural destructiveness (attitudes, policies and practices that use one’s power to eliminate the culture of another) 2) Cultural incapacity (attitudes, policies and practices that promote the superiority of one’s own culture while disempowering another’s culture); 3) Cultural blindness (attitudes, policies and practices that deny (cultural) differences between cultural groups), 4) Cultural pre-competence (attitudes, policies and practices recognizing cultural differences while acknowledging limitations in people’s skills and gaps in an organization’s practices); 5) Cultural competence (attitudes, policies and practices that proactively recognize cultural differences, and engage in ongoing education of oneself and others); 6) Cultural proficiency (attitudes, policies and practices that hold culture in high esteem, where older migrants

with dementia in this case are seen as a resource of personal change and transformation, and allies in an interdependent care relationship).

Regardless of which term is used, considering the ethnic cultural background of persons in care is believed to be the approach to ameliorate care provision. Culturally competent care has been argued to increase positive health outcomes and positive care relationships between cultural minority patients/clients and majority professional caregivers ((Olaussen & Renzaho, 2016). Intercultural care and support, conceptualized “as looking at ways to respect and respond to the cultural diversity of people with dementia, their relatives and friends and of those caring for people with dementia” (Gove et al., 2018, p. 6) is, according to Alzheimer Europe, also a way to move forward toward inclusive dementia care for older migrants with dementia (Gove et al., 2018). Although the different used terms and concepts of culturally sensitive care may aspire to guarantee better care for ethnic/cultural minorities, care practices show differently. In care practices, professional caregivers seem to perceive and implement culturally sensitive care, narrowly leading to the “othering” – as a form of micro-racism – of migrant care recipients (Claeys et al., 2020). More critique is therefore expressed in the emphasis on “culture” in culturally sensitive/competent care – care that may give the impression that only the migrant/ethnic minority “other” has a culture while professional caregivers from the dominant cultural group do not consider how their convictions and actions are culturally colored (Torres, 2019). Moreover, it starts from a one-sided definition of culture: culture only as the result of belonging to an ethnic group, whereas one’s own culture, or how we give meaning to the world in which we live, is dynamic and takes shape through belonging to different social groups (Van Robaeys, 2014). It also may give the impression that high-quality care for the cultural other is a cookbook recipe (Torres, Agard & Milberg, 2016). Moreover, the compass in provision of culturally sensitive care is mainly guided by assumptions about the cultural other, without an eye for complexity or diversity (Torres, Agard & Milberg, 2016; Kirmayer & Jarvis 2019).

Conducting research on older migrants with dementia

Issues related to older migrants with dementia are under-researched (Gove et al., 2019). The fact that older migrants and their family caregivers are considered as hard-to-reach participants in research is a common explanation for the limited research on older migrants and dementia (Gove et al., 2019). Torres’ scoping review (2019) of the last two decades of research on ethnicity and old age reveal other issues about gerontological research that can be extended to dementia research on older migrants. Torres (2019) concludes that gerontological research must overcome five challenges in order to more effectively address the intersection of ethnicity and old age:

First, the reviewed research is based mainly on literature from the United States, which tends to include only a narrow sample of ethnic diversity (Black and Hispanic groups) and mostly with reference to the majority group (“Whites”) (e.g. Ivey et al., 2012, Johl, Patterson & Pearson, 2016).

Second, a vast majority of research practices addressing limited topics (such as health inequalities, health and social care, intergenerational relationships, and caregiving) were not guided by a clear research agenda in addressing the intersection of ethnicity with these ageing-related topics (e.g. McDonald, 2011, Phillipson, 2015). In other words, ageing-related topics like health inequalities were the focus of the research, not questions related to ethnicity.

Third, studies often begin from a rather essentialist understanding of ethnicity that assumes that ethnic (and racial) groups are homogeneous and fixed “beings” that are easily identified (Johl, Patterson & Pearson, 2016). This stagnated understanding of ethnicity informs the non-differentiation between ethnicity, race, minority and culture in such research. The terms are conflated and their use is semantically ambiguous. This reflects how such groups are predominantly seen – namely, as the “other”, with an ethnicity – without recognizing key differences, such as that between ethnic minority status and racial status, or between an ethnic minority with immigration experience and one without. Ethnicity is often viewed as something only the “others” have, and experienced problems are often explained as something specific due to their ethnicity (race, minority status and/or culture). This “other” is also often compared to the normative group of older persons that is autochthonous, White and Western.

Fourth, in addition to the conflation of ethnicity, race and culture, gerontological studies on the intersection of old age and ethnicity seldom operationalize their angles of investigation. For example, the vast majority of studies about the differences in caregiving networks between White, Black and Hispanic respondents, as reviewed in Chapter 6 of Torres’s book (Torres, 2019), do not operationalize what they mean by cultural values. These studies found differences between groups and attributed them to either cultural values or ethnicity/race, without actually studying this angle.

Fifth, gerontological scholarship on the intersection of ethnicity and old age appears to rely upon a small number of methodological approaches. Two shortcomings are identified. First, a large number of studies rely upon narrow study designs, mainly quantitative, that were not actually designed to investigate the intersection of old age and ethnicity. The second methodological shortcoming identified relates to the use of a narrow approach to the social positions studied. Most studies lack intersectional approaches and rely on “the one variable at a time approach”, thereby disregarding other societal positions – such as gender, class, and historical and regional differences – as influencing aspects in the topic addressed in the intersection of ageing and ethnicity.

These five challenges lead to two negative outcomes. First, a reproduction of narrow assumptions about ethnic “others” and old age. Or as Torres (2019a: 3062) formulates: “that are passed on as ‘research findings’ by sheer virtue of the fact that we have attached a reference to them and made them seem like they are evidence-based understandings”. Second, the way current gerontological research involving older persons from ethnic minorities is conducted reproduces societal inequality within and through research itself.

2. Research Gaps & Questions

Research gaps

Gap 1: Limited knowledge about dementia and older migrants in Belgium

We learned from Part 1 that knowledge about dementia experience and dementia care among ethnic minorities is limited and still in development. What we know about the situation of older migrants with dementia has its sources mainly in countries with a longer history of ethnic diversity, as is the case in the US, UK and Australia. Research on this topic in continental Europe is very limited (Gove et al., 2018). To our knowledge, there is no expertise on this topic in Belgium (Smachtenberg et al., 2020). This dissertation is therefore a first contribution to this topic in Flanders and Belgium.

Gap 2: Culture as dominant one-sided gaze to examine the situation of older migrants with dementia

Not only is this topic under-researched, the dominant image drawn from the available studies seems to be a one-sided emphasis of the importance of “culture” in the dementia experience and care provision among families with a migration background. These studies agree that the cultural background of older migrants with dementia and their family caregivers is key in addressing their experience of dementia, provision of family care, and access to professional dementia care (Gove et al. 2018). And yet it is often unclear what exactly is meant by “cultural background”, as ethnicity, culture and religion are used fluidly and interchangeably (Torres 2019). Having a different cultural background is also mainly presented as underlying reason for migrant families’ preference for family care and the underusage and even rejection of formal dementia care (van Wezel, 2016; Gove et al., 2018, Ahmad et al., 2020). Still, Sagbakken, Spilker & Ingebersten (2018) argue that a more complex picture about family dementia care provision can also be drawn among migrant families. With this study we therefore aim to examine nuances in the dementia care experience and dementia care provision among families with a labor migration background.

Gap 3: Limited knowledge on how to conduct ethical research on dementia among older migrants

In 2019 Alzheimer Europe (Gove et al., 2019) published a research report manifesting a growing awareness that the way current dementia research is conducted can lead to underrepresentation of marginalized subgroups with dementia, like ethnic minorities with and without a migration background. These groups are easily considered as hard-to-reach and portrayed as homogenous, leading to distorted knowledge about them. The authors consider that this research practice leads to unequal outcomes for these groups. They illustrate with a blunt image about the experiences of dementia and its needs that hamper the development of adequate dementia care. The report was therefore an attempt to raise awareness about this overlooked spot in dementia research. It also invites researchers and research systems to a more inclusive and ethical way of conducting research on dementia and migrant/nonmigrant ethnic minorities. A suggested angle to look at my own research on the topic was Crenshaw’s concept of intersectionality as described on page 23 of the report:

Whilst it is important to identify characteristics which are commonly associated with discrimination, it is also important to look at ways in which socially constructed categories intertwine and may create new forms of discrimination which are not immediately obvious

(Angelucci 2017). This is often described as intersectionality, a term coined by Kimberlé Crenshaw in 1989 to describe the different lines of oppression and marginalisation in society that can affect a person, based on their ethnicity, age, gender, ability, sexual orientation, class or the intersection of two or more of those aspects. It is a lens to explain the underlying mechanisms of the multidimensionality of marginalised subjects' lived experiences (Nash 2008). Intersectionality therefore provides a lens to address complexities that different identities entail and the position of these identities, as an advantage or disadvantage, on a structural level.

Alzheimer Europe's report confirmed the general gaps in research on ethnicity and old age identified by Torres' review (2019, pp. 22-23). Torres suggested intersectionality as possible gaze to transcend the one-sided portrayals of older migrants in research and to avoid reproduction of societal inequality within and through research itself. Both works encourage examination of how research on older migrants can avoid these pitfalls and strive toward a more nuanced representation of the realities of this underresearched group.

Research Questions

The overarching goal of this dissertation is to contribute to knowledge about dementia experience and dementia care provision among older migrants' families. As labor migrants form the first wave of older migrants in Belgium, the focus will lie on these Belgians with a migration background who are facing dementia. More specifically, it zooms in on Moroccan families as the largest group of Belgian citizens with a migration background. This general aim is divided into two central aims:

- a) Exploring a multilayered image of the dementia experience and dementia care provision among labor migrant families.
- b) Exploring methodological pathways to contribute to more ethical research involving this population.

These aims are translated into four research questions corresponding with the two aims:

Aims	Research questions
Aim A	1) How are dementia and dementia care experienced by Moroccan families in Belgium? (RQ1) 2) How is dementia care currently provided to older Moroccan migrants? (RQ2) 3) Which factors influence the dementia care provision? (RQ3)
Aim B	4) How can we improve gerontological research on older migrants and their family caregivers? (RQ4)

3. Methodological approach

The initial intention of this dissertation was to conduct research on Gaps 1 and 2, aiming to detect nuances formulated by the research participants when addressing the research questions about dementia experience and dementia care provision. The literature available on dementia and older migrants mentioned earlier portrayed a rather essentialist one-sided image of dementia and older migrants. Culture as dominant gaze to examine the specific situation of older migrants with dementia is still the prevailing narrative about this group (Gove et al., 2018; 2019). In other words, the third (essentialist) and fourth (lack of operationalization of concepts as culture) approaches challenged in Torres' review (2019) are rather present in dementia research on older migrants with dementia. This one-sided image conflicted with the field experience of the dissertation author. This experience has led to cautiousness not to recreate one-sided stories about the situation of older migrant families dealing with dementia while attempting to capture their reality. A quote by D.H. Lawrence reflects the initial caution at the start of the dissertation: "The map appears to us more real than the land". Being led by the reassuring effect of a structured map can keep us from seeing the nuances and the complexity of a reality. The map can be seen as a metaphor for the methodology used. This reflects the initial general awareness of the importance of the choice of methodology, which induced a methodological search and reflection process for this dissertation.

As the focus of the empirical part of this dissertation lies on the experience of dementia and dementia care provision among migrant families, the choice for a qualitative approach was relevant. Qualitative approaches have proven their suitability in social gerontological research: "to learn about the voices of marginalized persons, understand the thoughts and processes that people engage with in their everyday lives, and potentially develop theory" (Phoenix, 2018, p. 81). Qualitative research has also been recommended for conducting gerontological research on insufficiently understood matters and complex topics like care provision (Cobb & Forbes, 2002; Phoenix, 2018). The merger of two gazes, constructivist grounded theory and critical gerontology, shaped this qualitative inquiry.

Looking through constructivist grounded theory

The search and reflective process started by adopting an inductive qualitative research method inspired by constructivist grounded theory (CGT) (Charmaz, 2017) for research questions 1, 2 and 3, while reflecting on how methodology can contribute to a nuanced picture about this research topic. Grounded Theory, developed by Glaser & Strauss (1967), is a qualitative research method whose defining purpose is to develop new concepts through the research process that offers an abstract understanding of one or more core concerns regarding the studied topic (Charmaz & Thornberg, 2020). The research process determines the analytical focus rather than it being determined before the empirical inquiry starts. The logic of the method is simultaneous data collection and analysis. This approach helps researchers "steadily focus on developing concepts about the data and to gather further data that flesh out their nascent concepts" (Charmaz & Thornberg, 2020, p. 3). It moves beyond a descriptive synthesis of data toward constructions of new concepts that help explain what is happening. The Grounded Theory approach is considered suitable for several research targets: exploring new areas of study, understanding a process, making situations of unheard people visible, developing recommendations for policy and professional practice (Charmaz & Thornberg, 2020). All of these aspects are present in this dissertation.

GCT is a contemporary version of Grounded Theory that uses the methodological strategies of the original version of Grounded Theory, of a cyclic engagement with and collection of data by initial, focused and theoretical coding and memo writing, but emphasizing the following aspects (Charmaz & Thornberg, 2020):

- 1) Permission to use existing research and theoretical literature but with critical skepticism.
- 2) Assumption that data is co-constructed with research participants, highlighting the importance of engaging in good relationships with research participants while seeking to understand meanings and actions instead of explaining or predicting them.
- 3) Awareness that data analyses and methods are constructed in specific times, locations and situations and therefore cannot lead to context-free generalizations regardless of time, place and individuals, or be based on neutral methods. Methods are considered to be resting on values that are predominantly from the global north due to “exportation” of qualitative methods from that area.

CGT advocates therefore for a development of “methodological self-consciousness” through reflexivity “about unearned privileges such as those deriving from race, gender, social class, and/or health” (Charmaz, 2017, p. 5) and how these power-related aspects influence our data and data collection practices.

Methodological self-consciousness means taking a reflexive stance to detect and dissect “our worldviews, language, and meanings and revealing how they enter our research in ways we had previously not realized.” (Charmaz, 2016). Individualization, as a Western exported value, dominates current qualitative approach (Charmaz, 2016; Charmaz & Thornberg, 2020): this is often seen in the fact that data is collected and analyzed at the individual level. Hence methodological self-consciousness invites the interrogation of this tacit methodological individualism. It includes examination of researchers’ actions and interaction with research participants during the research process, plus careful consideration of how data is collected and analyzed. The latter means taking time to think, for example, about how to find participants; how to engage with participants; what is the position of the participants in the interaction with research and researchers; how do values influence our field notes; and analysis aspects.

Looking through a critical gaze

Essential in methodological self-consciousness as a reflexive process suggested by GCT is doubt (Charmaz, 2016; Charmaz & Thornberg, 2020). This is doubt about tacit assumptions, about research practices, leading to critical research methodologies that connect individual views, meanings and experiences with collective institutionalized processes, and which allow questions on how these individual views, meanings and experiences are situated in accordance with macro-level processes like social justice and inequities (Charmaz, 2016). In other words, the CGT approach supports/reinforces critical thinking during the research process. This is important when investigating topics concerning underresearched and unheard voices, like migrant families dealing with dementia. By adopting this critical attitude for conducting research, this dissertation situates itself within critical gerontology.

Critical gerontology emerged in the 1980s as “a vibrant and hybridized sub-field blending humanities and social science ideas to broaden aging studies beyond biomedical models and ageist social policies and practices” (Katz, 2019, p. 396). The “critical” in critical gerontology “includes a strong reflexive and

self-critical dimension about the subjective conditions of doing gerontological research, especially in the face of gerontology's claim to be an objective science." (Katz, 2015, p. 21). Critical gerontology therefore questions "neutrality" in research and is aware of how dominant social constructs and macro-mechanisms influence the way we conduct research. Critical gerontology likewise questions how epistemological choices contribute to further marginalization of the studied groups (Baars, 1991), and argues that it is important not only to focus on individual aspects of ageing but to examine how macro-mechanisms and power structures influence the individual experience of ageing (Baars et al., 2006). Critical gerontology has a tradition to look to its own discipline for inspiration, and fuses inspiration from critical theory, feminist theory and political economy (Moody, 2008; Baars et al., 2006). It is also critical gerontologists who have raised critical questions about how gerontological research is conducted on the intersection of ageing and migration, such as the above-mentioned essentialist use of ethnicity in gerontological research (Zubair & Norris, 2015; Torres, 2015).

To sum up, Constructive Grounded Theory and critical gerontology seem to share common ground to conduct critical gerontological research with awareness of the social construct of research, emphasizing reflexivity during the research process with attention to what defines researchers' choices and actions during research.

Reflexivity of the author

As mentioned earlier, both CGT and critical gerontology promote reflexivity through methodological self-consciousness (CGT) or self-scrutinization as formulated by critical gerontologist Katz (2015). As this process is close to the person of the researcher, this Section will be written in first-person form. Reflecting on several aspects defining my intersectional social position, life and environments is challenging and can be done elaborately, resulting in papers and even dissertations (Katz, 2015). However, for the purpose of this dissertation I chose to put forward three aspects resulting from a broader reflexive approach that were important in the research process leading to the dissertation:

1) Experienced tension between education and field experience

The experience of this tension fueled my methodological self-consciousness during the entire process of this dissertation. As a master in biomedical sciences and gerontological sciences, my training highlighted the following aspects of scientific research: distance, objectivity, neutrality, categorization, comparison, generalization. My field working experience with people in general, and with ethnic minorities more specifically, highlighted the aspects of flexibility, fluidity, complexity, tailored approaches, influence of structures and systems. It was the first time in my life that these two axes of experience came together and I had to navigate between their conflicted messages. This led to a process of reading books, discussions with activists and academics of color, and making field notes, initially meant as my own personal trajectory to understand what is going on. This soon changed into the insight that this personal process is what Charmaz (2017) calls "methodological self-consciousness", and that it has to be integrated into the process of the dissertation. This led to research question 4, with two papers echoing parts of this reflection process. The two papers are different and reflect the evolution of my thinking and learning process, starting with how to conduct research on dementia experience among migrant families (Chapter 5) and evolving to insights about improving gerontological research on the intersection of aging and ethnicity (Chapter 6).

2) Being perceived as a woman of color with a migration background

Like everyone else, my social position is defined by age, gender, race, ethnicity, ability,... and the intersections of these socially constructed categories, also known as intersectionality (Crenshaw, 1989). In this Section I only focus on the intersection of gender, ethnicity and having a migration history. Being perceived as a woman of color with a migration background in Belgium is a dominant constructed category into which I am perceived to fit during my adult life in Belgium, even if this mostly disagrees with my self-categorization. This reductionistic category has impacted my life and accordingly also my research process. In interaction with family caregivers with a migration background, this position was mainly an asset to gain access to families, build a trust relationship with them, and understand the different facets of their experience, the different roles that you have to fulfill as a woman in relation to family, kids, work, community, society; the experiences of discrimination and racism; the bridging role between my own reality, influenced by being in a diaspora, and the rest of societal structures like professional care and transnational ties.

However, I was aware of the pitfalls of this recognition of background from my perspective and that of family caregivers, namely to forget the diversity within positions and experiences, even with this shared intersection. I therefore kept asking questions and observing non-verbal communication, moments of silences, and moments when I thought “yes, I understand you”. I was also aware that this intersection is also influenced by my socioeconomic position. This means that I represented something unfamiliar to some family caregivers: a highly educated researcher linked to an institution. This position also came with privileges (e.g. having competencies, thanks to my education and work experience, to navigate White institutions, which is helpful for communicating with professional caregivers with a Belgian background) that shaped my context – a context far from that of some family caregivers who were lower educated and/or first-generation migrants.

On the other hand, being perceived as a woman of color with a migration background in Belgium also had a negative influence with respect to autochthonous professional caregivers I interviewed and my peers in academia. There was a risk of being assimilated into the topic and the researched group, leading to reactions indicating that my position as an academic is overlooked and essentializing me to “an expert by experience”. This can often lead to hidden and sometimes outspoken assumptions of being subjective, less qualified as a researcher, and therefore not to be taken seriously. This experience of colored/diaspora female academics is beautifully expressed by Grada Kilomba (2016/2020, pg. 26):

*When they speak, it is scientific;
When we speak, it is unscientific.
When they speak, it is universal;
When we speak, it is specific.
When they speak, it is objective;
When we speak, it is subjective.
When they speak, it is neutral;
When we speak, it is personal.
When they speak, it is rational;
When we speak, it is emotional.
When they speak, it is impartial;
When we speak, it is partial.*

*They have facts, we have opinions.
They have knowledges, we have experiences.
We are not dealing here with a 'peaceful
Coexistence of words' but rather with a
Violent hierarchy, which defines Who can
Speak, and What We Can Speak About.*

3) Lack of experience with dementia and dementia care provision

By the start of this dissertation the only knowledge I had about dementia and dementia care provision was learned from my gerontology textbooks. I didn't know anyone with dementia in my close environment nor had experience in providing care to a person with dementia as a family or professional caregiver. I considered this as a blind spot that had to be compensated for by using my auditive, visual and sometimes tactile senses in trying to capture the experience of what it means to live with someone with dementia, to provide informal care to a person with dementia (with a migration background), or to provide professional care to a person with dementia (with a migration background). A positive aspect of this distancing from the experience is that I was less tempted to fill in what some experiences mean. On the other hand, it also prevented me from having a deeper understanding of some experiences. This hypothesis was confirmed in a later stage of this dissertation when my uncle, a first-generation Moroccan migrant, developed dementia and the family asked me to search for a dementia day center sensitive to the needs of older migrants. The time and effort I had to put into this quest for a day center, with my privileged socioeconomic position, was fruitless in the end. After just one visit to the day center my uncle was no longer welcome because – as formulated by the day center director – “He cannot speak our language”! This experience made me re-examine on a deeper level the testimonies given by the family caregivers included in this study.

4. Dissertation Outline

The following table outlines the different chapters of this dissertation.

Table 1: Overview of the articles included in this dissertation

Chapters	Type of study	Population	Research question addressed	Publication status
Chapter 2: Invisible realities: Caring for older Moroccan migrants with dementia in Belgium.	Study 1 Qualitative cross-sectional study	12 (+3) informal and 13 (+3) professional caregivers (n= 31)	RQ1 & RQ3	Published in Dementia
Chapter 3: Caring for migrant older Moroccans with dementia in Belgium as a complex and dynamic transnational network of informal and professional care: A qualitative study.	Study 2 Qualitative cross-sectional study	12 (+3) informal and 13 (+3) professional caregivers (n= 31)	RQ2 & RQ3	Published in International Journal of Nursing Studies
Chapter 4: Influence of religion in the experiences of family caregivers of older migrants with dementia.	Study 3 Qualitative cross-sectional study	34 religious and non-religious family caregivers caring for older migrants with dementia of Moroccan, Turkish and Italian origin	RQ2 & RQ3	Under revision in Journal of Religion and Health
Chapter 5: How to (qualitatively) involve older people with dementia and their informal carers with a migration background in research? Insights from a longitudinal project in Brussels.	Study 4 Qualitative cross-sectional study & literature review	10 experts	RQ4	Published in Proceedings of European Congress of qualitative inquiry
Chapter 6: Doing research on the intersection of ethnicity and old age: Key insights from decolonial frameworks.	Study 5 Theoretical paper	No population	RQ4	Published in Journal of Aging Studies
Chapter 7: General discussion	Discussion of the main results of all five studies		RQ 1, 2, 3 & 4	Discussion of the five papers

References

- Ahaddour, C., van den Branden, S., & Broeckaert, B. (2016). Institutional Elderly Care Services and Moroccan and Turkish Migrants in Belgium: A Literature Review. *Journal of Immigrant and Minority Health*. <https://doi.org/10.1007/s10903-015-0247-4>
- Ahmad, M., Broeke, J. Van Den, Saharso, S., & Tonkens, E. (2020). Persons With a Migration Background Caring for a Family Member With Dementia: Challenges to Shared Care. *Gerontologist*, *60*(2), 340–349. <https://doi.org/10.1093/geront/gnz161>
- Ahmed, S., Baker, I., Thompson, S., Husain, M., & Butler, C. R. (2016). Utility of testing for apraxia and associated features in dementia. *Journal of Neurology, Neurosurgery and Psychiatry*, *87*(11), 1158–1162. <https://doi.org/10.1136/jnnp-2015-312945>
- Albert, I., Ferring, D., & Lang, F. R. (2016). Introduction to the Special Issue on 'Aging and Migration in Europe'. *GeroPsych*, *29*, 2, 53-5. Botsford, J. 2015. Introduction. In Julia Botsford and Karen Harrison Denning (eds), *Dementia, Culture and Ethnicity, Issues for All*. (pp 9-18). London: Jessica Kingsley Publishers
- Berdai, S. (2005). Vergrijzing... een kleurrijk gegeven! Brussel: Vlaamse Gemeenschapscommissie.
- Baars, J. (1991). The challenge of critical gerontology: the problem of social constitution. *Journal of Aging Studies*. *5*(3), 219-243.
- Baars, J., Dannefer, D., Phillipson, C., & Walker, A. (2006). *Aging, globalization, and inequality: The new critical gerontology*. Amityville, NY: Baywood Publishing Company.
- Berriane, M., de Haas, H., & Natter, K. (2015). Introduction: revisiting Moroccan migrations. *Journal of North African Studies*, *20*(4), 503–521. <https://doi.org/10.1080/13629387.2015.1065036>
- Bremer, P., Challis, D., Hallberg, I. R., Leino-Kilpi, H., Saks, K., Vellas, B., Zwakhalen, S. M. G., & Sauerland, D. (2017). Informal and formal care: Substitutes or complements in care for people with dementia? Empirical evidence for 8 European countries. *Health Policy*, *121*(6), 613–622. <https://doi.org/10.1016/j.healthpol.2017.03.013>
- Brooker D. (2019 a) preface. In Kitwood T (2019) *Dementia reconsidered, revisited. The person still comes first*. (Eds. Brooker, D.) London: Open University Press
- Brooker, D. (2019 b) Personhood maintained. In Kitwood T (2019) *Dementia reconsidered, revisited. The person still comes first*. (Eds. Brooker D.) (pp 78-82) London: Open University Press
- Bousetta, H., & Martiniello M. (2003). Marocains de Belgique: du travailleur immigré au citoyen transnational. *Hommes et Migrations* 1242: 94–106.
- Buffel, T. (2015). Ageing Migrants and the creation of home: mobility and the maintenance of transnational ties. *Population, Space and Place*. <https://doi.org/10.1002/psp.1994>
- Caceres, B. A., Frank, M. O., Jun, J., Martelly, M. T., Sadarangani, T., & De Sales, P. C. (2016). Family caregivers of patients with frontotemporal dementia: An integrative review. *International Journal of Nursing Studies*, *55*, 71–84. <https://doi.org/10.1016/j.ijnurstu.2015.10.016>
- Canevelli, M., Lacorte, E., Cova, I., Zaccaria, V., Valletta, M., Raganato, R., Bruno, G., Bargagli, A. M., Pomati, S., Pantoni, L., & Vanacore, N. (2019). Estimating dementia cases amongst migrants living in Europe. *European Journal of Neurology*, 1191–1199. <https://doi.org/10.1111/ene.13964>
- Charmaz, K. (2016). The Power of Constructivist Grounded Theory for Critical Inquiry. *Qualitative Inquiry*, *23*(1), 34–45. <https://doi.org/10.1177/1077800416657105>
- Charmaz, K. (2017). Special Invited Paper: Continuities, Contradictions, and Critical Inquiry in Grounded Theory. *International Journal of Qualitative Methods*, *16*(1), 1–8. <https://doi.org/10.1177/1609406917719350>

- Charmaz, K., & Thornberg, R. (2020). The pursuit of quality in grounded theory. *Qualitative Research in Psychology*, 00(00), 1–23. <https://doi.org/10.1080/14780887.2020.1780357>
- Cerejeira, J., Lagarto, L., & Mukaetova-Ladinska, E. B. (2012). Behavioral and psychological symptoms of dementia. *Frontiers in Neurology*, MAY(May), 1–21. <https://doi.org/10.3389/fneur.2012.00073>
- Cès, S., Schmitz, O., Lambert, A., Pauwen N. & Macq, J. (2016). Mantelzorgers van thuiswonende ouderen in België: een cruciale en complexe rol. Data-onderzoek. Brussels: KBS-FRB
- Claeys, A., Berdai Chaouni, S., Tricas-Sauras, S., De Donder, L. (2020). Culturally sensitive care: definitions, perceptions, and practices of health care professionals. *Journal of Transcultural Nursing*. <https://doi.org/10.1177/1043659620970625>
- Ciobanu, R. O., Fokkema, T., & Nedelcu, M. (2017). Ageing as a migrant: vulnerabilities, agency and policy implications." *Journal of Ethnic and Migration Studies*. 43(2): 164-181. doi: 10.1080/1369183X.2016.1238903
- Cobb, A.K. & Forbes, S. (2002). Qualitative research: what does it have to offer to the gerontologist? *Journal of Gerontology: Medical Sciences*, 57 (4) 197-202.
- Crenshaw, K. (1989). Demarginalizing the Intersection of Race and Sex: A Black Feminist Critique of Antidiscrimination Doctrine, Feminist Theory and Antiracist Policies. *The University of Chicago Legal Forum*, (1), 139–167. <https://doi.org/10.1525/sp.2007.54.1.23>.
- Cross, T. L., Bazron, B. J., Dennis, K. W., & Issacs, M. R. (1989). Towards a culturally competent system of care: A monograph on effective services for minority children who are severely emotionally disturbed. <https://files.eric.ed.gov/fulltext/ED330> 171.pdf
- Cuyvers, G., & Kavs, J. (2001). De huidige en toekomstige behoeften van allochtone ouderen aan welzijns- en gezondheidsvoorzieningen. Geel: Katholieke Hogeschool Kempen; Brussel: Ministerie van de Vlaamse Gemeenschap
- De Graaff, F. M., Mistiaen, P., Deville, W. L., & Francke, A. L. (2012). Perspectives on care and communication involving incurably ill Turkish and Moroccan patients, relatives and professionals: A systematic literature review. *BMC Palliative Care*, 11, 1–35.
- Dewing, J. (2019) On being a person. In Kitwood T (2019) *Dementia reconsidered, revisited. The person still comes first*. (Eds. Brooker D.) (pp 17-23). London: Open University Press
- Dely, H., Verschraegen, J. & Steyaert, J. (2018). *You and me, together we are human: a reference framework for quality of life, housing and care for people with dementia*. Antwerpen: EPO
- Erol, R., Brooker, D. & Peel, E. (2015). *Dementia and Women: an international review*. London: Alzheimer's Disease International (ADI)
- Expertise Centrum Dementie Vlaanderen. (2020 a) <http://www.dementie.be/home/sample-page/prevalentie/> Retrieved on 15 December 2020
- Expertise Centrum Dementie Vlaanderen. (2020 b). <http://www.dementie.be/home/sample-page/vormen/> Retrieved on 15 December 2020
- Fazio, S., Pace, D., Flinner, J., & Kallmyer, B. (2018). The Fundamentals of Person-Centered Care for Individuals with Dementia. *Gerontologist*, 58, 10–19. <https://doi.org/10.1093/geront/gnx122>
- FDA. (2021). FDA's decision to approve new treatment for Alzheimer's disease. <https://www.fda.gov/drugs/news-events-human-drugs/fdas-decision-approve-new-treatment-alzheimers-disease> Retrieved on 23 June 2021
- Glaser, B. G., 1 Strauss, A. L. (1967). *The discovery of grounded theory: Strategies for qualitative research*. New York: Aldine de Gruyter.

- Goudsmit, M., Uysal-Bozkir, Ö., Parlevliet, J.L., van Campen, J.P.C.M., de Rooij S.E. & Schmand, B. (2017). The Cross-Cultural Dementia Screening (CCD): A new neuropsychological screening instrument for dementia in elderly immigrants. *Journal of Clinical and Experimental Neuropsychology*, 39(2), 163–172.
- Gove, D., Georges, J., Nielsen, T. R., Plejert, Ch., Rauf, M.A., Lahav, D., Jaakson, S., Kaur, R., Her, M., Parveen, S., Golan-Shemesh, D. & Smits, C. (2018). The development of intercultural care and support for people with dementia from minority ethnic groups. *Alzheimer Europe: Ethics Report*. <https://www.alzheimer-europe.org/Ethics/Ethical-issues-in-practice/2018-Intercultural-care-and-support>
- Gove, D., Georges, J., Rauf, M. A., van den Broeke, J., Berdai Chaouni, S., Claeys, A., & Watchman, K. (2019). Overcoming ethical challenges affecting the involvement of people with dementia in research: Recognising diversity and promoting inclusive research. *Alzheimer Europe: Ethics Report*. [https://www.alzheimer-europe.org/Ethics/Ethical-issues-in-practice/2019-Overcoming-ethical-challenges-affecting-the-involvement-of-people-with-dementia-in-research/\(language\)/eng-GB](https://www.alzheimer-europe.org/Ethics/Ethical-issues-in-practice/2019-Overcoming-ethical-challenges-affecting-the-involvement-of-people-with-dementia-in-research/(language)/eng-GB)
- Ingleby, D., Chiarenza, A., Deville, W., & Kotsioni, I. (2012). *COST Series on Health and Diversity: Inequalities in health care for migrants and ethnic minorities*. (pp. 9–28). Antwerp/Apeldoorn, Belgium: Garant Publishers.
- Ivey, S. L., Laditka, S. B., Price, A. E., Tseng, W., Beard, R. L., Liu, R., Fetterman, D., Wu, B., & Logsdon, R. G. (2012). Experiences and concerns of family caregivers providing support to people with dementia: A cross-cultural perspective. *Dementia*, 12(6), 806–820. <https://doi.org/10.1177/1471301212446872>
- Janssens, A. & Timmerman, C. (2003). *Hoe elkaar de hand reiken? De zoekende interactie tussen de allochtone ouderen en het zorgaanbod in de stad Antwerpen*. Antwerpen: Steunpunt Gelijkekansenbeleid.
- Johl, N., Patterson, T., & Pearson, L. (2016). What do we know about the attitudes, experiences and needs of Black and minority ethnic carers of people with dementia in the United Kingdom? A systematic review of empirical research findings. *Dementia*. <https://doi.org/10.1177/1471301214534424>
- Katz, S. (2015). *Five eye-openers in my life of critical gerontology*. 10(1), 21–34.
- Katz, S. (2019). Critical Gerontology for a New Era. *The Gerontologist*, 59(2), 396–397. <https://doi.org/10.1093/geront/gnz008>
- Kilomba G., (2016). “Decolonizing Knowledge”. Retrieved from internet on 15 of March 2019 from: <https://voicerepublic.com/talks/grad-a-kilomba-decolonizing-knowledge-016ae920-48de-445f-845d-dcf6926c4b4>
- Kilomba G. (2020). *Plantation memories. Episodes of everyday racism*. 6th edition. Münster: Unrast-Verlag. ISBN 978-3-89771-267-6
- Kirmayer, L. J., & Jarvis, G. E. (2019). Culturally responsive services as a path to equity in mental healthcare (Vol. 18, Issue 2). DOI:10.12927/hcpap.2019.25925.
- Kitwood, T. (1997). *Dementia reconsidered. The person comes first*. Buckingham: Open University Press
- Kitwood, T. (2019). *Dementia reconsidered, revisited. The person still comes first*. (Eds. Brooker D.) London: Open University Press
- Kontos, P.C. (2005). Embodied selfhood in Alzheimer’s disease: Rethinking person-centred care. *Dementia*. <https://doi.org/10.1177/1471301205058311>
- Lafleur, J-M., Mardouk, A., Fadil, N. (2018). *21 vragen over Migratie*. Leuven: Universitair Press Leuven. ISBN 9789462701489
- Lemey, L. & van den Ameele, J. (2019). Medische aspecten van dementie. In *Kleine Gids Dementie*. (pp17-86). Brugge: Vanden Broele.
- Livingston, G., Sommerlad, A., Orgeta, V., Costafreda, S. G., Huntley, J., Ames, D., Ballard, C., Banerjee, S., Burns, A., Cohen-Mansfield, J., Cooper, C., Fox, N., Gitlin, L. N., Howard, R., Kales, H. C., Larson, E. B., Ritchie, K.,

- Rockwood, K., Sampson, E. L., & Mukadam, N. (2017). Dementia prevention, intervention, and care. *The Lancet*. [https://doi.org/10.1016/S0140-6736\(17\)31363-6](https://doi.org/10.1016/S0140-6736(17)31363-6)
- Lodewijckx, E. (2014). Ouderen van vreemde herkomst in Vlaanderen anno 2011: een korte demografische schets. In C. De Kock, E. Vens, Y. Beljoudi, & C. Van Kerckhove (Eds.), *Ouder worden in een veranderende samenleving*. (pp. 77–95). Apeldoorn/Antwerp, Belgium: Garant Publishers.
- Lopez Hartmann, M.(2020). *Social support for informal caregivers of community-dwelling frail elderly*. University of Antwerp: PhD dissertation
- Ludden, G. D. S., van Rompay, T. J. L., Niedderer, K., & Tournier, I. (2019). Environmental design for dementia care - towards more meaningful experiences through design. *Maturitas*, 128(March), 10–16. <https://doi.org/10.1016/j.maturitas.2019.06.011>
- Martens, A. (2017). Moroccan migration in Belgium’s labor policy and labor market. In *Moroccan migration in Belgium: More than 50 Years of Settlement*. (Eds. Timmerman C., Fadil N., Goddeeris I., Clycq N & Ettourki K.).(pp. 87-105). Leuven: Leuven University Press
- Martiniello, M. (2003). Belgium’s immigration policy. *International Migration Review*. <https://doi.org/10.1111/j.1747-7379.2003.tb00135.x>
- McDermott, O., Charlesworth, G., Hogervorst, E., Stoner, C., Moniz-Cook, E., Spector, A., Csipke, E., & Orrell, M. (2019). Psychosocial interventions for people with dementia: a synthesis of systematic reviews. *Aging and Mental Health*, 23(4), 393–403. <https://doi.org/10.1080/13607863.2017.1423031>
- McDonald, L. (2011). Theorising about aging, family and immigration. *Ageing and Society*, 31(7), 1180–1201. <https://doi.org/10.1017/So144686X11000511>
- Mitchell, G., & Agnelli, J. (2015). Person-centred care for people with dementia: Kitwood reconsidered. *Nursing Standard*, 30(7), 46–50. <https://doi.org/10.7748/ns.30.7.46.s47>
- Morhardt, D. & Spira, M. (2013). From Person-Centered Care to Relational-Centered Care. *Journal of the American Society on Aging*. 37 (3):37–44.
- Moniz-Cook, E., Vernooij-Dassen, M., Woods, B., & Orrell, M. (2011). Psychosocial interventions in dementia care research: The INTERDEM manifesto. *Aging and Mental Health*, 15(3), 283–290. <https://doi.org/10.1080/13607863.2010.543665>
- Monsees, J., Schmachtenberg, T., Leiz, M., Cardona, M.I., Stentzel, U., van den Berg; N., Hoffmann, W., Thyrian J.R. (2021). *EU-Atlas: Dementia & Migration - Estimated number, care situation, and policies regarding people with a migration background with dementia in the EU, EFTA, and UK*. Rostock/Greifswald: Deutsches Zentrum für Neurodegenerative Erkrankungen (DZNE). ISBN: 978-3-9823426-0-3
- Moody, H. (2008). The maturing of critical gerontology. *Journal of Aging studies*, 22, 205-209.
- Morelli, A. (1988). L’appel à la main d’oeuvre italienne pour les charbonnages et sa prise en charge à son arrivée en Belgique dans l’immédiat après-guerre. *Revue Belge d’Histoire Contemporaine*, XIX(1–2), 83–130.
- Moriarty, J., Sharif, N., & Robinson, J. (2014). Black and minority ethnic people with dementia and their access to support and services. *Research Briefing*. www.scie.org.uk/ publications
- Mukadam, N., Cooper, C., Basit, B., & Livingston, G. (2011). Why do ethnic elders present later to UK dementia services? A qualitative study. *International Psychogeriatrics/IPA*, 23, 1070–1077.
- Mukadam, N., Cooper, C., & Livingston, G. (2013). Improving access to dementia services for people from minority ethnic groups. *Current Opinion in Psychiatry*, 26(4), 409–414. <https://doi.org/10.1097/YCO.0b013e32835ee668>
- Nielsen, T.R., Vogel, A., Phung, T.K.T., Gade, A. & Waldemar, G. (2011a). Over- and under-diagnosis of dementia in ethnic minorities: a nationwide register-based study. *Int Journal of Geriatric Psychiatry*, 26(11), 1128–1135.

- Nielsen, T.R., Vogel, A., Riepe, A.M., de Mendonça, A., Rodriguez, G., Nobili F., Gade, A. & Waldemar, G. (2011 b). Assessment of dementia in ethnic minority patients in Europe: a European Alzheimer's disease consortium survey. *International Psychogeriatrics*, 23,1, 86-95.
- Nielsen, T.R., Andersen, B.B., Kastrup, M., Phung, T.K.T. & Waldemar, G. (2011c). Quality of Dementia Diagnostic Evaluation for Ethnic Minority Patients: A Nationwide Study. *Dementia and Geriatric Cognitive Disorders*, 31(5), 388–396.
- Nielsen, T. R., & Waldemar, G. (2015). Knowledge and perceptions of dementia and Alzheimer's disease in four ethnic groups in Copenhagen, Denmark. *International Journal of Geriatric Psychiatry*, <https://doi.org/10.1002/gps.4314>
- Nielsen, T.R., Segers, K., Vanderaspolden, V., Bekkhus-Wetterberg, P., Bjørkløf, G.H., Beinhoff, U., & Waldemar, G. (2018a). Validation of the Rowland Universal Dementia Assessment Scale (RUDAS) in a multicultural sample across five Western European countries: diagnostic accuracy and normative data. *Int Psychogeriatrics*, 1–10.
- Nielsen, T.R., Segers, K., Vanderaspolden, V., Bekkhus-Wetterberg, P., Minthon, L., Pissioti, A., Hanevold Bjørkløf, G., Beinhoff, U., Tsolaki, M., Gkioka, M., & Waldemar, G. (2018b). Performance of middle-aged and elderly European minority and majority populations on a Cross-Cultural Neuropsychological Test Battery (CNTB). *Clin Neuropsychol*. DOI: 10.1080/13854046.2018.1430256
- Nielsen, T. R., Antelius, E., & Waldemar, G. (2019). Cognitive Advantages in Adult Turkish Bilingual Immigrants – a Question of the Chicken or the Egg. *Journal of Cross-Cultural Gerontology*, 34(2), 115–129. <https://doi.org/10.1007/s10823-019-09375-7>
- Olaussen, S. J., & Renzaho, A. M. N. (2016). Establishing components of cultural competence healthcare models to better cater for the needs of migrants with disability: A systematic review. *Australian Journal of Primary Health*, 22(2), 100–112. <https://doi.org/10.1071/PY14114>
- Ouali, N. (2003). Les Marocaines en Europe: diversification des profils migratoires. *Hommes et Migrations*, 71–82. http://www.hommes-et-migrations.fr/docannexe/file/1242/1242_08.pdf
- Parlevliet, J. L., Uysal-Bozkir, Goudsmit, M., van Campen, J. P., Kok, R. M., ter Riet, G., Schmand, B., & de Rooij, S. E. (2016). Prevalence of mild cognitive impairment and dementia in older non-western immigrants in the Netherlands: a cross-sectional study. *International Journal of Geriatric Psychiatry*. <https://doi.org/10.1002/gps.4417>
- Petty S., Harvey K., Griffiths A. Coleston D.M., & Dening T. (2018). Emotional distress with dementia: a systematic review using corpus-based analysis and meta-ethnography. *Int J Geriatr Psychiatry* 33(5),679-687.
- Phillipson, C. (2015). Placing ethnicity at the centre of studies of later life: Theoretical perspectives and empirical challenges. *Ageing and Society*, 35, 917–934. <https://doi.org/10.1017/S0144686X14001032>
- Phoenix, C. (2018). Why qualitative research is needed in gerontology and how we can do it better. *Journals of Gerontology - Series B Psychological Sciences and Social Sciences*, 73(7), E81–E85. <https://doi.org/10.1093/geronb/gby079>
- Prince, M., Bryce, R., Albanese, E., Wimo, A., Ribeiro, W., & Ferri, C. P. (2013). The global prevalence of dementia: A systematic review and meta-analysis. *Alzheimer's and Dementia*. <https://doi.org/10.1016/j.jalz.2012.11.007>
- Prince, M., Wimo, A., Guerchet, M., Ali, G.-C., Wu, T.-Z., Prina, M. (2015). *World report of Alzheimer 2015. The global impact of dementia. An analysis of prevalence, incidence, cost and trends*. Alzheimer's Disease International. <https://www.alz.co.uk/research/world-report-2015>
- Prizer, L. P., & Zimmerman, S. (2018). Progressive support for activities of daily Living for persons living with dementia. *Gerontologist*, 58, 74–87. <https://doi.org/10.1093/geront/gnx103>
- Reisberg, B., Ferris, S.H., de Leon, M.J., & Crook, T. (1989). The global deterioration scale for assessment of primary degenerative dementia. *American Journal of Psychiatry*, 139: 1136-1139.

- Reniers, G. (1999). On the history and selectivity of Turkish and Moroccan migration to Belgium. *International Migration*, 37(4), 679–713. <https://doi.org/10.1111/1468-2435.00090>
- Riffi, A., Devroey, D., Van De Vijver, E. (2012). A comparison between Moroccan and Belgian type-2 diabetic patients. *Acta Clin Belg.*67(4), 246-9.
- Sagbakken, M., Spilker, R. S., & Ingebretsen, R. (2018). Dementia and migration: Family care patterns merging with public care services. *Qualitative Health Research*, 28(1), 16–29. <https://doi.org/10.1177/1049732317730818>
- Sampson, E. L., Candy, B., Davis, S., Gola, A. B., Harrington, J., King, M., Kupeli, N., Leavey, G., Moore, K., Nazareth, I., Omar, R. Z., Vickerstaff, V., & Jones, L. (2018). Living and dying with advanced dementia: A prospective cohort study of symptoms, service use and care at the end of life. *Palliative Medicine*, 32(3), 668–681. <https://doi.org/10.1177/0269216317726443>
- Schmachtenberg, T., Monsees, J., Hoffmann, W., Van Den Berg, N., Stentzel, U., & Thyrian, J. R. (2020). Comparing national dementia plans and strategies in Europe - Is there a focus of care for people with dementia from a migration background? *BMC Public Health*, 20(1), 1–10. <https://doi.org/10.1186/s12889-020-08938-5>
- Segers K., Benoit F., Colson C., Kovac V., Nury D. & Vanderaspolden V.(2013). Pioneers in migration, pioneering in dementia: first generation immigrants in a European metropolitan memory clinic. *Acta Neurol Belg.* 113(4), 435-40. doi: 10.1007/s13760-013-0245-z.
- Statbel. (2021). <https://statbel.fgov.be/nl/themas/bevolking/herkomst>
- Steyaert, J., (2016). *Dementie de essentie*. Antwerpen: EPO
- Steyaert J, (2016). Prevalentie hoeveel personen in Vlaanderen hebben dementie? In M. Vermeiren (Ed.), *Dementie, van begrijpen naar begeleiden*. Brussel: Politeia
- Tao of care. (2020) <https://tao-of-care.nl/sociale-benadering-dementie/social-trials>, Retrieved on 20 December 2020
- Timmerman, C., Fadil, N., Goddeeris, I., Clycq, N., & Ettourki, K. (Eds.). (2017). *Moroccan Migration in Belgium. More than 50 Years of Settlement*. Leuven: Leuven University Press
- Torres, S. (2015). Expanding the gerontological imagination on ethnicity: conceptual and theoretical perspectives. *Ageing & Society*. 35 (7), 935-960. DOI: 10.1017/So144686X14001030
- Torres, S. (2019). *Ethnicity and old age. Expanding our imagination*. Policy Press. ISBN-10: 1447328116
- Torres, S., Ågård, P., & Milberg, A. (2016). The ‘Other’ in End-of-life Care: Providers’ Understandings of Patients with Migrant Backgrounds. *Journal of Intercultural Studies*, 37(2), 103–117. <https://doi.org/10.1080/07256868.2016.1141756>
- Uysal-Bozkir, Ö. (2016). *Health status of older migrants in the Netherlands Cross-cultural validation of health scales*. PhD thesis, Amsterdam: University of Amsterdam. www.dare.uva.nl
- van Heelsum, A. (2003). Moroccan Berbers in Europe, the US and Africa and the Concept of Diaspora. *UCLA: Center for European and Eurasian Studies*. <https://escholarship.org/uc/item/3f35d97x>
- Van Mol, C., & de Valk, H. (2016). Migration and Immigrants in Europe: A Historical and Demographic Perspective. https://doi.org/10.1007/978-3-319-21674-4_3
- Van Robaey, B.(2014). De reflectieve professional: inzichten over verschil. Vol 40. Alert. www.alertonline.be
- Van Wezel, N., Francke, A., Kayan-Acun, E., Lim Deville´ , W., van Grondelle, N. J., & Blom, M. M. (2016). Family care for immigrants with dementia: The perspectives of female family carers living in The Netherlands. *Dementia*, 15, 69–84.

Verbraeck, B. & van der Plaats, A. (2016). *De wondere wereld van dementie*. Houten: Bohn Stafleu van Loghum. ISBN: 9789036815550

Vernooij-Dassen, M., & Moniz-Cook, E. (2014). Raising the standard of applied dementia care research: Addressing the implementation error. *Aging and Mental Health*, 18(7), 809–814. <https://doi.org/10.1080/13607863.2014.899977>

Vermeulen, B., Daems A., Hermans, K., Spruytte, N., Declercq, A., & Van Audenhove, Ch. (2020). Schattingen van prevalentie en incidentie van dementie in België en Scenario's voor de toekomst. https://www.kuleuven.be/lucas/nl/Publicaties/publi_upload/2020_prevalentie_dementie

Weech-Maldonado, R., Elliot, M., Pradhan, R., Schiller, C., Dreachslin, J., & Hays, R.D. (2012). Moving Towards Culturally Competent Health Systems: Organizational and Market Factors. *Soc Sci Med*, 75(5): 815–822. doi:10.1016/j.socscimed.2012.03.053.

WHO. (2020). <https://www.who.int/news-room/fact-sheets/detail/dementia>. Retrieved on 15 January 2020

WHO. (2017). Global action plan on the public health response to dementia 2017 -2025. http://www.who.int/mental_health/neurology/dementia/action_plan_2017_2025/en/ Retrieved on 19 January 2020.

Wolters, F. J., Chibnik, L. B., Waziry, R., Anderson, R., Berr, C., Beiser, A., Bis, J. C., Blacker, D., Bos, D., Brayne, C., Dartigues, J. F., Darweesh, S. K. L., Davis-Plourde, K. L., de Wolf, F., Debette, S., Dufouil, C., Fornage, M., Goudsmit, J., Grasset, L., & Hofman, A. (2020). Twenty-seven-year time trends in dementia incidence in Europe and the United States: The Alzheimer Cohorts Consortium. *Neurology*, 95(5), e519–e531. <https://doi.org/10.1212/WNL.000000000010022>

Zubair M. & Norris M. (2015). Perspectives on ageing, later life and ethnicity : ageing research in ethnic minority contexts. *Ageing & Society* 35: 897-916.

Letter to my father

Father,

I'm back where you set foot in Antwerp: la gare, your station.

I feel the magic coming and go: this immense hall with marble columns

full of rushing people on their way to the busy, big city.

I take the escalators, scan the platforms looking for

footprints that resemble yours. I see the contours

who you could have been, push you away, wonder

if I'll ever be able to understand. Or ever a question

less, an answer more. The silence hardens the knot

in my stomach. Words get stuck in your throat.

There's a story on your lips.

1966. The booming Belgian economy attracts workers

in the mines and industry: people recruited

from Italy, Spain and Greece. Later also from Morocco.

You passed the test flawlessly. A healthy young man.

I see you before me: with your sharp jawline and your

hair combed back tightly. Stately, decked out in a suit

with a tie. Talking to the conductor in French. You look

around, absorbing everything, without even realizing that this

is the beginning of a long, long journey.

With the station – la gare – as a reference point, you will wander to find a way.

Like you always wanted to go back. One leg here, the other in the station to take the train,

to board the plane to hometown. Always looking for a place to be at home.

With your head here and your heart still there you descended into the

dark mines. You told mother about the horror under the ground,

about the accidents in which colleagues sometimes lost an arm or a leg

that were hastily removed. It was swallow and carry on.

Work had to be done to survive. There were mouths to feed, there was rent too

pay, there were bills to settle. When the mines closed you did all the work you

could get: in the catering industry, the port, in all kinds of factories.

Time passed, your children grew up. A temporary situation was extended.

...

You got sick when I was twelve. The Alzheimer's Beast slowly took hold of you.

You were cared for at home, we loved having you with us. There was no cure.

Heavy medication slowed down the decline. I've often sat next to you those years,

holding your hand. Your eyes lit up. You shut them on a cold January day.

I still held your hand. I stayed there, sure I could warm you up as long as I didn't let go.

And I'm still holding you, father. Your hands, your hair, your head. I kiss your forehead. Farewell.

The mourning is an eternal longing for peace, for a place to finally call home.

I'm ready, like you, to surrender to the days. And to ignore the fear in darkness.

Looking up. Always up. Because after every dark shower of rain the sky clears up,
a rainbow blossoms with raindrops finding their way down. I have dug and rooted in wet earth.

Collected all scattered stories into a bundled power. I want to set them in for the future you have for
envisioned for us.

...

On Sunday we ate out of one plate: mommy's couscous. We still do that

now even more, because we have a father in our midst to miss.

Mother – a village girl straight from the Atlas to a confident strong woman – misses you.

She still misses the man who colored her days. Who came home with
a barrel full of stories, with a bag full of treasure. The father of her children.

Her map and compass. The other half of her heart.

Missing you crawled under her skin and homesickness silently wrapped around her, like a blanket.

...

We are from here and from there.

We bring here to there and there to here.

We connect. We eat together.

I have something to carry out, father.

I have something to carry you with.

I also write your story.

Own translation of the poem "Brief aan mijn vader" of Amina Belorf (2020). In *Zonder het licht te breken*, Antwerp: EPO

Chapter 2: Invisible realities: caring for older Moroccan migrants with dementia in Belgium¹

Abstract

The number of older Moroccan migrants reaching the age of high risk for dementia is increasing in Belgium. Yet no study has been performed to explore how Moroccan families facing dementia experience and manage the condition. The study employed a qualitative design using semi-structured interviews with 12 informal and 13 formal caregivers to answer this research question. Findings indicate that the experience of dementia includes several invisible realities that challenge the informal and formal caregivers: 1) the invisibility of dementia as a condition; 2) the invisible subtleties of the informal care execution; 3) the invisibility and inaccessibility of care services as explanation for these family's non-use of available services; and 4) the overlooking of culture, migration and religion as invisible influencers of the overall dementia experience. A better understanding of these hidden realities of migrant older people with dementia and their caregivers could lead to interventions to provide effective and tailored person-centred care that is sensitive to the individual's life experiences, culture and religious background.

¹ Published as: Berdai Chaouni, S., & De Donder, L. (2018). Invisible realities: Caring for older Moroccan migrants with dementia in Belgium. *Dementia*, 18(7-8), 3113-3129. <https://doi.org/10.1177/1471301218768923>

1. Introduction

In 2016 the Flemish governmental research centre estimated that in Flanders, the Dutch-speaking region of Belgium, 6% of all persons aged 65 and older had a migration background (Lodewijcks, 2017). The number is much higher in those cities and regions that hosted the majority of migrants who came to Belgium during the nineteen-sixties and seventies (Lodewijcks, 2014, 2017). Moreover, the share of older persons of diverse ethnic background will grow in the future (Lodewijcks, 2014). Ethnic minorities of Moroccan origin constitute the largest group of non-European migrants in Flanders (Ouali, 2004): 10% of the ethnic minority older people in Flanders are of Moroccan background. This percentage is higher in cities and regions with strong migration history, such as Antwerp, Brussels and Limburg. For example, in 2010, 28% of older persons in Brussels who were of migration background had Moroccan roots (Lodewijcks, 2014).

These Moroccan older people migrated to Belgium during the nineteen-sixties and seventies under the guest worker program to work in mining and other industries (Van Mol & de Valk, 2016). The host country initially expected that these migrants would work for a temporary period and then return to their home country; reality proved different, however. The migrants, sometimes counter to their own original aspirations, ended up staying, having developed emotional attachment (Buffel, 2015) to their host country, in particular by having children and grandchildren there, and having realized the value of a high-quality healthcare system (Albert, Ferring & Lang, 2016). This migration history has been a key negative influence on the current socio-economic position of these older people. A low literacy has been confirmed by the quantitative data of Lodewijcks (2014): 70% of seniors of Moroccan origin aged 70 or older had never had any type of formal schooling. The adverse socio-economic status of older immigrants is something that European labour migrants appear to share in old age (Liversage & Jacobson, 2016).

Older Moroccan migrants with dementia

In 2016 the Flanders government estimated that 122 000 persons in the region had dementia. This prevalence of dementia is projected to increase by 25% by 2030 (Actualized Dementia Plan Flanders, 2016). Given the difficulty of diagnosing dementia in ethnic minority seniors, it remains a challenge to accurately estimate the prevalence of dementia amongst such groups (Nielsen et al., 2010). Recent research by Parlevliet et al. (2016) using culturally sensitive diagnostic tools shows a higher prevalence of dementia among non-European older people in the Netherlands. The prevalence of dementia among older people of Moroccan background in the Netherlands was four times higher than among native-born older people. Segers et al. (2013) detected an increase from 6% to 16% of newly referred non-European patients from 2005 until the first half of 2012 in their memory clinic in Brussels. Dementia centres in 15 European countries have reported similar increases (Nielsen et al., 2011).

Although clinical manifestations of dementia may be similar across different countries, migration and cultural background can influence the experience of the condition (Johl et al., 2015). This is suggested by research performed in countries with longer migration histories, such as the United States (Cooper et al. 2010; Livney et al., 2011). The results of previous studies are valuable, though difficult to apply to the Belgian context. This is also the case for studies about older migrants with Moroccan background in neighbouring countries. As documented by Ouali (2003) the migration patterns, profiles of

Moroccans in Europe differ, as it is the case for the migration policy of the different European hosting countries having a different impact on these migrants. An example is the policy of family reunification: Belgium stimulated familie reunification of its Moroccan labour migrants from the start of the labour migration in the sixties, whereas neighbouring countries like France and the Netherlands only started this policy after the migration stop in 1973. Recent insights (Torres, 2015; Ferrer et al., 2017) also recommend an intersectional approach in studies dealing with the intersection of migration and ageing, taking into account the macro context influence on the individual life courses. As migration history, ethnicities and migration policies are markedly different in each national context; thus, we must be cautious in trying to establish general conclusions (Constant, García-Muñoz, Neuman, & Neuman, 2017; Kuo, 2014; Sodowsky & Plake, 1992).

Older migrants with dementia are a relatively new phenomenon and this is reflected in the limited research on the topic for Belgium (Nielsen et al. 2011; Segers et al., 2013).

Barriers to help-seeking for dementia in ethnic minority groups

Dementia has a great impact on older people and their caregivers (Snyder et al., 2014). Janevic and Connell (2001) stress the importance of accounting for cultural factors when dealing with dementia. Detecting these group-specific elements is essential for developing suitable care and support both for the older people and for their informal caregivers. According to Mukadam, Cooper and Livingston (2013), ethnic minority groups in Western countries such as the United Kingdom and the United States face three barriers in seeking help when confronted with dementia. The first concerns how dementia is perceived. As compared to the majority population, ethnic minorities appear to perceive dementia as a normal consequence of aging. They do not recognize it as an illness and they attribute associated behavioural changes, such as forgetfulness, to normal aging-related behaviour (Mukadam, Cooper & Livingston, 2011; Mukadam, Cooper, Basit & Livingston, 2011; Van Wezel et al., 2016).

The second barrier concerns society- and community-related factors. Care for relatives is perceived as an engagement that family members will execute until it becomes unmanageable or otherwise unfeasible. This attitude towards care, in combination with less frequent use of care services and with pressures to conform to cultural expectations related to caring for family members can lead to an especially heavy care burden (Van Wezel et al., 2016; Moriarty, Sharif, & Robinson, 2014). Cultural aspects appear to play a major role in defining how family care should be executed. For example, ethnic minorities expect more from women and adult children as caregivers (Moriarty, 2015). This is confirmed by Van Wezel's study (2016), which examined non-European migrants in the Netherlands. Family care is seen as a task imposed by culture and religion and one ascribed primarily to women.

The third barrier refers to the healthcare system and the experience with healthcare professionals. European healthcare systems present structural barriers towards ethnic minorities, leading to inequity in accessing this care. These barriers result from national policies of lesser entitlement to health for ethnic minorities in combination with the "one size fits all" approaches practiced by healthcare facilities (Ingelby et al., 2012). These structural barriers are enforced by personal and cultural barriers, thereby leading to underuse of dementia care by ethnic minorities (Mukadam et al., 2013). The perceived pressure to care for one's parents, the sense of stigma felt when using the services, together with the experienced or perceived lack of culturally suitable care for older people, reinforce the

wariness and hesitation to make use of these services (Denier & Gastmans, 2013; La fontaine et al. 2007; Nielsen et al. 2011. Mukadam et al. 2013). These studies underscore the need for individually tailored dementia services through which ethnic minority older people and their relatives can receive support that is both effective and positive.

The information described above suggests that older Moroccan migrants, the largest subgroup within the ethnic minority older population of Belgium, are growing older and have an expected high risk for dementia (Lodewijcks, 2017; Parlevliet et al. 2016). To our knowledge, there is no data available on how their caregivers experience dementia or how these experiences affect the Moroccan population in Belgium. This study aims therefore to answer the following research questions: 1) How do (informal and formal) caregivers experience the dementia and care of a Moroccan migrant elder? 2) How do culture and religion influence this dementia experience?

2. Methods

Design

A qualitative study with semi-structured interviews was held to collect in-depth information about the experiences of informal and formal caregivers of older persons of Moroccan origin with dementia (Gibson et al., 2004).

Participants

Inclusion criteria for the informal caregivers were: being a child (or child-in-law) or partner of a senior with dementia; having experience in tending to someone with dementia; and being of Moroccan origin. Experience is seen as any form of engagement, current or previous, in caring for a senior with dementia. Dementia can be any subtype of the condition.

The participation criterion for professional caregivers was: being a care professional with experience in caring for Moroccan seniors with dementia. To include different perspectives, these professional caregivers were active in different care disciplines, ranging from general practitioners to nurses, to intercultural mediators (see Table 3). This corresponds with the multidisciplinary approach to dementia. The search area was chosen based on typical migrant settlement patterns in Belgium. Regions that attracted large numbers of people of Moroccan origin include Antwerp, Brussels and Mechelen (Lodewijcks, 2014).

IC	Age	Gender	Soc-econ. profile	Relationship	Diagnose	Region
IC 1	50	f	Care professional, bachelor	Mother	Dementia	Antwerp
IC 2	55	f	Unemployed, bachelor	Father	AD	Antwerp
IC 3	42	m	Worker, secondary school	Father	AD	Antwerp
IC 4	63	f	1st generation, illiterate	Spouse	AD	Antwerp
IC 5	43	f	Employee, secondary school	Mother	AD	Antwerp

IC 6	50	f	Care professional, bachelor	Mother	AD	Antwerp
IC 7	51	f	Employee, bachelor	Mother	Dementia	Antwerp
IC 8	43	f	Unemployed, secondary school	Father	AD	Mechelen
IC 9	46	f	Unemployed, secondary school	Father	Dementia	Mechelen
IC 10	47	f	Unemployed, secondary school	Mother	AD	Gent
IC 11	36	f	Human Recourses Manager, master	Father	FTD	Brussels
IC 12	36	f	Care professional, bachelor	Mother-in-law	Dementia	Antwerp

Table 2: Participants among Moroccan informal caregivers' (IC) demographics (age, gender, socio-economic profile) and relationship to person with dementia (PD) and his/her diagnosis: AD (Alzheimer's Disease) FTD (Frontotemporal Dementia). Region refers to where the caregiver lives.

Table 3: Participants among professional caregivers' (PC) demographics (gender, origin), profession and working area.

PC	Gender	Profession	Origin	Working area
PC1	m	Psychologist	Moroccan	Brussels
PC2	m	Neurologist	Belgian	Brussels
PC3	f	General practitioner	Belgian	Antwerp
PC 4	m	Neurologist	Belgian	Antwerp
PC 5	m	Head nurse of geriatric department	Belgian	Antwerp
PC 6	f	Nurse	Belgian	Antwerp
PC 7	m	Social nurse	Moroccan	Antwerp
PC 8	m	General practitioner	Moroccan	Mechelen
PC 9	f	Intercultural mediator	Belgian	Gent
PC 10	f	Intercultural mediator	Moroccan	Antwerp
PC 11	f	Intercultural mediator	Moroccan	Antwerp
PC 12	f	Head nurse of dementia department	Belgian	Mechelen
PC 13	f	Rheumatologist/Revalidation doctor	Moroccan	Antwerp

Interview scheme

Twenty-two semi-structured interviews were the main data collection method in this qualitative study. One initial focus group was organized to determine relevant themes for further elaboration during the interviews (Gill et al., 2008). Based on these themes two different interview schedules were composed, one for informal carers and one for professionals. Topics covered in both schedules are stated in Table 4.

Table 4: Topics covered in interviews with informal and professional carers

Informal carers	Professional carers
Demographics	Demographics
Diagnosis trajectory	Diagnosis trajectory
First signals, experienced diagnosis process	First signals, experienced diagnosis process
Meaning of Dementia	Facing Dementia
Meaning experienced by IC and relatives, communication about dementia	Specificities in dealing with dementia by Moroccan families, meaning of dementia
Challenges encountered	Professional care challenges
Encountered difficulties, how managed, help-seeking	Match demand/supply, which professional care is needed
Informal Care	Informal Care
Care needed, care division, who is care provider,	Care execution by these families
Use of professional care & appreciation	Encountered care difficulties by these families
Influence of culture and religion in dealing with dementia	Influence of culture and religion in dealing with dementia
Recommendations for better dementia care for ethnic minorities	Recommendations for better dementia care for ethnic minorities
Future expectations & dementia care tips	Occurrence condition (Evolution of) Moroccan population with dementia,

Data collection procedure

Recruitment of the participants proceeded in steps. Six key figures within the Moroccan community were involved (e.g. (social) care professionals, community leaders); they identified informal carers within their respective networks and introduced the researcher to them. Care professionals were also recruited in several steps. Several care professionals were already known by reputation as having diverse client population, in particular owing to their location in ethnically diverse neighbourhoods. Using the snowball method, additional professionals were contacted in the selected search area. Data was collected in the period of November 2014 until March 2015. Each interview was conducted at a location chosen by the participant and took between 38 and 168 minutes. Dutch was the main data collection language, with some use of Arabic expressions by informal carers. One interview was held in French. The researcher is fluent in each of these languages.

Analysis

The interviews were recorded using Audacity recording software and then transcribed verbatim. The data analysis was conducted in an inductive way, with the data taken as primary source for the conceptualization process (Charmaz, 2011). The analysis respected the steps needed for qualitative research, by first deconstructing the data by open, axial coding as an analytic process where the individual concepts and their properties are identified, followed by linking those concepts to categories with subcategories (Dierickx de Casterlée et al., 2012). The next phase of reconstruction began with selective coding, where these categories are integrated and refined. These steps reflect the analytic process of qualitative research seen as de-conceptualization followed by reconceptualization (Cobb & Forbes, 2002).

Ethical Aspects

All participants gave both written and verbal consent at the beginning of the individual interviews and focus group. An informed consent document was presented to the participants, detailing the broader objectives of the study, possibility to withdraw from the study at any time and information about data governance. To maintain confidentiality identifiable information was altered and participants were coded. The audio recordings were destroyed after the completion of the study. The study followed the guidelines of Human Sciences Ethical Committee of the VUB, respecting the European Framework for Research Ethics. (http://ec.europa.eu/research/participants/data/ref/fp7/89888/ethics-for-researchers_en.pdf). Since, the study only included competent human subjects and didn't invade the participant's privacy, no additional approval was needed by the committee (<http://www.vub.ac.be/onderzoek/beleid/ethische-commissie>).

3. Results

Invisibility of dementia as a condition

The results suggest that dementia was invisible to the respondents as an actual condition. This invisibility manifested itself during and after the diagnosis phase.

During the diagnosis phase, older adults, family members and professionals struggled with detecting and recognizing dementia. Family members often were the initiators of the diagnosis process, especially after witnessing alarming symptoms such as markedly "unfamiliar" and/or dangerous behaviours. They started the process in search of explanation.

The second way the condition was diagnosed was via accidental contact with professional care during hospitalization for other matters. Care professionals confirmed this tendency for "accidental diagnosis" through late contact with medical help. The first contact with Moroccan older people was often at a later stage of dementia when there were fewer possibilities for stabilizing the condition. Suggested reasons for this delay were lack of insight about dementia being a condition and the perception that "forgetting" is normal age-related behaviour, as stated by an informal caregiver.

"One day on his way back from the bank he gave all his money to anyone who looked needy. [Laughs] We thought this is maybe due to age... Every time something else happened, until they [hospital staff] told us that he is ill."

Professionals appraised the combination of an absence of adequate assessment tools alongside the presence of a language barrier as the most challenging aspects in diagnosing these migrant older people. For these reasons diagnostic tests such as the Mini-Mental State Examinations (MMSE) were not used, as mentioned by a General Practitioner:

“It stops there already... I have to invent half of the test. Which day are we today? Does every Moroccan illiterate housewife have to know that it is the 23rd of February? Does she have dementia because she cannot count backwards from 100? “

In formulating their diagnoses, the physicians relied instead on their observational skills, experience, communication with informal caregivers and/or biomedical tests. Obvious symptoms of late dementia stages often provided more certainty. Professional caregivers articulated the need for adequate culture-sensitive tests and language-bridging-tools such as assistance from a translator or intercultural mediator. Conversely, the intercultural mediators among the participants stated that a major problem was their not being consulted to perform an MMSE, despite their being trained to do so. The neurologists raised the issue of the resulting financial disadvantage for older Moroccan migrants when diagnostic tests are not used. The social security policy only refunds dementia medication in the early stage of dementia when the MMSE-scores are still high and the effectiveness of the medication is the highest. Accordingly, the Moroccan seniors don't benefit from this refund:

“A major problem of medication is that its reimbursement (through the healthcare system) depends on the MMSE score. These older seniors tend to score lower because of their low education, not because the dementia is in a severe stage, and [consequently they] don't receive any refund.” (A neurologist)

Even after receiving diagnosis, older people with dementia were sometimes not informed of their condition. Accumulation of communication barriers sustained this invisibility. Physicians generally communicated the diagnosis to the informal caregivers, though not always in the presence of the older person. Language barriers and/or the advanced stage of the dementia were used to justify this choice. The informal carers were left with the task of conveying the diagnosis to the older person, which did not always happen.

All participants mentioned that dementia is often labelled differently. These labels fall into two major categories: culturally known descriptions and biomedical labels. The first category reflects unfamiliarity with dementia (the older person is assumed to be forgetful, crazy, possessed, spoiled “fsoesh”, a confused head) while the second acknowledges dementia as a biomedical condition (Alzheimer, Zheimer, Dementia). The use of the first category partially reflects non-acceptance of the condition by denying its severity:

“None! She [mother with dementia] doesn't use any words. It isn't an illness for her, she doesn't want to accept it.” (Informal carer 11)

Some informal caregivers had difficulties employing biomedical terminology in their communication with the person with dementia. They used the same label as the person with dementia, out of concern for the latter's feelings. These informal caregivers feared that their using biomedical labels would exacerbate the older person's feelings of uncertainty, as formulated by a female informal carer who looked after her mother:

“Mother says, “I’m confused in my head (‘trwent frasi’), you understand... then you will not say “Mama, you have dementia”. We didn’t even find any Arabic words for it”. (Informal carer 6)

Other reasons were a lack of Arabic terms for this condition, and respecting the frame of reference of the first-generation migrants with dementia:

“They didn’t know Alzheimer, in Morocco neither.” (Informal carer 10)

Only one professional caregiver stated the importance, for his work as a psychologist, of using the same label as the person with dementia as a way of connecting sincerely and effectively with the person:

“I don’t use “dementia” – they don’t use it, so I don’t! Some professionals persist in using biomedical terminology, but these older people don’t understand it and they seek confirmation. Sometimes you need to follow their words to approach the senior with sincerity.”

The first generation of Moroccans who came to Belgium shared a similar migration trajectory. They and their informal caregivers were the first migrant group to experience dementia as an age-related condition. These migration-related events explain, according to a majority of respondents, why dementia, being an effectively unknown condition, causes such “inappropriate” reaction from the community. The Moroccan community needed to prioritize other migration-related challenges and thereby failed to anticipate aging-related issues and potential consequences such as dementia. As formulated by a daughter:

“This is the first generation reaching that age. We [the Moroccan community], sadly, weren’t prepared for it. We also had to face a lot of challenges (education, employment issues, etc.)... we cannot anticipate everything.”

Invisibility of the involved parties and tasks in informal care

Findings suggest that professional caregivers saw only a glimpse of the meaning and the organization of informal care within these Moroccan families. They mentioned only females (e.g. wife, daughter or daughter-in-law) as informal caregivers in Moroccan families. Informal caregivers, however, displayed different views: they noted that both men and women were assuming informal caregiving tasks. Four roles of informal carers were derived from the analysis, nuancing the concept of “the” informal caregiver: these roles are the coordinator, the assistant, the legal responsible and the main nurse (Table 5).

Table 5: Types and descriptions of informal caregivers of Moroccan origin.

Type	Specificities	Quotes by informal carers
Coordinator	<p>Coordinates the care for the parent (or parent-in-law) inside and outside the family.</p> <p>Initiates actions like family meetings, search for care assistance, etc.</p> <p>Communicates with professional care and other siblings.</p> <p>Generally a daughter, highly educated and/or active in care sector.</p>	<p>“I actually did the work of a social worker! OK, I’m a nurse, but I didn’t learn those social work tasks during my education”.</p>

Main Nurse	Responsible for the continuous nursing of the person with dementia. Generally a daughter or male/female spouse. There are two profiles of spouses: 1) A first-generation migrant, high in age, low education or illiterate. 2) A woman selected in Morocco by the children to marry the patient and brought to Belgium for the purpose of nursing the person with dementia.	"It's actually mother who cares for him, day in day out – we are only here for her assistance".
Assistant	A relative who is standby for all-round assistance (e.g. support for the main nurse, stopping by for nursing, night watch, etc.)	"I step by when it is needed. When my sister calls, even at 3 a.m., I go to help with our mother".
Legal Representative	The acting guardian (spouse or oldest son) responsible for legal administration and financial expenses as receiver of the older person's pension funds.	"My brother received his [our father's] pension. If we needed something for his [our father's] care we would ask him [my brother] for the money".

In most cases, these various types of informal caregivers contributed as a care network to provide informal care for the older person with dementia. They all shared a tremendous devotion in providing informal care. The professional participants found this attitude to be typical of Moroccan informal caregivers. Several professional caregivers voiced concern about this aspect, however, having seen problems such as self-abandonment and long-term (mental) health issues (e.g. depressions, exhaustion) emerge among informal caregivers as a result of their devotion.

Invisible and inaccessible dementia care services

Informal caregivers encountered several obstacles when they decided to seek professional help. The majority of the informal caregivers had been unaware of the extent of professional care for dementia that was available in Belgium. (Accidentally) encountering a professional caregiver who informed them about such care was decisive in their learning about potential options, as expressed by an informal carer:

"It was by chance. I was talking to my physiotherapist ... he asked me if I knew about night care, and gave me the name of the organization.... I wouldn't know about it if he hadn't told me."

Some professional caregivers were aware of this inaccessibility to regular dementia care and took extra measures to inform their patients and workplace surroundings about it. Similarly, they also worried that some colleagues, though aware of this inaccessibility, did not act on it.

Another obstacle related to how professional caregivers performed their care. Informal carers felt that a person-centred approach was often lacking. They experienced a lack of (cultural) sensitivity in combination with swift technical execution of care with little room for the humane aspects of such care. Despite the informal caregivers' appreciation for the professionalism of these caregivers, these

humane aspects were decisive in their opting whether or not to use professional care, either at home and residential. Due to the language barrier, Moroccan seniors were unable to formulate their needs to professional caregivers. This enhanced the informal caregiver's anxiety to entrust the patient to professional caregivers who exhibited little cultural sensitivity. This anxiety was often based on experience with professional carers who did not respect religious rituals (such as prayer), halal dietary practices or gender matching.

Professional caregivers were generally unaware that the absence of culture- and religion-sensitive care was a primary reason that informal carers avoided using professional care. They often mentioned the informal carers' culture as the main reason for this lack of professional care use. The apparent pressure on children to care for their parents was also mentioned by informal carers as an additional source of hesitation against seeking professional help. Children and other family members feared gossip and disapproval from the Moroccan community. Some informal caregivers even postponed professional aid, as described by a daughter:

"It took me six months to call the night care. Yes, what would people say....?"

Invisibility of culture and religion as influencing factors

In addition to this more natural reflex on the part of the family to care for their elder with dementia, other positive aspects of the Moroccan culture that were described include collective support and concern. The aspects were mentioned mainly by professional caregivers with Belgian roots. Informal caregivers and professional caregivers with Moroccan origin introduced certain subtleties to this image of solidarity. The solidarity they experienced was limited to expressions of moral support and did not entail concrete actions.

Professional carers stressed the importance of culture as a motivator for providing informal care to the older people. According to most, informal care was a duty to be performed and not to be questioned. Informal caregivers themselves, however, presented a more complex reality about the meaning of informal care within their families. The initial religious- and culture-inspired values to provide informal care are commingled with more pragmatic reasons for doing so. The informal caregivers agreed that caring for older people as they had once cared for you is a natural cultural, religious and emotional norm. Professional caregivers frequently mentioned that dementia remains a taboo, as formulated by this nurse:

"I don't have the impression that you can talk about dementia with them, it's taboo in their culture."

Informal caregivers partly agreed, but added that dementia is generally perceived as one of many conditions brought to us by God and thus not something to be ashamed of, as formulated by an informal carer:

"I talk to everyone about it, my sisters do too. There are people from the Moroccan community who don't. I find that unfortunate. The person with dementia didn't choose it, neither did we."

Some informal carers felt ashamed by public displays of dementia-related behaviour and sought to avoid such situations. Some older people were ashamed of their condition and avoided contact with other community members. An informal caregiver questioned whether this shame-induced behaviour is in fact "a human reaction, not cultural related".

Some respondents said that dementia is a condition that comes from God (Allah). Some informal caregivers considered the illness to be a way that their spouse or parent with dementia could erase all the bad deeds they had done in their life. This was experienced both as something positive and as something that helped in coping with the condition, as formulated by a son:

“Allah wanted it like this... that he has dementia; maybe my father did something in his life and by experiencing these illnesses he’s being forgiven by Allah.”

For some individuals with dementia, religious practices such as prayer, ritual washing and recitation of the Quran were the only things they still recognized and remembered. Other benefits of their religious background were that it afforded the person with dementia not just structure, by organizing their day according to prayer times and rest, but also a way to stay mentally and physically active and thereby increase their quality of life, especially by going regularly to the mosque to pray and interact with others. An informal caregiver formulated this as follows:

“Our father, that’s the only thing that he had. He kept praying. He forgot everything except that. He found his peace of mind in it. Also with the Quran: when we put it on, he recited with the reciter.”

4. Discussion

This study investigated how caregivers experienced dementia and care for first-generation seniors of Moroccan origin with dementia. We also explored the role of culture, migration and religion as influencing factors for these experiences.

Our results indicate an accumulation of invisibilities in the course of the dementia trajectory which lead to a specific experience of dementia by the Moroccan population. It begins with the invisibility of dementia as a condition, which leads to delay in initiating the diagnosis process and in applying accurate labels to the condition. The participants among the informal carers initiated the diagnosis process only after emergence of obvious dementia-related behavioural abnormalities. This confirms previous research which found that initial symptoms such as forgetfulness are considered normal age-related behaviours and not yet medically relevant enough to seek help for (Botsford et al., 2011; Van Wezel et al., 2016). A lack of information about and understanding of dementia can also explain this delay (Johl et al., 2015). Our findings confirm the lack of culture-sensitive assessment tools, which research has shown leads to diagnostic evaluations of lesser quality (Nielsen et al., 2011). Informal caregivers find it challenging to communicate with their elders about their dementia diagnosis. The capability of the ill relative to bear and to understand such news is taken into consideration when deciding whether and to what extent to be open with them about the diagnosis (van Eechoud et al., 2015). Different ethnic minorities use different labels for dementia, based on their perceptions of the condition (Nielsen & Waldemar, 2015). Thus, informal caregivers employ a (culture-) specific combination of social and biomedical labels to communicate about the condition. It is typical, for these migrant seniors and their informal caregivers, that the term dementia is not used as a reference (Segers et al., 2013; Shanley et al., 2012). The accumulation of these underlying aspects renders dementia invisible and difficult to grasp, both for the person with dementia and for his or her carers, informal and professional.

A second invisible reality concerns the execution of informal care within Moroccan families in Belgium. Our results show a mixed image of the parties involved in performing informal care. Whereas the professional carers mentioned only females as informal carers, the informal carers themselves reported the involvement of a network of informal carers that included males and females. This involvement of a non-gender-specific informal care network is not in line with Van Wezel's study (2016) of non-European migrants in the Netherlands. On the other hand, Jabobs et al. (2014) showed the invisibility of the subnetworks of caregivers and their importance in providing informal care. Moreover, several other cultures appear to have different definitions of "primary caregiver" and to view care as belonging within a family system (Janevic & Connell, 2001). Our participants confirmed culture and religion (Johl, Paterson & Pearson, 2015) as motivators for caring for seniors with dementia, yet they also included emotional and practical reasons as equal motivators. Being a second-generation migrant (Laurence et al., 2008) can explain the emergence of less traditional views of informal care held by a majority participants.

Our results suggest a third invisible factor underlying the non-use of professional dementia care. Dementia care options are inaccessible (Gillespie, Harrison and Mullan, 2015) and unused (Moriarty, 2015) by informal carers for reasons that are not always evident to the professional carers. In line with the findings of de Graaf et al. (2012), we find that the lack of culture-sensitive and person-centred approach deters Moroccan informal caregivers from seeking professional care, even though doing so would likely relieve their burden. Language barriers, lack of awareness about dementia and stigma about the condition, as well as negative experiences with dementia services, contribute towards poor access to dementia care (Moriarty, 2015). These aspects, in addition to stereotyping and racism among professionals, result in delays in use of dementia services. These aspects can explain the third mutual invisibility of help and care options of informal and professional carers. Our findings emphasize that understanding these underlying elements is critically important for developing more effective culturally sensitive care (Cipriani & Borin, 2014; Johl et al., 2015; Mukadem et al., 2011).

Finally, our findings confirm previous studies which found that migration (Jutlla, 2015) in addition to culture (Cipriani & Borin, 2014; Ivey et al., 2012) and religion (Regan, 2013) influence the experience of dementia both for the older people and for their informal carers. Migration from Morocco is a critically important life event that shapes the dementia experience and the execution of informal care (Jutlla, 2015). The "ethnic minority" status of Moroccan older people and their offspring and their experiences of discrimination influence their reluctance to turn to professional care (Jutlla, 2015; Mukadem et al., 2011). Being Belgian and of Moroccan background is a key cultural aspect influencing the experience of dementia and the execution of informal care (Regan, 2013). Regan (2013) argues that research should consider religion as a distinct part of culture to discover any overlooked aspects. The majority of our participants were not aware, however, of the interplay between migration, culture and religion as influencing factors of the dementia experience.

Results suggest several implications for practice. The invisibilities described by the informal and formal caregivers highlight the importance of further research to identify these invisible realities within our societies. Dementia should be made visible as a condition through investing in awareness and education programs for (potential) informal carers (Ivey et al., 2013) and by investing in culturally sensitive diagnostics for professional carers (Nielsen et al., 2015). It is also necessary to invest in actions to strengthen the relationship between informal and formal carers (Gillespie, Harrison & Mullan,

2015). This can be achieved by investing in the cultural competence of the dementia care services. There is also need for more culture-, religion- and migration-sensitive dementia care services that do not lose the individual approach to migrants with dementia (Gillespie, Harrison & Mullan, 2015; Regan, 2014). More suitable care option can further aid the informal carers in fulfilling their care role by reducing the risks that the carer will suffer adverse consequences from the care burden.

5. Study limitations and further research

Our findings should be considered in light of the following limitations. This study uses a relatively small sample with a concentration of informal caregivers from Antwerp, which makes generalizing the findings difficult (Moriarty, Sharif & Robinson, 2014). Also, these informal carers are mainly female, highly educated and second-generation migrants. Inclusion of males and first-generation carers from various socio-economic backgrounds is needed in future research (Johl et al., 2014). Inclusion of the immediate experience of persons from migration backgrounds who have dementia is also needed to present a fuller picture of the overall experience of dementia.

6. Conclusion

Our findings confirm the universality of the experience of dementia alongside specific social-contextual aspects. For older adults with migration background and their family carers, this experience is influenced by their migration history, culture and religion. We now see a first generation of informal and professional caregivers in Belgium who are confronting how to deal with this migrant group of seniors with dementia. The mutual invisibilities and mismatch of expectations appear to undermine the search process for appropriate dementia care for these older persons. In order to establish positive and effective migration-, culture- and religion-sensitive dementia care, it is necessary to integrate these different perspectives. This requires further research on practical actions in which the parties collaborate and a care policy that endorses this innovative approach.

References

- Actualized Flemish Dementia Plan 2016–2019. *Samen verder bouwen aan een dementievriendelijk Vlaanderen*. Department of Welfare, Government of Flanders.
- Albert, I., Ferring, D., & Lang, F. R. (2016). Introduction to the Special Issue on “Aging and Migration in Europe”. *GeroPsych*, 29(2), 53–55.
- Botsford J., Clarke C., & Gibb C. (2011). Dementia and relationships: experience of partners in minority ethnic communities. *Journal of advanced Nursing*, 68, 2207–2217
- Buffel, T. (2015). Ageing Migrants and the Creation of Home: Mobility and the Maintenance of Transnational Ties. *Population, Space and Place*. <https://doi.org/10.1002/psp.1994>
- Charmaz, K. (2011). Grounded theory methods in social research. In N. Dinzin & Y. Lincoln (Eds.) *The SAGE handbook of qualitative research* (pp. 359–381). Thousand Oaks, CA: SAGE Publications, Inc.
- Cipriani, G., & Borin, G. (2014). Understanding dementia in the sociocultural context: A review. *International Journal of Social Psychiatry*, 61(2), 198–204.
- Cobb, A.K., & Forbes, S. (2002). Qualitative research: what does it have to offer to the gerontologist? *Journal of Gerontology: Medical Sciences*, 57A(4), 197–202.
- Constant, A.F., Garcia-Munoz, T., Neuman, S., & Neuman T. (2017). A « Healthy immigrant effect » or a « sick immigrant effect » ? Selection and policies matter. *Eur J Health Econ*, doi: 10.1007/s10198-017-0870-1
- Cooper, C., Tandy, A. R., Balamurali, T. B. S., & Livingston, G. (2010). A systematic review and meta-analysis of ethnic differences in use of dementia treatment, care, and research. *The American Journal of Geriatric Psychiatry*, 18(3), 193–203.
- De Graaff, F.M., Mistiaen, P., Devillé, P. L.J.M., & Francke, A.L. (2012). Perspectives on care and communication involving incurably ill Turkish and Moroccan patients, relatives and professionals: a systematic literature review. *BMC Palliative Care*, 10.1186/1472-684X-11-17
- Denier, Y., & Gastmans, G. (2013). Realizing good care within a context of cross-cultural diversity: an ethical guideline for healthcare organizations in Flanders, Belgium. *Soc Sci Med*. 93, 38–46.
- Dierckx de Casterlé, B., Gastmans, C., Bryon, E., & Denier, Y. (2012). QUAGOL: A guide for qualitative data analysis. *International Journal of Nursing Studies*, 49, 360–371.
- Ferrer, I., Grenier, A., Brotman, S., & Koehn, S. (2017). Understanding the experiences of racialized older people through an intersectional life course perspective. *Journal of Aging Studies*, 41, 10–17.
- Gibson, G., Timlin, A., Curran, S., & Wattis, J. (2004). The scope for qualitative methods in research and clinical trials in dementia. *Age and Ageing*, 33, 422–426.
- Gill, P., Stewart K., Treasure, E., & Chadwick, B. (2008). Methods of data collection in qualitative research. *British Dental Journal*, 204, 291–295.
- Gillespie, R.J., Harrison, L., & Mullan, J. (2015). Medication management concerns of ethnic minority family caregivers of people living with dementia. *Dementia*, 14(1), 47–62.
- Ingleby, D., Chiarenza, A., Devillé, W., & Kotsioni, I. (2012). *COST Series on Health and Diversity: Inequalities in health care for migrants and ethnic minorities*. Vol. 2 (pp. 9–28). Antwerp/Apeldoorn, Belgium: Garant Publishers.

- Ivey, S.L., Ladtko, S.B., Price, A.P., Tseng, W., Beard, R.L., Liu, R., Fetterman D., Wu B., & Logsdon, R.G. (2012). Experiences and concerns of family caregivers providing support to people with dementia: a cross-cultural perspective. *Dementia, 0*(0), 1–15.
- Jacobs, M., Van Tilburg, T., Groenewegen, P., & Van Groenou, M.B.(2015). Linkages between informal and formal caregivers in home-care networks of frail older adults. *Ageing and Society*, DOI: 10.1017/S0144686X15000598
- Janevic, M.R., & Connell, C.M. (2001). Racial, ethnic, and cultural differences in the dementia caregiving experience: recent findings. *The Gerontologist, 41*(3), 334–347.
- Johl, N., Patterson, T., & Pearson, L. (2015). What do we know about the attitudes, experiences and needs of Black and minority ethnic carers of people with dementia in the United Kingdom? A systematic review of empirical research findings. *Dementia, 15*(4), 721– 742.
- Jutlla, K. (2015). The impact of migration experiences and migration identities on the experiences of services and caring for a family member with dementia for Sikhs living in Wolverhampton, UK. *Ageing and Society, 35*(05), 1032–1054.
- Kuo, B. (2014). Coping, acculturation, and psychological adaptation among migrants , a theoretical and empirical review and synthesis of the literature. *Health Psychology & Behavioural Medicine, 2*(August), 16–33.
- La Fontaine, J., Ahuja, J., Bradbury, N. M., Phillips, S., & Oyeboode, J. R. (2007). Understanding dementia amongst people in minority ethnic and cultural groups. *Journal of Advanced Nursing, 60*(6), 605–614.
- Lavarone A., Ziello, A.R., Pastore, F., Fasanaro, A.M., Poderico, C. (2014). Caregiver burden and coping strategies in caregivers of patients with Alzheimer’s disease. *Neuropsychiatric Disease and Treatment, 10*, 1407–1413.
- Lawrence, V, Murray, J., Samsi, K., & Banerjee, S. (2008). Attitudes and support needs of Black Caribbean, South Asian and White British carers of people with dementia in the UK. *British Journal of Psychiatry, 192*(9), 240–246.
- Liversage, A., & Jakobsen, V. (2016). Unskilled, foreign and old. A life course perspective on immigrant poverty. *GeroPsych, 29*(2), 39–103.
- Livney, M.G., Clarck, C.M., Karlawish, J.H., Cartmell, S., Negron, M., Nunez-Lopez, J., Xie, S.X., Entenza-Cabrera, F., Vega I.E., & Arnold S.E. (2011). Ethnoracial differences in the clinical characteristics of Alzheimer Disease at initial presentation at an urban Alzheimer’s disease center, *Am J Geriart Psychiatry, 19*(5), 430–439.
- Lodewijcks, E. (2014). Ouderen van vreemde herkomst in Vlaanderen anno 2011: een korte demografische schets. In C. De Kock, E. Vens, Y. Beljoudi, & C. Van Kerckhove (Eds.), *Ouder worden in een veranderende samenleving (pp. 77–95)*. Apeldoorn/Antwerp, Belgium: Garant Publishers.
- Lodewijcks, E. (2017). *Huishoudens van ouderen. Verschillen naar herkomst. SVR Study Service Government of Flanders*.
- Moriarty, J. (2015). Accessing support and services. In J. Botsford, & K. Harrison Dening (Eds.), *Dementia, culture and ethnicity. Issues for all* (pp. 85–103). London, UK and Philadelphia, PA: Jessica Kingsley Publishers.
- Moriarty, J., Sharif, N., & Robinson, J. (2014). Black and minority ethnic people with dementia and their access to support and services. Research Briefing. Retrieved from www.scie.org.uk/publications.
- Mukadam, N., Cooper, C., Basit, B., & Livingston, G. (2011). Why do ethnic elders present later to UK dementia services? A qualitative study. *International Psychogeriatrics / IPA, 23*(7), 1070–1077.
- Mukadam, N., Cooper, C., & Livingston, G. (2011). A systematic review of ethnicity and pathways to care in dementia. *International Psychogeriatrics / IPA, 26*, 12–20.

- Mukadam, N., Cooper, C., & Livingston, G. (2013). Improving access to dementia services for people from minority ethnic groups. *Current Opinion in Psychiatry*, 26(4), 409–414.
- Nielsen, T.R., Vogel, A., Phung, T.K.T., Gade, A., & Waldemar, G. (2010). Over- and under-diagnosis of dementia in ethnic minorities: a nationwide register-based study. *Int. J Geriatric Psychiatry*, 26, 1128–1135.
- Nielsen, T.R., Vogel, A., Riepe, A.M., de Mendonça, A., Rodriguez, G., Nobili F, Gade, A., & Waldemar, G. (2011). Assessment of dementia in ethnic minority patients in Europe: a European Alzheimer's disease consortium survey. *International Psychogeriatrics*, 23(1), 86–95.
- Nielsen T.R., & Waldemar G. (2015). Knowledge and perceptions of dementia and Alzheimer's disease in four ethnic groups in Copenhagen, Denmark. *International Journal of Geriatric Psychiatry*, 31(3), 222–230.
- Ouali, N. (2003). Les Marocaines en Europe: diversification des profils migratoires. *Hommes et Migrations*, 71–82.
- Ouali, N. (2004). Quarante ans de presence de Marocains en Belgique. In N. Ouali (Ed.), *Trajectoires et dynamiques migratoires de l'immigration marocaine de Belgique* (pp. 25–35). Brussels, Belgium: Collection Carrefours, Éditions Bruylant-Academia S.A.
- Parlevliet, J.L., Uysal-Bozkir, Ö., Goudsmit, M., van Campen, J.P., Kok, R.M., ter Riet, G., Schmand, B., & de Rooij, S.E. (2016). Prevalence of mild cognitive impairment and dementia in older non-western immigrants in the Netherlands: a cross-sectional study. *Int J Geriatr Psychiatry* 31(9), 1040–1049.
- Regan, J.L. (2013). Redefining dementia care barriers for ethnic minorities: the religion–culture distinction. *Mental Health, Religion & Culture*, 17(4), 345–353.
- Regan, J.L. (2014). Ethnic Minority, Young Onset, Rare Dementia Type, Depression: A Case Study of a Muslim Male Accessing UK Dementia Health and Social Care Services. *Dementia* 15(4), 702–720.
- Reniers, G. (1999). On the History and Selectivity of Turkish and Moroccan Migration to Belgium. *International Migration*, 37(4), 679–713.
- Segers, K., Benoit, F., Colson, C., Kovac, V., Nury, D., & Vanderaspolden, V. (2013). Pioneers in migration, pioneering in dementia: first generation immigrants in a European metropolitan memory clinic. *Acta Neurol Belg.* 113(4), 435–440.
- Shanley, C., Boughtwood, D., Adams, J., Stantalucia, Y., Kyriazopoulos, H., Pond, D., & Rowland, J.A. (2012). Qualitative study into the use of formal services for dementia by carers from culturally and linguistically diverse (CALD) communities. *BMC Health Serv Res*. DOI: 10.1186/1472-6963-12-354
- Snyder, C. M., Fauth, E., Wanzek, J., Piercy, K. W., Norton, M. C., Corcoran, C., Tschanz, J.T. (2014). Dementia caregivers' coping strategies and their relationship to health and well-being: the Cache County Study. *Aging & Mental Health*, 19(5), 390–399. <https://doi.org/10.1080/13607863.2014.939610>
- Sodowsky, G. R., & Plake, B. S. (1992). A study of acculturation differences among international people and suggestions for sensitivity to within-group differences. *Journal of Counseling & Development*, 71(1), 53–59
- Swarbrick, C.M., Davis, K., & Keady, J. (2016). Visioning change: co-producing a model of involvement and engagement in research (innovative practice). *Dementia*, 0(0), 1–8. DOI: 10.1177/1471301216674559
- Taameeyapradit, U., Udomittipong, D., & Assanangkornchai, S. (2014). Development of a burden scale for caregivers of dementia patients. *Asian Journal of Psychiatry*, 8(1), 22–25.

Torres, S. (2015). Expanding the gerontological imagination on ethnicity: Conceptual and theoretical perspectives. *Ageing and Society*, 35(5), 935–960.

Van Eechoud, I.J., Grypdonck, M., Leman, J., Van Den Noortgate, N.J., Deveugele, M., & Verhaeghe, S. (2015). Caring for family members older than 50 years of Turkish and Northwest African Descent: The Meaning of Caregiving. *Cander Nurs.*, 39(1), 51–60.

Van Mol C., & de Valk, H. (2016). Migration and Immigrants in Europe: A Historical and Demographic Perspective. In B. Garcés-Masareñas, & R. Penninx (Eds.), *Integration processes and policies in Europe* (pp. 35–55). IMISCOE Research Series, Springer International Publishing.

Van Wezel, N, Francke, A., Kayan-Acun, E., Lim Devillé, W., van Grondelle N.J., & Blom M.M. (2016). Family care for immigrants with dementia: The perspectives of female family carers living in The Netherlands. *Dementia*, 15(1), 69–84.

Vandenheede, H., & Deboosere, P. (2009). Type 2 diabetes in Belgians of Turkish and Moroccan origin. *Arch Public Health*, 67, 62–87.

Chapter 3: Caring for migrant older Moroccans with dementia in Belgium as a complex and dynamic transnational network of informal and professional care²

Abstract

Due to its labour migration history, Belgium is confronted with an increasingly older population of people of Moroccan background who have been diagnosed with dementia. These migrants came to the country during the labour migration wave of the nineteen-sixties and seventies to work in mines and other industries and they are now ageing. Yet little is known about how dementia care is provided to this older population. This study explores how dementia care is provided to these Moroccan older people with dementia, and what challenges do caregivers face in providing care. A qualitative study including 31 informal caregivers of older Moroccan migrants with dementia and professional caregivers in the field of dementia care in several Belgian cities was conducted. After an initial focus group including 6 informal and professional caregivers, individual in-depth interviews were held with 12 informal caregivers of Moroccan decent and 13 professional caregivers. In order to be included in the study, informal caregivers had to have a recent experience in caring for a older family member with dementia. The professional caregivers had to be active in the field of dementia care (General Practitioners, nurses, psychologists,...) and have experience with older migrants with dementia. Analyses of the collected data reveal that current dementia care is a challenging, complex and dynamic search process. This process is shaped by 1) multiple factors reflecting the changing care needs of the care recipient during the course of the dementia, 2) the individual (transnational) recourses of the informal caregivers and the 3) current (lack of) accessibility of professional dementia care (driven by the absence of an accessible migration-, culture- and religion-sensitive professional care). The limited professional service-use is predominantly compensated through the search for transnational external helpers. The limited migration, cultural and religious sensitivity of current dementia care is often overlooked by professional caregivers. The study provides a better understanding of the complex reality of dementia care for older migrants in which these different aspects intersect. This understanding enable health professionals and policy makers to develop a better suited care for older migrants with dementia.

² Published as: Berdai Chaouni, S., Smetcoren, A.-S., & De Donder, L. (2020). Caring for migrant older Moroccans with dementia in Belgium as a complex and dynamic transnational network of informal and professional care: A qualitative study. *International Journal of Nursing Studies*. <https://doi.org/10.1016/j.ijnurstu.2019.103413>

1. Introduction

European cities are facing increased ethnic diversity among their older populations (White, 2006). These older immigrants are a growing group of European older persons (Lanzieri, 2011) and their number is expected to rise further in the coming decades (Lanzieri, 2011; Van Mol and de Valk 2016). In 2018, 40 per cent of persons in Brussels aged 60 and above were from migration backgrounds (BISA, 2019) and this number is expected to increase in the coming years (Lodewijcks, 2014, 2017). Ethnic minorities of Moroccan origin constitute the largest group of non-European migrants in Belgium (Pelfrene and Van Peer, 2014). In 2011, 28 per cent of older persons in Brussels with a migration background had Moroccan roots (Lodewijcks, 2014). These Moroccan immigrants came to Belgium in the nineteen-sixties as result of labour migration policy (Ouali 2004, Martens 2017). As in other European countries, these labour migrants in Belgium are now ageing and age-related conditions such as dementia are becoming increasingly manifest (Lanzieri, 2011; Nielson et al. 2011; Gove et al., 2018). Recent estimations of the prevalence of dementia in Flanders by the Centre of Expertise Dementia (2018) noted that there are no data available concerning older migrants with dementia. Segers and Benoit (2013), however, saw an increase from six per cent to 16 per cent of newly referred non-European patients from 2005 until the first half of 2012 in their memory clinic in Brussels. Using a more culturally sensitive diagnostic instrument Parlevliet et al. (2016) show that in the Netherlands the prevalence of dementia within the Moroccan subgroup is approximately four times higher than for native Dutch older people. The study confirms earlier studies addressing the higher susceptibility of Moroccan older migrants to dementia-related risk factors like diabetes and depression (Riffi, Devroey and Van De Vijver, 2012; Erdem et al. 2017). Based on demographic projections and previous studies we can assume that older Moroccan migrants with dementia will be a growing group in Belgium.

As concerns choices of care for older migrants with dementia, it is argued that family care is preferred or is culturally regarded as superior to formal care (Van Wezel et al., 2016), although inaccessibility and unsuitability of health services may contribute to this preference (Moriarty et al., 2014). According to Mukadam et al. (2013), ethnic minority groups face three critical barriers in seeking professional help when confronted with dementia: the sense of responsibility to care for one's parents; the perception of being stigmatized by the community when appealing to professional care; and the experienced or perceived lack of culturally suitable care for older people. Each of these factors reinforces hesitation and wariness to turn to health care services (Berdai-Chaouni and De Donder, 2018; Mukadam et al., 2011; Denier and Gastmans, 2013). However, there are several reasons and evolutions for why older people of migration background will opt for professional health care services, including decreased family proximity and shifting views about family care (Ahaddour et al., 2016).

Although caring for people with dementia has universal aspects, Shanley et al. (2012) argue that it cannot be assumed that all cultural and linguistic communities have the same issues and needs. There is growing evidence that migration, cultural (Botsford, 2015; Torres and Karl, 2016) and religious (Moriarty, 2015) backgrounds define how individuals and communities deal with dementia care, both informal and professional. However, there are no data available concerning dementia care provision to Moroccan immigrants in Belgium. Is their dementia care process uniquely driven by family care with minimal use of professional dementia care, as found by other European studies (de Graaff and Francke, 2003; de Graaff et al., 2012; van Wezel et al., 2016), or are there other local nuances in care provision

during their dementia care process? This study aims to fill this gap by investigating the following research questions:

- 1) How is dementia care provided in Belgium to older Moroccan migrants with dementia?
- 2) What challenges do formal and informal caregivers experience in the provision of this dementia care?

2. Methods

Design

The goal of this study is explorative and descriptive: it seeks to establish a better understanding of the experiences of informal and formal carers of older migrants with dementia, an emerging phenomenon in European societies. Therefore, a cross-sectional qualitative approach is employed. It has been argued that qualitative research is better suited and even required when seeking a greater understanding of the experiences of people with dementia and of their informal and formal carers, especially when the aim is to include specific groups such as ethnic minorities (Carmody et al. 2015). Qualitative approaches intrinsically strive for nuances and seek to adhere closely to the narratives of the participants; they are therefore preferred in research that engages marginalized voices such as ethnic minorities (Braun et al. 2014).

Participants

Inclusion criteria for the informal caregivers were: being a child (or child-in-law) or partner of a senior with dementia; having previous experience in tending to someone with dementia; and being of Moroccan origin. Experience was seen as any form of engagement, current or previous, in caring for a senior with dementia. Dementia could be any subtype of the condition. Table 6 provides an overview of characteristics of the 12 informal caregivers included in this study.

Table 6: Characteristics of participants among Moroccan informal caregivers (IC)

IC	Age	Gender	Soc-econ. profile	Relationship PD	Diagnose	Region
IC 1	50	f	Care professional, bachelor	Mother	Dementia	Antwerp
IC 2	55	f	Unemployed, bachelor	Father	AD	Antwerp
IC 3	42	m	Worker, secondary school	Father	AD	Antwerp
IC 4	63	f	1st generation, illiterate	Spouse	AD	Antwerp
IC 5	43	f	Employee, secondary school	Mother	AD	Antwerp
IC 6	50	f	Care professional, bachelor	Mother	AD	Antwerp
IC 7	51	f	Employee, bachelor	Mother	Dementia	Antwerp
IC 8	43	f	Unemployed, secondary school	Father	AD	Mechelen

IC 9	46	f	Unemployed, secondary school	Father	Dementia	Mechelen
IC 10	47	f	Unemployed, secondary school	Mother	AD	Gent
IC 11	36	f	Human Resources Manager, master	Father	FTD	Brussels
IC 12	36	f	Care professional, bachelor	Mother-in-law	Dementia	Antwerp

Note: PD (person with dementia) - AD (Alzheimer’s Disease) - FTD (Frontotemporal Dementia). Region refers to where the caregiver lives.

The included professional caregivers were currently care professionals with experience in caring for Moroccan seniors with dementia. In order to contain different perspectives corresponding to the multidisciplinary character of dementia care, these professional caregivers were active in different care disciplines. The search area was chosen based on typical migrant settlement patterns in Belgium. Regions that have attracted large numbers of people of Moroccan origin include Antwerp, Brussels and Mechelen (Lodewijcks, 2014). Table 7 provides a detailed overview of the 13 included professional caregivers.

Table 7: Participant professional caregivers’ (PC) demographics (gender, origin), profession and working area.

PC	Gender	Profession	Origin	Working area
PC1	m	Psychologist	Moroccan	Brussels
PC2	m	Neurologist	Belgian	Brussels
PC3	f	General practitioner	Belgian	Antwerp
PC 4	m	Neurologist	Belgian	Antwerp
PC 5	m	Head nurse of geriatric department	Belgian	Antwerp
PC 6	f	Nurse	Belgian	Antwerp
PC 7	m	Social nurse	Moroccan	Antwerp
PC 8	m	General practitioner	Moroccan	Mechelen
PC 9	f	Intercultural mediator	Belgian	Gent
PC 10	f	Intercultural mediator	Moroccan	Antwerp
PC 11	f	Intercultural mediator	Moroccan	Antwerp
PC 12	f	Head nurse of dementia department	Belgian	Mechelen
PC 13	f	Rheumatologist/Revalidation doctor	Moroccan	Antwerp

Interview scheme

25 semi-structured interviews formed the main data collection method in this qualitative study. One initial focus group with six informal and formal caregivers was organized to determine relevant themes for further elaboration during the interviews (Gill et al., 2008). Based on these themes two slightly different interview schedules were composed, one for informal carers and one for professionals. Topics covered in these schedules are presented in Table 8.

Table 8: Topics covered in interviews with informal and professional carers

Informal carers	Professional carers
Demographics	Demographics
Diagnosis trajectory First signals, experienced diagnosis process	Diagnosis trajectory First signals, experienced diagnosis process
Meaning of Dementia Meaning experienced by IC and relatives, communication about dementia	Meaning of Dementia Specificities in dealing with dementia by Moroccan families
Informal care challenges Encountered challenges, how managed, help- seeking	Professional care challenges Match demand/supply, needed form of professional care
Informal Care Care needed, care division, who is care provider Use of professional care & appreciation	Informal Care Care execution by these families Encountered care difficulties by these families
Influence of culture and religion in dealing with dementia	Influence of culture and religion in dealing with dementia
Recommendations for better dementia care for ethnic minorities	Recommendations for better dementia care for ethnic minorities
Future expectations & dementia care tips	Occurrence of the condition (Evolution of) Moroccan population with dementia

Data collection procedure

After the initial focus group, a target sample of eight to ten participants from each group (informal and formal caregivers) was defined for recruitment. The results are based on the final sample size of 25 participants. To ensure for data saturation, additional interviews were conducted. Recruitment of the participants was done in cooperation with six key persons from the Moroccan community (e.g. social care professionals, community leaders). These persons identified informal carers within their respective networks and introduced the researcher to them. For the recruitment of care professionals, the researchers appealed to their network. Several care professionals were already known (by reputation) to have diverse client populations, in particular owing to their locations in ethnically

diverse neighbourhoods. Using the snowball method, additional professionals were contacted in the selected search areas.

Data were collected by the primary researcher, who is completing a Ph.D. and has the necessary academic training in conducting qualitative research such as interviews and focus groups. The period of collections lasted from November 2014 until March 2015. Each interview was conducted at a location chosen by the participant and lasted between 38 and 168 minutes. Dutch was the main data collection language, with some use of Arabic expressions by informal carers. One interview was held in French. The primary researcher is fluent in each of these three languages. Field notes were kept of each encounter with a participant.

Analysis

The interviews were recorded using Audacity recording software and then transcribed verbatim. The data analysis was conducted in an inductive way following a grounded theory approach, with the data taken as primary source for the conceptualization process (Charmaz, 2011). The analysis respected the steps needed for qualitative research, by first deconstructing the data by open, axial coding as an analytic process where the individual concepts (e.g. informal care challenges) and their properties (e.g. encountered challenges, help-seeking actions) are identified, followed by linking these concepts to categories with subcategories (e.g. used care options) (Dierckx de Casterlée et al., 2012). The following phase of reconstruction began with selective coding, where these categories are integrated and refined (e.g. encountered challenges while using care options). The MaxQDA software was used to manage the data. The first researcher primarily performed the analyses, and several meetings were organized with co-authors to ensure the validity of the analytic process and the saturation of the emerging findings.

Ethical Aspects

All participants gave both written and verbal consent at the beginning of the individual interviews and focus group. An informed consent was presented to the participants, detailing the broader objectives of the study, the possibility to withdraw from the study at any time and information about data governance. To maintain confidentiality, identifiable information was altered and participants were coded. The audio recordings were destroyed after completion of the study. The study followed the guidelines of Human Sciences Ethical Committee of the VUB, respecting the European Framework for Research Ethics (European Commission, 2013). As the study included only competent human subjects and did not compromise any participant's integrity, no additional approval was needed by the committee (VUB, 2017).

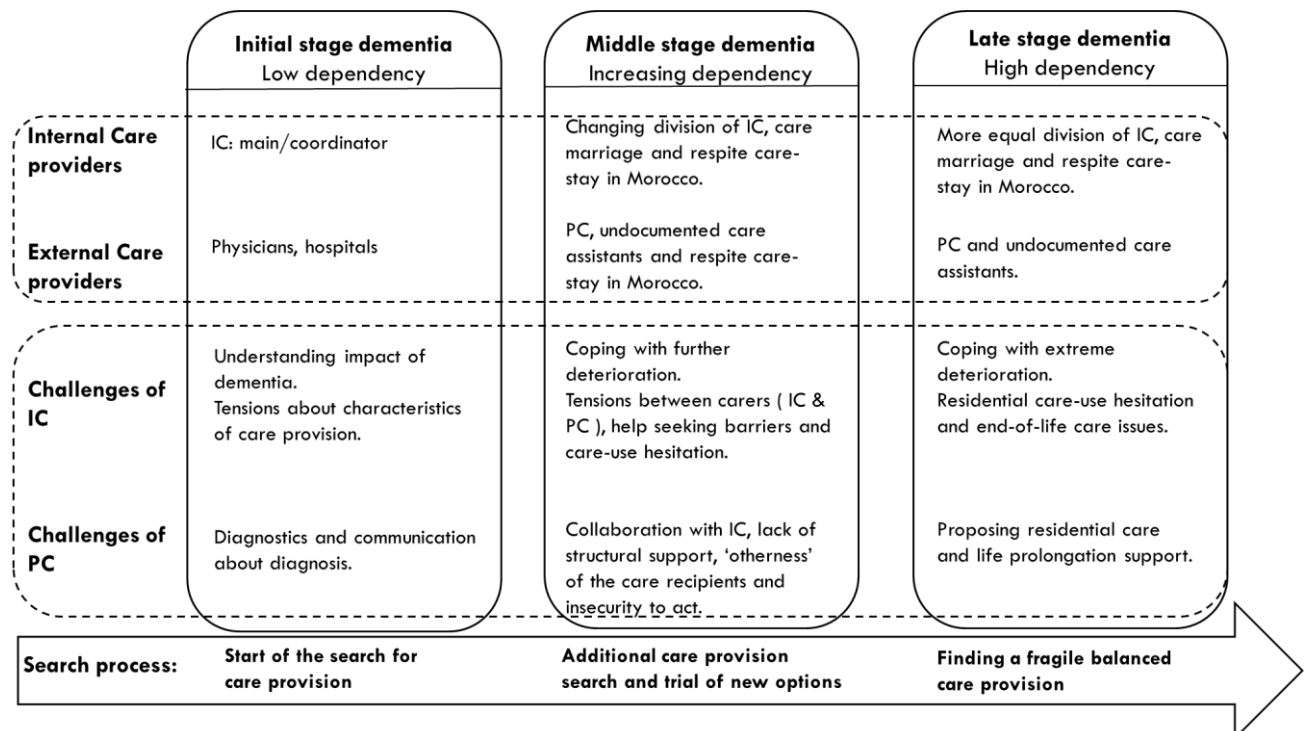
3. Results

How is care provided?

Dementia care: a dynamic search process

All the participants (n = 25) agreed that caring for older Moroccan migrants with dementia is a constantly evolving challenge. Informal caregivers called it ‘a continuous search process,’ thereby presenting a more dynamic image of dementia care than that offered by most of the professional respondents. Analysing the narratives of these informal carers revealed that dementia care was provided according to the increasing dependency of the person with dementia. Three general stages of dementia could be discerned within the respondents’ narratives: initial, middle and final stage. The initial stage is characterized by emergence of the first symptoms of the condition, the diagnostic process and adjustment to the first cognitive, personality and functional changes. The middle stage is characterized by the increasing cognitive and functional losses reflected in the increased need for assistance and care. During the final stage the person with dementia is dependent upon his or her caregivers for all basic life necessities (e.g. eating). The respondents experienced different care needs and challenges during these stages. Figure 2 offers a reconstruction of this dynamic dementia care process. This schema summarizes and structures the results, which are discussed in this section.

Figure 2: Dementia care as a dynamic search process



Note: IC = informal care; PC = professional care (physicians, nurses, etc.). This scheme summarizes and structures the results, which are discussed in this section.

Figure 1 describes the ‘search’ for dividing/balancing informal care responsibilities across the three stages, each stage reflecting different challenges. The initial stage of dementia was characterized by the respondents’ describing a challenging start, as family members were now required not just to recognize but also, and more importantly, to adapt to the reality of their relative’s dementia. Respondents testified this often entailed many family quarrels. Often during this stage one person (daughter/spouse) or a small group would take charge (e.g. to communicate with doctors, to observe medication intake). The informal caregivers guided their relatives with dementia through the diagnostic process and felt responsible for establishing the correct diagnosis. The middle stage was typified by an increase in care-solution-searching by more relatives. Because of increasing dependency (e.g. 24/24 alertness), more options were now taken into account. Approaching the later, final stage, informal caregivers found more acceptable (e.g. equal contribution by all informal caregivers, external help matched with specific desires) and applicable (e.g. sense of mastering the situation, division of burden) ways to provide care. Respondents said this balance was fragile, however, and in some cases the informal network faded. This often entailed restarting the entire search from the beginning, with the remaining informal network leading the new search. In two cases, for example, other siblings, both male and female, of the respondents withdrew from their care responsibilities.

“We are left only with two of us, me and my sister K – my other sisters and brother don’t help anymore.”
(Daughter, IC 1)

In one case, a single person carried out and performed the entire informal care process.

The role of informal carers

Our results show that informal carers are considered the most crucial and central actors in dementia care. In seeking solutions for increasing dependency, a combination of external professional care and non-professional care was used (Figure 2). In the initial stage of dementia, during the diagnosis process, medical services (general practitioners and hospitals) were used. In the middle stage, the increasing care needs of the person with dementia were addressed and more help was sought, including from outside the informal care possibilities. With the augmentation of care tasks, finding solutions to these needs became more important than adhering to culturally inspired images of care execution. Professional care was now considered and sometimes used to meet the care needs.

The role of professional carers

Professional health care, such as doctor and hospital visits, were in many cases performed during all phases. The general practitioner was especially important to the informal carers and the seniors, not only as a medical guide but also as a source of support and reassurance. Some informal carers opted for a general practitioner with Moroccan roots, in the hope that the parent’s being able to communicate directly with the doctor would enhance his/her independency. The criteria used by the informal caregivers in search of professional caregivers (e.g. home nurse, physiotherapist) during the middle and final stages were care expertise, communication capability and cultural sensitivity.

Residential care, such as nursing homes and day centers, although considered as options were often not used, due to 1) informal caregivers’ perceiving or having experienced a lack of sensitivity to the older person’s migration, cultural and religious background; 2) negative experience with (residential) care, personally or through acquaintances; and/or 3) the high costs of a nursing home.

The professional participants were aware of the families' non-use of these services. However, this sometimes resulted in stereotypical thinking and behaviour, such as assuming that these families would not consider professional care options and consequently not even proposing such measure to them. As a head nurse explained (PC 12):

"We often presume that these families go back home (after a hospital stay). We don't talk to them about the other options... Maybe this is a prejudice from us."

Professional carers had mixed opinions about the accessibility of care. Some thought that the professional care was accessible and that the migrant families did not want to use it because of their cultural background. Others were convinced that the services were inaccessible and cited different factors contributing to this inaccessibility, including financial barriers, lack of knowledge about the care possibilities and lack of culturally sensitive care services.

Alternative care provision sources

To meet the need for cultural sensitivity and financial prudence, informal carers considered alternative external care options, outside the classical Belgian professional care services, such as undocumented domestic helpers, temporary relocation to Morocco and care marriages.

First, enlisting the aid of undocumented helpers at home was a common solution mentioned by the participants. Half of the informal caregivers were assisted by an undocumented helper. Usually this was an adult Moroccan woman of recent migration history, often in a precarious situation herself. These women often did not have a place of residence, did not speak the local language and earned a living as domestic helpers. Informal caregivers called on their network within the Moroccan community to find these women. The domestic helpers mostly assisted the informal caregivers with various tasks such as cleaning, cooking, washing, giving medication and keeping watch over the person with dementia when the informal caregiver was away. Sometimes undocumented (distant) relatives were asked to assist. For their services, these helpers were paid modestly or given shelter and food as compensation. Only professional carers of Moroccan origin were aware that informal carers used this type of external care.

Second, most of the older care receivers still owned a residence in Morocco where informal carers could take their older relative. Relatives or strangers in Morocco (e.g. couples or adult women without children) were asked and paid to care for the person with dementia while the informal caregivers returned to Belgium. This financially affordable option was often chosen as a form of respite care and as a compromise between two forms of pressure: the heavy care burden that informal carers experienced in Belgium and the expected condemnation they would receive from within the community if they stopped caring for their relative.

"Every time I feel I cannot cope anymore, I send her (mother) to my cousin in Morocco for a month or three... this is the only way to regain my strength to sustain this situation, without bad talk from the community." (Daughter, IC 10)

The third alternative source of help was also based in Morocco. 'Care marriages' were used as a solution when a father with dementia was also widowed. The new marital arrangement would allow him to stay in his home and relieved the caregivers of their own care burden. The search for a suitable adult woman in Morocco, usually childless and living in humble conditions, was a task for one of the siblings. The woman was aware of the conditions and goal of this proposed 'marriage.' Only a few

professional caregivers were aware of this care practice. Some agreed with this solution and had seen that the arrangement could be beneficial to both parties. Professionals testified that such marriage arrangements can also provide the caregiver a better and more stable future, while the man with dementia benefits from care at home. As a general practitioner of Moroccan origin noted (PC 8):

"I often see such cases resulting in a good situation for both of them. The woman finds a stable home and the man improves because of better adherence of treatment."

According to the same GP, the marriage will sometimes even result in a positive, loving relationship between the marital partners. Conversely, this care solution sometimes resulted in vulnerable situations, especially when the female caregiver was dependant on the guidance and the goodwill of the children. As formulated by a psychologist (PC 1):

"I've seen it often with these women: the day the person with dementia dies is the day that her bags are packed and she is asked to leave."

Encountered challenges in provision of dementia care process

Challenges for informal carers

Dementia related challenges

Informal caregivers were challenged by universal dementia-related sources of distress combined with challenges specific to their search process. The informal caregivers identified the following dementia-related distress factors: 1) adjustment to behavioural changes and deterioration of the loved one; 2) role reversal between caregiver and the person with dementia; and 3) the combination of being a caregiver and having responsibilities towards one's own work, partner and children.

Professional help-seeking obstacles

Informal caregivers also encountered obstacles when they decided to seek professional help. Their lack of knowledge about professional care options made it difficult for them to find appropriate and effective help. The available information about dementia care options did not reach the participants. It was only by being assertive or happening to come across a professional that they received the needed information. Another obstacle related to how professional caregivers performed their care. Informal carers felt a person-centred approach was often lacking, due to a lack of (cultural) sensitivity in combination with quick technical execution of the necessary care tasks with minor attention for more humane aspects. Despite the informal carers' appreciation for the professionalism of these caregivers, these humane aspects were decisive in their opting not to use professional care. Some informal caregivers also experienced discrimination and racism during their encounters with professional caregivers, as formulated by an informal caregiver (IC 11):

"You should have seen the way how he (a doctor) talked to me and to my father. Without any respect, like we were animals...it hurts me that my father has to endure such racism at this stage of his life."

Such experiences enhanced the informal caregivers' anxiety to entrust the person with dementia to professional caregivers who evinced little sensitivity for cultural and religious aspects such as prayer, halal food and gender matching.

Challenges for professional carers

Collaboration with family members

The professional caregivers who participated in this study also experienced challenges (Figure 1) in providing care for older migrants with dementia. In these experiences there was a distinction between caregivers of Moroccan origin and those of non-Moroccan origin. Two challenges were named by all respondents: collaboration with the family members and structural support measures to deal with the diversity of care recipients. Most of the respondents found it challenging to collaborate with families of older migrants. They found it difficult to deal with the various family members involved in caring for the older Moroccan relative with dementia and preferred instead to deal with one contact person from the family. The various family members involved all wanted information, wished to participate in caring for the older person and had different opinions and expectations. All of this rendered it difficult to work in a context where there is already limited time and staff to meet multiple expectations. However, some professional carers anticipated this reality and tried to collaborate with the family by organizing family meetings. Some participants even noticed that having multiple family members involved could be a positive source of help, as stated by a head nurse in Antwerp (PC 5):

“If the family wants to come earlier to feed the patient, that’s fine by me. Less work for my colleagues.”

Others did not see this sort of potential and demanded that the family adjust to the regulations of the care facility.

Lack of structural support system

Professional caregivers also complained about the lack of investment in structural support measures such as affordable translation services and education and training that would prepare them to deal with this reality in general. Those who worked in care services did not feel supported by their management when making decisions. They needed room for flexibility, time and support measures. These same factors were also missing in a highly regulated context with increasing time pressures and budget cuts, as formulated by neurologist (PC4):

“You see, we could call intercultural care mediators or translation services when we had a patient with a different background – that was helpful, but due to hospital decisions we cannot use these services anymore.”

Challenges for native Belgian professionals

The following challenges were experienced only by participants of Belgian origin. The first challenge was the language barrier. This barrier resulted in poor communication, making it difficult to develop a good relationship with the patient’s family and to connect with older people with high risk of poor care provision.

Professional caregivers of Belgian origin also struggled with their own hesitancy to act. This hesitation stemmed from a perceived distance between their own culture and that of the care recipient. The caregivers perceived these older people with dementia as being different from themselves and referred to the patients in terms of ‘us’ and ‘them.’ Not sharing the same cultural background resulted in a sense of doubt and wariness as to how to provide effective care, as formulated by a head nurse (PC12):

“For us, you see, it is normal to wash someone in a dry way, just using a toilet glove, but he (patient with dementia) started to get agitated. We didn’t know what to do. We finally called the intercultural mediator, who explained to us that he needed to be wet washed...”

These professionals believed that having more knowledge about the patients and their culture would be helpful in resolving these feelings of uncertainty.

A last challenge experienced by caregivers of Belgian origin was fear of being accused of discrimination and racism. They did not understand why families sometimes accused them of such behaviour in discussions about provision of care, as stated by a head nurse in Antwerp (PC 5):

“I’m very careful about what I say (to the family members), to avoid being blamed for discrimination.”

4. Discussion

The elderly population of Europe is becoming increasingly more ethnically diverse, yet little is known about how dementia care is provided within migrant families (Gove et al., 2018). This study meets that gap by examining the dementia care provision within Moroccan families, specifically in Belgium. In response to the first research question, the results of this study indicate that provision of dementia care within these families is a dynamic, continuous and transnational search process across the three care stages of dementia. In each stage, various constellations of informal and external help are engaged. This complex reality of dementia care within migrant populations aligns with recent findings of Sagbakken et al. (2017), who highlight fluctuating care needs and decisions among migrant families in Sweden.

This complexity challenges the current, one-dimensional image of dementia care within migrant families, according to which such care is performed only by female informal caregivers (van Wezel et al., 2016). On one hand, informal carers are still crucial actors within dementia care, as is already evident during the diagnostic process (Botsford et al., 2011; Berdai-Chaoui and De Donder, 2018). On the other hand, our results reveal that the reality of the course of dementia, with care needs that increase over time, challenges the informal caregivers to adjust their culturally and religiously inspired conceptions of care. Their continuous search for internal and external care solutions confirms the need for additional professional support during all stages of dementia (Zwaanswijk et al., 2013), especially when the care burden increases. Because of its limited culture-sensitive and person-centred approach, Moroccan informal caregivers generally do not seek professional care, although doing so could relieve their burden (de Graaff et al., 2012). These older people of Moroccan origins fall into a gap between the inaccessible provision of elderly care and the fragmentation of traditional family caregiving (Moriarty et al., 2014; Ahanddour et al., 2015; Suurmond et al., 2016). This situation appears to force the respondents in this study to use their transnational resources of care (Näre et al., 2017) and to generate new forms of culturally and religiously acceptable external care, i.e. engaging in a care marriage, bringing in undocumented domestic helpers and sending the person with dementia to Morocco for a short stay.

Regarding the second research question, about encountered challenges, both informal and professional carers experience different sources of challenges. Informal caregivers of Moroccan origin face many challenges, resulting in a care burden. Conceptual models, such as the stress model of

Campbell (2009), regard the care burden as a result of different stress factors. Our results confirm primary (e.g. behavioural and psychological changes due to dementia) and secondary stress factors (e.g. family quarrels) as sources of caregivers' distress. In line with findings of Zwaanwijk et al. (2013), informal caregivers' problems and needs differ during the distinct stages of dementia. While informal caregivers would, in the first stage, benefit from information concerning dementia (e.g. how to recognize the different stages, how to deal with associated behavioural changes) and where to find help, in the last two stages more emphasis needs to be focused on care supply and respite care to cope with diminishing social networks.

However, these studies do little to address stress factors related to the caregivers' societal position as an ethnic minority (e.g. tensions with professional care, pressure from the Moroccan community, discrimination). Our findings underscore the importance of understanding the underlying migration, cultural and religious elements of dementia care so as to develop more effective culturally and religiously sensitive care (Mukadem et al., 2011; Cipriani and Borin, 2014; Johl et al., 2015). Although these considerations are critical for effective care, professional dementia care is not sensitive to these various aspects and upholds an essentialist 'othering' view of older migrants (Forssell et al., 2015; Sagbakken et al., 2017).

Professional caregivers are also confronted with challenges in providing care to older people of Moroccan origin with dementia. Collaboration with the numerous family members involved in a patient's treatment is experienced as being difficult, especially in a context of acute time and performance pressures. However, some professional caregivers were able to see the 'win-win' scenario in such collaboration. Sagbakken et al. (2017) emphasize that increased collaboration and care sharing with relatives can facilitate better and more coherent care. Inclusion of family carers in professional care is a near universal wish among family members and one that transcends ethnicity (Wittenberg et al., 2017)

Professional caregivers of Belgian background struggle with what Torres et al. (2006) have termed the 'otherness' of elderly immigrants. In addition to navigating language and communication barriers (Drewniak et al., 2017), these caregivers also feel uncertain in how to respond when a care recipient's demand seems to deviate from what they categorize as 'normal' (Sagbakken et al., 2017). In line with these studies, the participants respond individually to care questions they perceive as non-confirming. Their response results from internal negotiation between the patient's request and what is perceived as a standard care and the organizations' guidelines. Such an equation, where a reasonable question is one that does not differ significantly from what is perceived as a standard (i.e. the Belgian) practice and which is expressed in terms of 'us' and 'them,' leads to an ethnocentric care approach that is discriminatory toward ethnic minority care recipients (Forssell et al., 2015).

Fear of being accused of discrimination and racism is also a challenge for caregivers of Belgian origin. This genuine fear of being perceived as racist does not mean that the professional caregivers will challenge the existing stereotypes, as shown by Markey et al. (2017). The professional caregivers in our study were not aware of the discrimination and racism experienced by the informal caregivers, and regarded possible accusations against themselves as unreasonable. This aligns with a general unawareness of harmful activation of implicit biases and stereotypes towards ethnic minorities by health professionals, as discussed by Drewniak et al. (2017). Our respondents experience a lack of knowledge about the culture of the 'others.' They wish for organizational support actions that could help bridge culture and language gaps, such as investment in education and collaboration with

intercultural mediators and interpreters (Regan, 2013). Such actions have limited results, however, and therefore actions on a 'deep structure' level are needed (Resnicow et al., 1999). This means that care professionals and organizations should be aware of their ethno-centric, essentialist approach and move towards an intersectional approach which can address the complexity and the heterogeneity of ethnic minority care recipients (Zubair and Norris, 2015; Torres, 2015).

The findings raise a number of issues for policy and practice concerning this first generation of caregivers – both informal and professional – now facing a rather new population of Moroccan older people with dementia in Belgium. They need a different kind of knowledge and support in order to provide effective care to these patients, thereby enhancing the wellbeing of all parties. The results of our study underscore the need for investment in migration-, culture- and religion-sensitive care on several levels. Policy makers and professional care providers should also be aware of and validate the creativity and transnational recourses (Wildler and Baldassar, 2018) of these informal caregivers. Another recommendation is to eliminate barriers that impede people in this minority community from seeking help (Mukadem, 2011; Regan, 2016) and to provide tailored and effective support to family carers (Johl et al., 2015). Tailored care that enables professional caregivers to feel competent in caring for these older people requires both a multi-faceted care policy that is aware of its own ethno-centricity, and development of 'deep structure' support measures that take into account the complex identities of minority care recipients (Resnicow et al., 1999; Torres, 2015, Drewniak et al., 2017). This requires health policy planning (Denier and Gastmans, 2013) that involves the perspectives of all concerned parties (Stephan et al., 2015; Jutlla, 2015).

5. Study limitations

Our findings should be considered in light of the following limitations. The informal carers were mostly second-generation Moroccans and female. Half of these participants were highly educated, which is not representative of the labour market position of migrants in Belgium (Laurijssen and Glorieux, 2015). Recent data suggest that Belgium has the lowest employment rate for non-EU migrants: 54 per cent, as compared to the European average of 65 per cent (Eurostat, 2019). More research is needed that would involve caregivers from various socio-economic profiles (Nazroo, 2006) and caregivers who are male (Snyder et al. 2014). Adding the perspective of Moroccan older people with dementia – through observations, tailored interviews or longitudinal approach – could improve on the limited triangulation (e.g. both informal and formal carers, focus group and interviews) of our approach (Cobb and Forbes, 2002). Such research is necessary, despite the fact that engaging ethnic minorities in general (Carmody et al., 2015) and older migrants specifically (Berdai Chaouni et al. 2018) is considered challenging as a methodological approach. Researchers face different challenges in their attempts to gain access to ethnic minority communities, not least because they often have limited skills by which to engage and to collaborate with these communities and so require more time and resources than that provided by 'classic' research approaches (Carmody et al., 2015; Berdai Chaouni et al., 2018). Researchers must therefore develop additional skills by which to gain access to and engage older migrants, such as flexibility, cultural competences and communication skills (Shanley et al., 2013). They must also invest in strategies to overcome the multiple barriers that ethnic minorities face when considering whether to participate in research: such barriers include distrust in research and researchers, fear of being abused or exploited, and reluctance to become involved in unfamiliar

research projects, especially those with an essentialist Western framework or with no clear added value to the minority participants or their community (Shanley et al., 2013; Berdai Chaouni et al., 2018).

6. Conclusion

Our study looked at the current dementia care provision for older Moroccan migrants in Belgium. How is dementia care provided and what challenges do the caregivers, both informal and professional, encounter? The results show a dynamic and complex picture of how dementia care is provided. The dementia course, with its increasing care needs, defines the continuous search process to provide good care to these people. At first glance, this search process, led by the informal caregivers, is driven by universal dementia-related care needs and challenges. Regardless of ethnic background, the condition's impact includes similar aspects, such as adjusting to the degenerative character of the condition, balancing the care burden, finding proper information and obtaining suitable professional care. On closer examination, it is clear that migration, culture and religious background affect this search process; these factors add a different layer to the care burden, resulting in alternative transnational solutions and strategies to manage the burden. Moreover, professional caregivers also search for suitable dementia care for these migrant older people. However, they appear to do so in an ethno-centric and essentialist context, often unaware of the individual complex reality of both the migrant older people and their informal caregivers. Structurally supportive policy and organizational measures with more space for flexibility and collaboration with informal caregivers are needed; this is especially relevant for nurses and physicians, as in our research they were the only health professionals involved during all stages of the care process. A better understanding of this complex reality in which different aspects intersect could lead to interventions that would not only relieve the informal care burden but also provide effective and tailored person-centred care that is sensitive to the elderly patient's life experiences, culture and religious background.

References

- Ahaddour, C., van den Branden, S. and Broeckaert, B. (2016). Institutional elderly care services and Moroccan and Turkish migrants in Belgium: a literature review. *J Immigrant Minority Health*. <https://doi.org/10.1007/s10903-015-0247-4>
- Berdai Chaouni, S. and De Donder, L. (2018). Invisible realities : Caring for older Moroccan migrants with dementia in Belgium. *Dementia*. <https://doi.org/10.1177/1471301218768923>
- Berdai Chaouni, S., Claeys, A., De Donder, L. (2018). How to (qualitatively) involve older people with dementia and their informal carers with a migration background in research? Insights from a longitudinal project in Brussels. In T. F. Hannes, K., Dierckx de Casterlé, B., Heylighen, A. (Eds.), *European Congress of qualitative inquiry Proceedings*. (pp. 63–71) KU Leuven NQRL. ISBN 9789067842082.
- BISA. Brussels Instituut voor Statistiek en Analyse deeper calculation for this research made by Sierens A. based on the statistical data of Brussels on 1 January 2018. www.bisa.be. Accessed 06 June 2019.
- Botsford, J., Clarke, C. and Gibb, C. (2011). Dementia and relationships: experience of partners in minority ethnic communities. *Journal of Advanced Nursing*, 68, 2207-17. <https://doi.org/10.1111/j.1365-2648.2011.05905.x>
- Botsford, J. (2015). Introduction. In Botsford, J. and Harrison Denning, K (eds.), *Dementia, Culture and Ethnicity, Issues for all*. (pp 9-18) Jessica Kingsley Publishers, London
- Braun, K. L., Browne, C. V, Sue, L., Kim, B. J., & Mokuau, N. (2014). Research on indigenous elders: from positivistic to decolonizing methodologies. *Gerontologist* 54 (1): 117–126. <https://doi.org/10.1093/geront/gnt067>
- Carmody, J., Traynor, V., and Marchetti, E. (2015). Barriers to Qualitative Dementia Research. *Qualitative Health Research*, 25(7):1013–19. <https://doi.org/10.1177/1049732314554099>
- Centre of Expertise Dementia, The centre for expertise of the Flemish Government. (2018). The latest prevalence data on dementia in Flanders: <https://www.dementie.be/nieuwe-cijfers-dementie-per-gemeente/> Accessed on 14 May 2019
- Charmaz, K. (2011). Grounded theory methods in social research. In Dinzin, N. and Lincoln, Y. (eds), *The SAGE handbook of qualitative research*. (pp 35-55) SAGE Publications, Inc., Thousand Oaks
- Cipriani, G. and Borin, G. (2014). Understanding dementia in the sociocultural context: A review. *International Journal of Social Psychiatry*, 61(2):198-204. doi: 10.1177/0020764014560357
- Cobb, A.K. and Forbes, S. (2002). Qualitative research: what does it have to offer to the gerontologist? *Journal of Gerontology: Medical Sciences*, 57A(4):197-202.
- De Graaff, F.M. and de Francke, A.L. (2003). Home care for terminally ill Turks and Moroccans and their families in the Netherlands: carers' experiences and factors influencing ease of access and use of services. *International Journal of Nursing Studies*: 40 (8): 797-805
- De Graaff, F.M., Mistiaen, P., Devillé P, L.J.M. and Francke, A.L. (2012). Perspectives on care and communication involving incurably ill Turkish and Moroccan patients, relatives and professionals: a systematic literature review. *BMC Palliative Care*, 11: 1-35. <https://dx.doi.org/10.1186/1472-684X-11-17>
- Denier, Y. and Gastmans, G. (2013). Realizing good care within a context of cross-cultural diversity: an ethical guideline for healthcare organizations in Flanders, Belgium. *Soc Sci Med*. 93, 38-46. <https://doi.org/10.1016/j.socscimed.2013.03.045>

- Dierckx de Casterleé, B., Gastmans, C., Bryonc, E. and Denier, Y. (2012). QUAGOL: A guide for qualitative data analysis. *International Journal of Nursing Studies*, 49, 360-71. <https://doi.org/10.1016/j.ijnurstu.2011.09.012>
- Drewniak, D., Krones, T., Wild, V. (2017). Do attitudes and behavior of health care professionals exacerbate health care disparities among immigrant and ethnic minority groups? An integrative literature review. *International Journal of Nursing Studies*. 70: 89-98 DOI: 10.1016/j.ijnurstu.2017.02.015
- European Commission. Directorate-General for Research and Innovation. (2013). *The European Framework for Research Ethics*. Available online at http://ec.europa.eu/research/participants/data/ref/fp7/89888/ethics-for-researchers_en. Pdf. Accessed 14 May 2019
- Eurostat. (2019). Migrant integration, employment rates. <https://ec.europa.eu/eurostat/web/products-eurostat-news/-/DDN-20190529-1?inheritRedirect=true&redirect=%2Feurostat%2F>. Accessed 04 June 2019
- Erdem, O., Riva, E., Prins, R.G., Burdorf, A. Van der Doef, M. (2017). Health-related behaviours mediate the relation between ethnicity and (mental) health in the Netherlands. *Ethnicity and Health*, 5, 1-14. <http://dx.doi.org/10.1080/13557858.2017.1346181>
- Ferrer, I., Grenier, A., Brotman, S., Koehn, S. (2017). Understanding the experiences of racialized older people through an intersectional life course perspective. *Journal of Aging Studies*, 41, 10-17. <http://dx.doi.org/10.1016/j.jaging.2017.02.001>
- Forsell, E., Torres, S., Olaison, A. (2015). Care managers' experiences of cross-cultural needs assessment meetings: the case of late-in-life immigrants. *Ageing and Society*, 35(3):576–601. <https://doi.org/10.1017/S0144686X13000901>
- Gill, P., Stewart, K., Treasure, E. Chadwick, B. (2008). Methods of data collection in qualitative research. *British Dental Journal*, 204, 291-5. <https://doi.org/10.1038/bdj.2008.192>
- Gove, D., Plejert, Ch., Georges, J., Rauf, M. A., Rune Nielsen, T., Lahav, D., Jaakson, S., Parveen, S., Kaur, R., Golan-Shemesh, D., Herz, M., Smits, C. (2018). *The development of intercultural care and support for people with dementia from minority ethnic groups*. Alzheimer Europe. <https://www.alzheimer-europe.org/.../Alzheimer-Europe-Reports>. Accessed 19 May 2019
- Gräßel, E., Adabbo, R. (2011). Perceived Burden of Informal Caregivers of a Chronically Ill Older Family Member. *GeroPsych: The Journal of Gerontopsychology and Geriatric Psychiatry*, 24(3):143–54. <http://dx.doi.org/10.1024/1662-9647/a000042>
- Johl, N., Patterson, T., Pearson, L. (2015). What do we know about the attitudes, experiences and needs of Black and minority ethnic carers of people with dementia in the United Kingdom? A systematic review of empirical research findings. *Dementia*, 15(4): 721-42. <https://doi.org/10.1177/1471301214534424>
- Jutlla, K. (2015). The impact of migration experiences and migration identities on the experiences of services and caring for a family member with dementia for Sikhs living in Wolverhampton, UK. *Ageing and Society*, 35(05): 1032-54. <https://doi.org/10.1017/S0144686X14000658>
- Lanzieri, G. (2011). Fewer, Older and Multicultural? Projections of the EU Populations by Foreign/National Background. Luxembourg, Eurostat. <https://ec.europa.eu/eurostat/documents/.../KS-RA-11-019-EN.PD...>
- Laurijssen, I., Glorieux, I. (2015). Early career occupational mobility of Turkish and Moroccan. *Journal of Youth Studies* 18(1):101-117. <https://doi.org/10.1080/13676261.2014.933194>
- Lodewijcks, E. (2014). Ouderen van vreemde herkomst in Vlaanderen anno 2011: een korte demografische schets. In De Kock, C, Vens, E., Beljoudi, Y., Van Kerckhove, C. (Eds), *Ouder worden in een veranderende samenleving*. (pp 77-95). Garant Publishers, Antwerp/Apeldoorn

Lodewijcks, E. (2017). Huishoudens van ouderen. Verschillen naar herkomst. SVR Study Service Government of Flanders.

Markey, K., Tilki, M., Lecturer, P., Taylor, G. Kathleen Markey, C. (2017). Understanding nurses' concerns when caring for patients from diverse cultural and ethnic backgrounds, 27, e259-68. <https://doi.org/10.1111/jocn.13926>

Martens, A. (2017). Moroccan migration in Belgium's labor policy and labor market. In Timmerman C, Fadil N, Goddeeris I, Clycq N and Ettourki K (Eds.), *Moroccan Migration in Belgium: More than 50 years of settlement.* , (pp 87-104) University of Leuven Press, Leuven

Moriarty, J., Sharif, N. and Robinson, J. (2014). Black and minority ethnic people with dementia and their access to support and services. *Research Briefing*. Available online at www.scie.org.uk/publications. Accessed 18 May 2019

Moriarty, J. (2015). Accessing support and services. In Botsford J and Harrison Denning K (eds.), *Dementia, Culture and Ethnicity. Issues for all.* (pp 85-103) Jessica Kingsley Publishers, London and Philadelphia

Moriarty, J., Sharif, N., Robinson, J. (2014). Black and minority ethnic people with dementia and their access to support and services. *Research Briefing*. www.scie.org.uk/publications Accessed 15 February 2019

Mukadam, N., Cooper, C., Basit, B., Livingston, G. (2011). Why do ethnic elders present later to UK dementia services? A qualitative study. *International Psychogeriatrics / IPA*, 23(7): 1070-7. <https://doi.org/10.1017/S1041610211000214>

Mukadam, N., Cooper, C., Livingston, G. (2013). Improving access to dementia services for people from minority ethnic groups. *Current Opinion in Psychiatry*, 26 (4):409-14. doi: 10.1097/YCO.0b013e32835ee668

Nazroo, J. (2006). Demography of multicultural Britain. In Nazroo, J. (Ed.), *Health and Social Research in Multiethnic Societies.* (pp.1-19) Routledge, Abingdon

Näre, L., Walsh, K., Baldassar, L. (2017). Ageing in transnational contexts: transforming everyday practices and identities in later life. *Identities*, 24(5): 515-523, <https://doi.org/10.1080/1070289X.2017.1346986>

Nielsen, T.R., Vogel, A., Riepe, A.M., de Mendonça, A., Rodriguez, G., Nobili F, Gade, A. Waldemar, G. (2011). Assessment of dementia in ethnic minority patients in Europe: a European Alzheimer's disease consortium survey. *International Psychogeriatrics*, 23(1) : 86-95. <https://doi.org/10.1017/S1041610210000955>

Ouali, N. (2004). Quarante ans de presence de Marocains en Belgique. In Ouali, N. (ed.), *Trajectoires et dynamiques migratoires de l'immigration marocaine de Belgique.* (pp. 25-35) Collection Carrefours, Éditions Bruylant-Academia S.A., Brussels

Parlevliet, J.L., Uysal-Bozkir, Ö., Goudsmit, M., van Campen, J.P., Kok, R.M., ter Riet, G., Schmand, B. de Rooij, S.E. (2016). Prevalence of mild cognitive impairment and dementia in older non-western immigrants in the Netherlands: a cross-sectional study. *Int J Geriatr Psychiatry*, 31(9): 1040-9. <https://doi.org/10.1002/gps.4417>

Regan, J.L. (2013). Redefining dementia care barriers for ethnic minorities: the religion–culture distinction. *Mental Health, Religion & Culture*, 17(4): 345-53. <https://doi.org/10.1080/13674676.2013.805404>

Regan, J.L. 2016. Ethnic minority, young onset, rare dementia type, depression: a case study of a Muslim male Accessing UK Dementia Health and Social Care Services. *Dementia*. 15(4): 702-20. <https://doi.org/10.1177/1471301214534423>

Resnicow, K., Baranowski, T., Ahluwalia, J. S., Braithwaite, R.L. (1999). Cultural sensitivity in public health: defined and demystified. *Ethnicity & Disease*, 9 (1):10-21.

- Riffi, A., Devroey, D., Van De Vijver, E. (2012). A comparison between Moroccan and Belgian type-2 diabetic patients. *Acta Clin Belg.*, 67(4):246-9. DOI:[10.2143/ACB.67.4.2062667](https://doi.org/10.2143/ACB.67.4.2062667)
- Rosendahl, S.P., Söderman, M. Mazaheri, M. (2016). Immigrants with dementia in Swedish residential care: an exploratory study of the experiences of their family members and nursing staff. *BMC Geriatrics*, 16(16): 18 <https://doi.org/10.1186/s12877-016-0200-y>
- Sagbakken, M., Spilker, R.S. Ingebretsen, R. (2017). Dementia and Migration: Family Care Patterns Merging With Public Care Services. *Qualitative Health Research*, 28(1): 16-29. <https://doi.org/10.1177/1049732317730818>
- Segers, K., Benoit, F., Colson, C., Kovac, V., Nury, D., Vanderaspoilden, V. (2013). Pioneers in migration, pioneering in dementia: first generation immigrants in a European metropolitan memory clinic. *Acta Neurol Belg.* 113(4): 435-40. <https://doi.org/10.1007/s13760-013-0245-z>
- Shanley, C., Boughtwood, D., Adams, J., Santalucia, Y., Kyriazopoulos, H., Pond, D., Rowland, J. (2012). A qualitative study into the use of formal services for dementia by carers from culturally and linguistically diverse (CALD) communities. *BMC Health Services Research*. <https://doi.org/10.1186/1472-6963-12-354>
- Shanley, C., Leone, D., Santalucia, Y., Adams, J., Ferrerosa-Rojas, J.E., Kourouche, F., Gava, S., Wu, Y. (2013). Qualitative Research on Dementia in Ethnically Diverse Communities: Fieldwork Challenges and Opportunities/ *American Journal of Alzheimer's Disease & Other Dementias*, 28(3): 278-28, <https://doi.org/10.1177/1533317513481099>
- Snyder, C.M., Fauth, E., Wanzek, J., Piercy, K.W., Norton, M.C., Corcoran, C. Tschanz, J.T. (2014). Dementia caregivers' coping strategies and their relationship to health and well-being: the Cache County Study. *Aging & Mental Health*, 19, (5): 390-9. <https://doi.org/10.1080/13607863.2014.93961>
- Suurmond, J., Rosenmöller, D.L., Mesbahi, H., Lamkaddem, M., Essink-Bot, M.L. (2016). Barriers in access to home care services among ethnic minority and Dutch elderly – A qualitative study. *International Journal of Nursing Studies*, 54, 23-35. doi:10.1016/j.ijnurstu.2015.02.014.
- Torres, S. (2006). Elderly immigrants in Sweden: otherness under construction. *Journal of Ethnic and Migration Studies*. 32, (8): 1341-58. <https://doi.org/10.1080/13691830600928730>
- Torres, S. (2015). Expanding the gerontological imagination on ethnicity: conceptual and theoretical perspectives. *Ageing and Society*, 35, (5): 935-60. <https://doi.org/10.1017/S0144686X14001330>
- Torres, S., Karl, U. (2016). A migration lens on inquiries into ageing, old age and elderly care. Carving a space while assessing the state of affairs. In Ute Karl, U. and Torres, S. (Eds.) *Ageing in Contexts of Migration*. (pp 56-66) Routledge, Abingdon
- Van Mol, C. de Valk, H. (2016). Migration and Immigrants in Europe: A Historical and Demographic Perspective. In Garcés-Masareñas, B. and Penninx, R. (Eds.), *Integration Processes and Policies in Europe. IMISCOE Research Series*. (pp 35-55) Springer International Publishing
- Van Wezel, N., Francke, A., Kayan-Acun, E., Lim Devillé, W., van Grondelle, N.J. Blom, M.M. (2016). Family care for immigrants with dementia: The perspectives of female family carers living in The Netherlands. *Dementia*. <https://doi.org/10.1177/1471301213517703>
- VUB. (2017). Richtlijnen. <http://www.vub.ac.be/onderzoek/beleid/ethische-commissie>. Accessed 18 May 2019
- White, P. (2006). Migrant populations approaching old age: prospects in Europe. *Journal of Ethnic and Migration Studies*, 32, 1283-1300.

Wittenberg, Y., Kwekkeboom, R., Staaks, J., Verhoeff, A., de Boer, A. (2017). Informal caregivers' views on the division of responsibilities between themselves and professionals: A scoping review. *Health and Social Care in the Community*. <https://doi.org/10.1111/hsc.12529>

Wilding, R., Baldassar, L. (2018). Ageing, migration and new media: the significance of transnational care. *Journal of Sociology*. 54 (2): 226-35. <https://doi.org/10.1177/1440783318766168>

Zubair, M., Norris, M. (2015). Perspectives on ageing, later life and ethnicity: ageing research in ethnic minority contexts. *Ageing and Society*, 35(5): 897-916. <https://doi.org/10.1017/S0144686X14001536>

Zwaanswijk, M., Peeters, J.M., van Beek, A.P., Meerveld, J.H. Francke, A.L. (2013). Informal caregivers of people with dementia: problems, needs and support in the initial stage and in subsequent stages of dementia: a questionnaire survey. *The Open Nursing Journal*, 7, 6-13. <https://dx.doi.org/10.2174/1874434601307010006>

Chapter 4: The influence of religion on the experiences of family caregivers of older migrants with dementia³

Abstract

The number of older migrants with dementia in Western European cities is growing, and so is the share of their family caregivers. However, little is known about the influence of religion in their dementia and dementia care experience. This study explores the influence of religion on these experiences of family caregivers of older labor migrants. In-depth interviews were conducted with 34 religious and non-religious family caregivers of older Moroccan, Turkish, and Italian migrants with dementia. The results show: the importance of religion as 1) a co-definer of the meaning of dementia, 2) a way to deal with dementia and a care burden enhancer, 3) a family care supporting tool, and 4) an influencer of family care practice and professional care use; and that 5) religious sensitivity is missing in professional dementia care. Recognizing religion as a part of the dementia experience offers opportunities for a more holistic dementia care.

³ In revision at Journal of Religion and Health

1. Introduction

Europe faces a growing population of older migrants with dementia. Although accurate figures for dementia prevalence rates within this population are scarce and difficult to attain, Canevelli et al. (2019) estimate nearly 6.5% of overall cases of dementia in Europe to involve foreign-born populations. The risk of dementia is estimated to be higher among non-Western populations. Parlevliet et al. (2016), for example, estimated that for the Netherlands mild cognitive impairment and dementia affect non-Western Dutch populations, such as those of Moroccan and Turkish backgrounds, three to four times more than those of Dutch background. As the numbers of older persons with a migrant background grow, the numbers with dementia will also rise. Belgium faces a growing older migrant population, especially in regions like Brussels, which hosted former labor migrants in the 1950s and 1960s (Lodewijckx 2014). In 2020, 39.3% of Brussels' population over 65 had a migration background (Statbel 2021). Despite there being no accurate dementia prevalence estimates for the Belgian older migrant population, a recent attempt calculated that approximately 7% of older migrants over 65 have dementia (Monsees et al. 2021).

Although every individual dementia trajectory is unique, many aspects of the trajectory are primarily human and universal, such as dementia-related emotional and care challenges, and challenges in coping with the various dementia symptoms (Petty et al. 2018). However, an increasing body of work has focused on the assumed specific experience of dementia of older migrants in continental Europe and black and ethnic minority seniors in the United Kingdom, reflecting their historical migration-related differences. These studies mainly focus on the need for specific diagnostic instruments (Nielsen et al. 2011), family caregiving (Sagbakken et al. 2017), and access to professional dementia care (Mukadam et al. 2013) among this population. The studies agree that the cultural background of older migrants with dementia and their family caregivers is an important factor to consider in addressing the experience of dementia, the provision of family care, and access to professional dementia care among this population (Gove et al. 2018). And yet it is often unclear what exactly is meant by "cultural background" and ethnicity, as culture and religion are used fluidly and interchangeably (Torres 2019). Although migration, culture, and religion have been established to be critical influencers on the dementia experience of older migrants (Berdai-Chaouni and De Donder 2019), it remains unclear how these influencers operate individually. Regan et al. (2013) argued that research on access barriers experienced by black and minority ethnic (BME) persons with dementia could benefit from a focus on how religion influences this experience rather than labelling the experience as "cultural". Studying religion and culture distinctively is required to provide a nuanced picture of experiences, although the two concepts are intertwined and difficult to define (Assad 1986; Beyers, 2017), especially in multi-religious, multi-cultural and multi-ethnic social contexts resulting from global migration (Beyers 2017). This has also been argued in the case of dementia: such a distinction between religion and culture provides a nuanced picture of the barriers and therefore clearer knowledge about accessibility barriers faced by black and minority ethnic persons with dementia (Regan 2014). Moriarty (2015) even argues that religion can sometimes dominate a person's attitude toward dementia and dementia care.

Culture and religion are difficult to delineate, as they are related to each other. Saroglu and Cohen (2011, pp. 1309–10) state that "Religion may be part of culture, constitute culture, include and transcend culture, be influenced by culture, shape culture, or interact with culture in influencing cognitions, emotions, and actions.". Nevertheless, over the years scholars have formulated several definitions for both (Cohen 2009), and some criteria seem to be distinctive to religion: relationship

with the divine; beliefs, practices, and rituals related to the sacred and the sacred object; beliefs about life after death, spirits, angels, and demons; and rules and guidelines about how to live within a social group (Cohen 2009; Koenig 2009; Saroglu and Cohen 2011). Religion can be practiced privately and in a religious community that shares beliefs, rituals, and traditions transmitted across generations (Cohen 2009; Koenig 2009; Saroglu and Cohen 2011).

Studies have shown the importance of religion in the experience of dementia. First, religion is an important coping strategy for both persons with dementia and their family caregivers. On the one hand, for persons with dementia maintaining religious practices and social interactions with their religious community appears to stabilize and reduce their cognitive decline (Agli et al. 2015). Thanks to their religion, a person with dementia can more easily manage the unpredictability and uncertainty of dementia, preserve social relationships, and find hope and meaning in life (Agli et al. 2015; Daly et al. 2019). On the other hand, religious coping as emotion-focused coping is the most commonly used coping strategy among caregivers of persons with dementia, with positive outcomes for reduction of care burden, anxiety, and depressive symptoms (Monteiro et al. 2018). Scholars therefore examined the use of spiritual care as a way to support family caregivers of persons with dementia. Wilks et al. (2018) found that spiritual support has a positive impact on caregivers' resilience but did not significantly moderate the risk of care burden among either African or Caucasian family caregivers.

Second, recent evidence underscores the importance of religion in the experience of dementia among ethnic minority persons with dementia and their family caregivers. Epps and Williams (2018) portray the importance of spiritual connection and continuation of religious practices for the wellbeing of African Americans with dementia and their family caregivers. The spiritual connection to a God that is believed to take care of elders with dementia helps live with, cope with, and endure dementia. Continuation of religious practices like worship in church resulted in improved wellbeing through reconnection with one's own identity and other worshipers (Epps and Williams 2018) Investing in efforts to help make African American churches dementia-friendly is important to support the continued attendance at church activities by older African Americans with dementia and their family caregivers (Epps et al. 2020). In the United Kingdom, the religion of Christian and non-Christian ethnic minorities hinders access to dementia care services due to religious labelling of dementia as divine punishment, the importance given to the religious duty of family care, and the lack of sensitivity of care services toward these ethnic minority populations (Regan et al. 2013; Regan 2014).

In conclusion, literature underpins the importance of religion in the experience of dementia and dementia care by both persons with dementia and their family caregivers. However, this body of evidence is based mainly on studies of the experiences of white-dominant indigenous populations, and existing studies on the influence of religion on ethnic minorities with dementia are limited primarily to the United States and the United Kingdom. Despite the valuable insights from these studies, little research has examined how religion shapes the experience of dementia among migrant families in continental Europe. The present study seeks to fill this gap by answering the following questions: 1) How does religion influence the dementia experience of migrant families in Belgium?, and 2) How does religion influence dementia care for older labor migrants in Belgium?

2. Methods

Design

The goal of this study is exploratory and descriptive: it seeks to establish a better understanding of the experiences of family caregivers of older migrants with dementia, therefore a cross-sectional qualitative approach is employed. It has been argued that qualitative research is better suited and even required when seeking a greater understanding of the experiences of persons with dementia and of their informal caregivers, especially when the aim is to include disadvantaged groups such as ethnic minorities (Gove et al. 2020).

Data collection

Recruitment of participants was carefully prepared following an approach based on the insights proposed by ten experts on engaging older migrants and their close environment in research (Berdai-Chaouni, Claeys, De Donder 2018). The recruitment process started by identifying and contacting key persons, community organizations, and medical and social services. The next step was to develop a trusted relationship with these gatekeepers interested in supporting the first and second authors to contact the family caregivers. The following recruitment strategies were followed: first, initial information sessions and dialogue meetings about dementia were held to create a reciprocal cooperation between the researchers and key persons and organizations. These sessions and meetings answered a need of these migrant communities to learn about dementia (Berdai-Chaouni and De Donder 2019), at the same time providing clear oral information about the research project. Attendees of these meetings were either candidates to participate in the research project or gatekeepers to other family caregivers. The second strategy was the snowball method, by which gatekeepers (e.g., social care professionals, community leaders) identified informal carers within their respective networks and introduced the researcher to them.

The data was collected by the first and second authors between April 2017 and January 2019. Each interview was conducted at a location chosen by the participant and lasted between 45 and 114 minutes. Six interviews were held at home, in the presence of the person with dementia. Dutch and French were the main data collection languages. Two interviews were held in Moroccan Arabic (*Darija*) by the first author. For two interviews a Turkish translator was present. Field notes were kept of each encounter with a participant.

The face-to-face individual interviews covered the following topics: 1) experience of the diagnostic process of the person with dementia, 2) impact of dementia on daily lives, 3) coping with dementia, 4) process of division of care tasks, 5) description of the individual's own care task, 6) experience of being a family caregiver and coping with related challenges, 7) inclusion process of professional dementia care, 8) experience with professional dementia care, and 9) influence of religious and cultural background throughout the caregiving experience. This study will zoom in on the intersection of migration and religion (Crenshaw 1991): whether and how religion influenced the dementia and dementia care experience of family caregivers of older labor migrants. In the scope of this study, participants provided their own interpretations of what is considered religion and religious and of whether they identified as religious or not, following James' (1997) definition of religion as an individual relationship with the divine.

Sample size and characteristics

The final sample size included 34 family caregivers: 10 of Turkish descent, 11 of Italian descent, and 13 of Moroccan descent. The choice for Moroccan, Turkish, or Italian descent was based on these being the largest groups of guest workers during the labor migration wave, and constitute Belgium's largest migrant population besides migrants from the Netherlands and France (Lafleur, Marfouk, and Fadil 2018). Inclusion criteria for the family caregivers were: being a child (or child-in-law) or partner of an older person with dementia; having a current or previous experience tending to someone with dementia; and being of Moroccan, Turkish, or Italian origin and living in Belgium. Experience was seen as any form of engagement, current or previous, in caring for an older person with dementia. The older person with dementia was to be a first-generation older migrant who settled in Belgium as part of the labor migration wave of the 1950s and 1960s (Martens 1973). The person could have any subtype of dementia.

Family caregiver	Origin	Age	Sex	Religion	Educational level	Location	Relationship to person with dementia
FC 1	Italian	53	F	Catholic	Elementary	Rebecq	Daughter (mother with dementia)
FC 2	Italian	65	F	Catholic	Bachelor	Mons	Daughter-in-law (mother-in-law with dementia)
FC 3	Italian	51	M	Catholic	Elementary	Genk	Son (father and mother with dementia)
FC 4	Italian	68	M	Atheist	Bachelor	Houthalen-Helchteren	Son (mother with dementia)
FC5	Italian	47	F	Spiritual	Bachelor	Herne	Daughter (mother with dementia)
FC 6	Italian	82	M	Catholic	Secondary	Brussels	Husband (wife with dementia)
FC 7	Italian	63	F	Atheist	PhD	Brussels	Cousin (uncle with dementia)
FC 8	Italian	56	F	Catholic	Master	Brussels	Daughter (mother with dementia)
FC 9	Italian	46	F	Catholic	Bachelor	Brussels	Daughter (mother with dementia)
FC 10	Italian	73	M	Catholic	Elementary	Brussels	Husband (wife with dementia)
FC 11	Turkish	57	M	Muslim	Secondary	Houthalen	Son (father with dementia)
FC 12	Turkish	26	F	Muslim	Bachelor	Houthalen	Granddaughter (grandfather with dementia)
FC 13	Turkish	47	M	Muslim	Secondary	Louvain	Son (mother with dementia)
FC 14	Turkish	71	F	Muslim	No education	Ghent	Wife (husband with dementia)
FC 15	Turkish	37	F	Atheist	Secondary	Ghent	Daughter (father with dementia)
FC 16	Turkish	37	F	Muslim	Bachelor	Londerzeel	Daughter (father with dementia)
FC 17	Turkish	62	F	Muslim	No education	Londerzeel	Wife (husband with dementia)
FC 18	Turkish	40	F	Atheist	Bachelor	Brussels	Daughter (father with dementia)
FC 19	Turkish	47	F	Muslim	Bachelor	Antwerp	Daughter (father with dementia)
FC 20	Turkish	30	F	Muslim	Bachelor	Antwerp	Granddaughter (grandfather with dementia)
FC 21	Turkish	55	F	Muslim	Secondary	Lier	Daughter-in-law (mother-in-law with dementia)
FC 22	Moroccan	35	F	Muslim	Bachelor	Brussels	Daughter (father with dementia)
FC 23	Moroccan	34	F	Muslim	Bachelor	Brussels	Daughter (father with dementia)
FC 24	Moroccan	49	F	Atheist	Bachelor	Brussels	Daughter (father with dementia)
FC 25	Moroccan	37	M	Muslim	Bachelor	Antwerp	Son (father with dementia)

FC 26	Moroccan	64	F	Muslim	No education	Antwerp	Wife (husband with dementia)
FC 27	Moroccan	32	F	Muslim	Master	Brussels	Daughter (mother with dementia)
FC 28	Moroccan	33	F	Atheist	Bachelor	Brussels	Daughter (father with dementia)
FC 29	Moroccan	51	F	Muslim	Bachelor	Brussels	Daughter (mother with dementia)
FC 30	Moroccan	41	F	Muslim	Secondary	Brussels	Daughter (father with dementia)
FC 31	Moroccan	43	F	Muslim	Secondary	Brussels	Daughter (father with dementia)
FC 32	Moroccan	47	F	Muslim	Secondary	Brussels	Daughter (father with dementia)
FC 33	Moroccan	48	F	Muslim	Secondary	Brussels	Daughter (father with dementia)
FC 34	Moroccan	37	F	Muslim	MD	Brussels	Daughter (father with dementia)

Table 9: Demographics of the participating family caregivers (FC) and their relationship with the person with dementia

Table 9 gives an overview of the participants: 26 participants were caring for an older migrant with dementia when the individual interview was held. In 8 cases the person with dementia had been deceased between 3 months and 2.5 years before the interview. Of the family caregivers, 27 were female and 7 were male. Nearly two-thirds of the participants (N= 19 of 34) were highly educated (Bachelor's or Master's). Most participants (N= 19 of 34) were between ages 30 and 50, 9 were between ages 50 and 65, 4 between ages 65 and 75, 1 was under 30 and 1 was over 80. The majority of participants (N= 25 of 34) lived in regions that have attracted large numbers of labor migrants of Italian, Moroccan, and Turkish origin, including, in order of importance, Brussels, Antwerp, Ghent, Genk, and Mons (Martens 1973; Lodewijcks 2014). Nine participants lived in the surrounding areas of these cities. 27 participants identified themselves as religious (N= 20 Muslims, 7 Catholics) and 7 as non-religious (6 atheist, 1 spiritual).

Analysis

The interviews were recorded using Audacity recording software and then transcribed verbatim. The data analysis was conducted in an inductive way following a grounded theory approach, with the data taken as primary source for the conceptualization process (Charmaz 2011). The data was subjected to a rigorous qualitative analytical process, by first deconstructing the data by open, axial coding as an analytic process whereby the individual concepts (e.g., religious influence of family care) and their properties (e.g., religious coping, religious aspects shaping family care) were identified, followed by linking these concepts to categories with subcategories (e.g., religious arguments in professional care use) (Dierckx de Casterlée et al. 2012). The following phase of reconstruction began with selective coding, through which these categories were integrated and refined (e.g., encountered challenges while using care options). MaxQDA software was used to manage the data. The first round of analyses was conducted by the first author, the second round in collaboration with the second author. Several meetings were organized with co-authors to discuss and ensure the validity of the analytic process and the saturation of the emerging findings.

3. Results

The results show: the importance of religion as 1) a co-definer of the meaning of dementia, 2) a way to deal with dementia and a care burden enhancer 3) a family care supporting tool, 4) an influencer of family care practice and professional care use; and that 5) religious sensitivity is missing in professional dementia care.

1) Religion as a co-definer of the meaning of dementia

A majority of respondents indicated that religion co-defines the meaning-making of dementia, especially in the case of religion-practicing family caregivers and older persons with dementia. Although some family caregivers experienced intergenerational differences in their gradation of religiosity and its effect as meaning-maker, most respected the religious meaning of the older person with dementia:

“Religion is important for him [father with dementia], he sees it [dementia] as something given from God and I respect that ... I think God didn’t give us anything, it is just an illness, we have to deal with it.” – Anna, of Italian descent

Religion was also a co-reference in the explanation of dementia. A number of respondents considered dementia to be “a challenge that God places in front of us”. Caregivers used this framework complementarily to biomedical insights on dementia. Respondents observed that religious understanding of dementia as a life event could give positive as well as negative meanings for themselves and for older persons with dementia. Respondents who saw a positive connotation regarded dementia as yet another life test. Respondents, particularly Muslims, viewed this life test as an earthly opportunity to expiate bad deeds so as to increase one’s chances of a place in heaven:

“Everything in this life happens for a reason. What we get from Allah, good or bad, is welcome. Maybe this is an opportunity for my father to clear his possible sins.” – Hamid, family caregiver of Moroccan descent

Family caregivers also stated that religion could give a negative meaning to dementia, also for older persons with dementia:

“My mother [with dementia] was so depressed, she was always yelling, ‘God, what wrong did I do to you!’” – Laura, family caregiver of Italian descent

2) Religion as way to deal with dementia and a care burden enhancer

The respondents observed that religion was an important way to deal with dementia, both for them and for the person with dementia. It was used together with other ways, such as reframing and planning, to address the challenges stemming from dementia and dementia care. This was especially the case for religious older migrants with dementia and family caregivers. Religion helped them accept this challenge in this temporary life on Earth. Religious practices such as prayer, mass, supplications, and religious hymns were used to seek comfort and relief. These practices were helpful to use alone or accompanied by the older migrant with dementia:

“My father was very religious. I often told him, ‘Come and pray,’ to relax together.” – Caramella, informal caregiver of Italian descent

Religious practices were additionally used as a way to keep the connection with the relative with dementia:

“Whenever I could I took time off from work to accompany my father to the Friday prayer at the mosque. I really enjoyed walking with him and seeing the pleasure in his eyes to be able to do this together. Praying together at the mosque was our moment, and was beneficial for both of us. I’m grateful that we kept that routine as long it was (physically and mentally) possible for him.” – Ahmed, family caregiver of Turkish descent

Practicing Muslim caregivers also indicated that the promise of Allah’s satisfaction with their act of informal caregiving comforted them and gave them strength to carry on during difficult periods. Religion-inspired encouragements given by the older person and the religious community were likewise considered highly positive and satisfying:

“Hearing him say ‘Allah bless you’, even in times when he couldn’t even distinguish what is eatable, was like heaven on earth. It made me forget the fatigue, the long waking nights ... so powerful!” – Aicha, of Moroccan descent

Conversely, religion could also be a source of burden for caregivers. This was especially the case when these family caregivers felt that they could not always measure up to the standards set by their religion. A frequent example was feelings of failure for not always succeeding in being merciful and patient with the older person with dementia, as expected by their religious values. Religion was likewise a source of burden when respondents did not respect their own health and psychological limits in continuing to care for the relative with dementia, such as by prioritizing the promise of reward in the afterlife above self-care in the current life:

“Yes, I know. It is hard sometimes to keep caring for her (mother-in-law with dementia) with my health condition. Did you know, I have recently gone through a second episode of depression? ... Yet, I feel lucky with a chance to do such a great thing as caring for someone in need. The rewards for that in the afterlife are countless. This gives me power to keep going on.” – Hanife, family caregiver of Turkish descent

3) Religious practices as a family care supporting tool

Respondents observed additional beneficial effects of religious practices on older migrants with dementia: religious practices such as prayer, reciting Qur’anic or biblical verses, and joining religious gatherings such as Sunday Mass gave structure to older migrants with dementia, allowing them to stay cognitively active, connect, and deal with dementia. Regardless of personal religiosity, most family caregivers used the beneficial effect of religious practices as care facilitator in their provision of informal care. Religious older migrants had, for example, long-lasting ability to repeat Qur’anic or biblical verses in the advanced stages of dementia. Caregivers witnessed that recitation of these verses could “bring back” and calm the older persons with dementia. Some recited or played audio recordings of the verses while they cared for their relative with dementia. These religious verses were familiar and reassuring now that they had dementia:

“He forgot everything except Quran verses. I put the Quran tape regularly and then he [father with dementia] started to recite it. That did him good!” – Nadia, of Moroccan descent

A visit to the mosque or church could also have a similar effect on religious older migrants with dementia, hence some family caregivers continued visiting these religious gatherings as a way to bring joy to the older person’s life. However, these beneficial effects occurred only when the other people present responded positively to the behavioral changes of the person with dementia. Family caregivers who experienced a lack of understanding of dementia by their religious community felt discouraged from further attending religious gatherings and came to consider non-attendance as a way to protect themselves and their relative with dementia from uncomfortable situations:

“He [father with dementia] always wanted to pray on a particular spot in the Mosque. If the spot was already taken, he started to yell, this could result in quarrels with people who didn’t know him before [the dementia]. People who knew him before just made space for him. We didn’t know what to expect each time, so after a while we stopped bringing him to the mosque.” – Hamid, of Moroccan descent

4) Religion influences family care practice and professional dementia care use

For the majority of respondents, regardless of background or religiosity there was a natural reflex to care for the older relative with dementia. This reflex was fueled by personal values that are often influenced by one’s cultural and religious values about the responsibility to care for older persons in need. Depending on how religious or non-religious the respondent was, these values were labelled as religious or cultural. Respondents of Turkish and Moroccan background referred more to their interpretations of Islamic texts and traditions to highlight values such as respect for parents, reciprocity in care, and mercy as an additional religious inspiration to provide informal care:

“Of course we care for my father. He gave us everything he could to have a good life. We will not abandon him now that he needs us the most ... You know it is stated in the Quran to care for our parents as they cared for us when we were children.” – Rafike, family caregiver of Turkish descent

These religious arguments were less visible in the testimonies of those respondents of Italian background. Still, religious values co-determined what is considered as “good care” for most respondents, regardless of background. To respondents, religious and non-religious alike, good care was provided with compassion, respect, and patience. These values were accordingly sought in professional care, co-defining the professional care choices:

“You know, not every Catholic nursing home respects Catholic values. He [father with dementia] is now in a [non-Catholic] nursing home that respects the Catholic values of respect and compassion.” – Gio, of Italian descent

Family caregivers, religious and non-religious, considered it important that the professional caregiver show respect toward the religious identity and religious practices of the older migrant with dementia. The possibility to continue practicing one’s religious identity co-determined whether professional care was used. Respect for the older person’s religious customs and practices, such as eating halal food, praying or attending mass, and wearing a headscarf, were identified as important:

“The second nurse was a totally different story. She was more respectful of my father’s religious habits. She found the Wudu stone (for pre-prayer cleansing ritual) on his bedside table. She didn’t touch it until she asked me what it is for. I was so moved by her consideration. I was so happy that we changed the home care service.” – Birsen, of Turkish descent

Respondents formulated a need for religion-sensitive care professionals who show respect and openness for these religious practices. This need was mostly formulated by Muslim respondents. The current Christian-inspired range of professional care in Belgium could answer the religious needs of older migrants of Italian background, as long as this care is provided with respect for religious values as described above. However, such religion-inspired professional care does not exist for Muslim older persons with dementia. As a result, Muslim family caregivers experienced the search for care professionals with such sensitivity as challenging:

“We have looked for residential care that would respect the Muslim religious identity of my mother, but in Belgium there are no such care facilities ... We discovered that the Netherlands has such facilities.” – Busra, of Turkish descent

The existence of a nursing home that is open to the practice of Islamic customs would also lower the barriers impeding these family caregivers from using residential care.

5) Religious sensitivity is missing in professional care

In general, respondents experienced a lack of religious sensitivity and of knowledge about beneficial aspects of religious practices in professional care. On the one hand, some family caregivers testified that they had “accidentally” encountered professional caregivers who showed openness and respect for the religious identity of older migrants with dementia. In such cases, family caregivers witnessed good care encounters between these professionals and religious older migrants with dementia, which made the latter feel more relaxed and comfortable. This contributed to a good relationship with good communication between themselves and the professional caregiver. Experiencing an open attitude toward the religious identity of the older person was considered a sign of good quality of care:

“In nursing home X, it was totally different from the horrible experience in nursing home Y. Nursing home X had competent professionals with a warm heart for the residents, and the residents could fully be themselves. They even respected the fact that I played some Quran [recitations] in my mother’s room” – Dina, of Moroccan descent

Conversely, experiencing lack of respect toward the religious values of older migrants with dementia worsened the relationship between family caregivers and the care professionals. Such negative experiences informed decisions of some family caregivers to stop using the current care service and sometimes even future ones. This was also true for Christian-inspired care services, which did not always succeeded in providing care according to religious values like respect for the older person and patience:

“We had a nurse coming from a Catholic-inspired service, however the intimate care was given in a rush. The nurse was not patient, in one minute she washed her, done! ... She did not even talk to her... this is not dignified for an older person. Well, after witnessing that, I started to wash her. I spent at least 20 minutes doing that, I took time to talk with her while I was caring for her.” – Lidia, of Italian descent

Resistance to respect religious identity was mainly experienced by respondents of Turkish and Moroccan descent, both religious and non-religious. These family caregivers did not expect care professionals to be knowledgeable about Muslim religious practices, and they tried to support the professional caregivers so as to guarantee religion-sensitive care for their relative with dementia. Experiencing ongoing disrespect for this facet of the older person's identity led to feelings of hurt, anger, and distrust toward the professional caregivers:

"I was always a believer of diversity in care organizations. But now, after the experience with my father, I'm not. I cared seven years for my father, the six months in the nursing home are the only thing that I still find the most hurtful: I had to fight every day to guarantee that they took into account who he is. Although I'm not a practicing Muslim, my father is! You know, my father didn't want to get dressed in the bathroom where there is also a toilet – for him it is an impure room, so he felt that he had to wash himself again to be able to pray ... as at that time he couldn't express himself, he became aggressive every time the nurses dressed him in the toilet ... the nurses were angry, and complained to me ... I explained to them why this is the case and requested that they dress him in his room, as he was calm when I dressed him in his room – even after repeatedly explaining this to them, they refused to dress him in his room. I was so hurt, angry ... so after a while I made sure that only I or my brother could dress him." – Semra, family caregiver of Turkish descent

All respondents found it important that care professionals see the full identity of the older migrant with dementia, therefore sensitivity to possible religious identity was required. They also warned not to assume that every older Turkish, Moroccan, or Italian migrant with dementia is religious:

"I find it important that care professionals be sensitive to the full identity of these older migrants, so also their religious identity, but one should be careful not to reduce them to religious dementia patients ... not every Italian is Catholic!" – Maria, family caregiver of Italian descent

4. Discussion

This study examines how religion shapes both the dementia experience and the dementia care of older labor migrants in Belgium. First, concerning the first research question, religion influences the dementia experience of migrant families in Belgium by co-defining the meaning of dementia. This observation resonates with evidence that religious beliefs about dementia – e.g., that it is something given by the divine – are used alongside the biomedical framework in the perception of dementia (Regan et al. 2013; Berdai Chaouni and De Donder 2018). Our results additionally highlight that these definitions can entail positive meanings (normalization of life tests, a chance to atone for misdeeds) and negative ones (divine punishment). These meanings have an impact on how dementia is experienced: they can lighten the challenges of dementia (Lee et al. 2017) as well as lead to negative and depressive feelings (Koenig et al. 2012).

Second, religion provided a coping strategy for religious family caregivers to deal with dementia. As seen in other findings, our respondents used religious coping alongside other coping strategies to manage the challenges associated with dementia and family care (Regan et al. 2013; Agli et al. 2015; Epps and Williams 2018, Monteiro et al. 2018). Religious practices such as prayer, attendance at religious gatherings, supplications, and religious hymns are actively used by religious family caregivers as a dyadic or joint coping strategy (Nagpal et al. 2015) with religious older migrants with dementia to

find comfort and relief. Such religious practices are proven to enable older persons with dementia develop coping strategies to better accept their condition, maintain relationships, and thereby find meaning in life (Agli et al. 2015). Religious family caregivers confirm that doing something that is both defined as good by the divine and supported by the religious community, along with the promise of divine reward, helps them endure the challenges faced by family care (Ahmad et al. 2019). This positive impact of religious coping reduces the experienced care burden and improves resilience, as has been shown by spiritual support, such as spiritual group therapy to support family caregivers of persons with dementia (Mahdavi et al. 2017; Wilks et al. 2018). Conversely, religion can also contribute to the care burden. Family caregivers felt a keen sense of failure when they did not measure up to their personal interpretation of the expected religious values in family care, such as when they failed to remain continuously patient toward the person with dementia. This negative religious coping, where God is considered as controlling, becomes a care burden enhancer that is detrimental to the mental health of family caregivers (Rathier et al. 2015; Fieder et al. 2019). Additionally, several religious family caregivers among the participants prioritized the promise of reward from the divine above their own immediate self-care. Positive feelings like pride and moral superiority that are informed by religious and cultural moral frames can explain why family caregivers continue to endure their care burdens even when contending with their own poor mental or physical health (Ahmad et al. 2019).

Concerning the second research question, religion shaped dementia care for older migrants through the use of beneficial religious practices in family care, leading to requests for religious sensitivity in professional dementia care, which often seems to be missing. First, after observing the beneficial effects of religious practices such as prayer, reciting Qur'anic or biblical verses, and attending religious gatherings such as Sunday Mass or Friday prayer, family caregivers spontaneously used these as supporting tool in their family care provision. Religious practices like prayer (Reimer-Kirkham et al. 2018; Elaimi et al. 2018) and attending church (Plunkett and Chen 2016) have been shown to have beneficial effects on persons with dementia at all stages of dementia (Kevern 2015). These effects include enhancing quality of life, slowing cognitive decline, providing a positive coping style, and affording a means to maintain social connections (Kevern 2015; Agli et al. 2015). However, knowledge about the positive potentials of religious practices as care "tools" is mainly restricted to family caregivers.

Second, both religious and non-religious family caregivers find respect for the religiosity of older migrants with dementia to be important, and believe that this respect should be reflected in how care – both informal and professional – is provided to them. This starts by integrating these values into how family care is provided (Ahmed et al. 2019). Being able to maintain one's own religious identity when professional care is used, is also considered important. Consequently, religious values co-determine whether a professional care service will be used (Regan et al. 2013), as well as the choice of service (Berdai-Chaouni et al. 2020). Experiencing an open attitude toward the religious identity of the older migrant with dementia is welcomed and valued as a sign of "good professional care."

Third, sensitivity to the religious needs of older migrants with dementia is generally missing in professional dementia care. An open attitude and respect toward religious identity is not often encountered. This resonates with Keenan and Kirwan (2018), who state that although religious sensitivity improves the quality of care, it remains lacking and is typically encountered only "by chance" in professional care, depending on the individual professional caregiver's sensitivity toward religion. Additionally, professionals often feel unqualified to provide religion-sensitive care (Keenan and Kirwan

2018), even when the religion of the person with dementia is that of the country's dominant religion (Regan et al. 2013). It is therefore important to educate professional caregivers to include religious sensitivity as part of holistic person-centered care practice (Epps and Williams 2018; Keenan and Kirwan 2018). Experiencing this lack of sensitivity to religion, especially when professional caregivers refuse to respect this part of the identity of older migrants with dementia, enhances the emotional and psychological burden of family caregivers (Sagbakken et al. 2017) and can be a reason to quit using professional care service. The absence of religious sensitivity becomes an additional barrier to care access (Regan et al. 2013; Berdai-Chaoui et al. 2020). Provision of religion-sensitive care likewise appears to be dependent on how society perceives religion (Keenan and Kirwan 2018). Professional caregivers hesitate to include religion in their care provision because they do not know if it is "appropriate" (Reimer-Kirkham et al. 2018; Keenan and Kirwan 2018). Societal and political tendencies define what is considered professional, with a connotation of neutrality or non-neutrality. According to Ahaddour and Broeckaert (2017), the position a country takes toward neutrality defines which religious services are provided in that society. Belgium takes a middle-of-the-ground position between strict secular neutrality, without any religious expression in the public sphere, and religious pluralism (Ahaddour and Broeckaert 2017). When applying this to elderly care services, religion in the public sphere is evidenced by the existence and acceptance of Christian-inspired services as an extension of the historically developed Christian social pillar, yet new religion-inspired initiatives are resisted (Ahaddour and Broeckaert 2017). This is especially the case for Muslim-inspired elderly care services, which are lacking in Belgium (Ahaddour et al. 2016; Berdai-Chaoui et al. 2020).

This resonates with our finding that the need for religious sensitivity in professional care is mostly voiced by Muslim respondents. Such hesitation toward religious sensitivity in care services for Muslims is likely reinforced by another macro-level influencer: the popular image of Muslims, and of Muslim migrants in particular. Muslim migrants in Europe are subject to rather negative discourse about Islam in which they are portrayed as the "Other," as an integration "problem," and as "extremist" (Fadil 2019). Moreover, although the secularly influenced expectations that second-generation migrants of Muslim background will lose or forego their religiosity through social integration have been adjusted by some academics, such expectations remain implicit in the larger social mindset (Fadil 2019) and can be assumed in care services. These societal and organizational mechanisms influence the attitude of Muslim family caregivers toward professional care. Such mechanisms formulate lower expectations in terms of respect for this facet of the personal identity of the older migrant with dementia. Additionally, Muslim family caregivers become mediators between the values of these elders and those of the professional care organization, often explaining to and informing professional caregivers about the needs of these older migrants with dementia. This is a role that can contribute to their care burden. The religious needs of Catholic Italian migrants are more suitably met by the Christian-inspired range of professional care in Belgium. Nevertheless, even in cases where there is a general match between the religion of the person with dementia and the religious background of the organization – in this case, Christianity – there remains a need for sensitivity to cultural nuances in the manifestation of religion (Regan et al. 2013).

Our results point to several practical recommendations. To benefit from the positive effects of religious sensitivity and religious practices, a supportive care environment is needed that requires collaboration between family caregivers, religious communities, and professional caregivers (Agli et al. 2015; Epps and Williams 2018). To become a supportive environment for religious ethnic minorities these stakeholders will need to acquire three understandings: 1) knowledge about the process of dementia;

2) sensitivity to the religious needs of religious older persons with dementia; and 3) awareness of the possible positive outcomes of religious practices (Epps and Williams 2018; Berdai et al. 2020). As previously stated, religious sensitivity and knowledge about positive outcomes of religious practices are mainly restricted to family caregivers. Still, lack of knowledge about dementia and the dementia trajectory among migrant communities in Belgium (Berdai-Chaouni and De Donder 2018) can be extrapolated to their religious communities. This means that there is also work to be done at the level of religious migrant communities so as to enable these communities to become more supportive environments. Insights into the process of dementia, particularly about the gradual decline of cognitive and executive functions, would help religious communities understand, for example, that attending religious gatherings is challenging for a person with dementia and that others in attendance should be encouraged to avoid stressful negative reactions toward these persons (Agli et al. 2015). Several researchers (Regan 2014; Epps and Williams 2018) have therefore argued that religious communities need to create dementia-friendly places. Others (Plunkett and Chen 2016; Epps et al. 2020) maintain that these places are also suitable to provide dementia support for family caregivers and persons affected by dementia. Moreover, spiritual and religious care that endeavors to actively support the expression of religious beliefs of persons with dementia positively impacts their wellbeing (Epps and Williams 2018).

5. Limitations

Our findings should be considered in light of several limitations. First, the family caregivers were mostly second-generation migrants of Moroccan, Turkish, and Italian background, and female. Nearly two-thirds of these participants were highly educated, which is not representative of the labor market position of migrants in Belgium (Laurijssen and Glorieux 2015). Recent data suggest that Belgium has the lowest employment rate for non-EU migrants: 54% as compared to the European average of 65% (Eurostat 2019). More research involving caregivers from various socioeconomic profiles is needed (Nazroo 2006). Second, our respondents were predominantly female. Although dementia family care is mainly provided by females worldwide (Erol et al. 2015), there remains a need for more research that includes the male perspective (Snyder et al. 2014; Ahmed et al. 2019). Third, this study presents information about the experience of older migrants with dementia concerning religion via family caregivers as proxies who contribute to knowledge about this topic without including the perspective of the older persons themselves (Daly et al. 2019). Inclusion of older migrants with dementia – through observations, tailored interviews, and longitudinal approaches – in future research would be preferable. Such research is necessary, even though engaging ethnic minorities with dementia in research (Berdai Chaouni et al. 2018; Gove et al. 2020) is considered challenging. Fourth, focusing on religion in the dementia experience gives the opportunity to learn more about an invisible influencer of migrant families' experience of dementia (Berdai Chaouni and De Donder 2018) but does not capture the complexity of influencers of this experience. An intersectional approach would be preferable, as intersectionality (Crenshaw 1991) offers an analytical lens by which to examine the intersection of key social statuses such as age, class, gender, sexuality, and ethnicity, and their impact on individual experiences of ethnic minorities like older migrants and their family caregivers (Torres 2019). Recent attempts (Brotman et al. 2019), including the life course intersectional approach (Ferrer et al. 2017), do state that it is challenging for participants to explicitly link the different aspects of their intersectional identity to their lived experience. More research looking for suitable methodologies to capture the complex reality of older migrants with dementia is therefore needed (Gove et al. 2020).

6. Conclusion

This study shows that focusing on religion as one dimension within the multilayered identity of religious older migrants with dementia provides interesting nuances that can be helpful in moving toward a more tailored dementia care for this growing population. Using religious practices as supportive care tools in family care points to the beneficial potential of religious sensitivity in dementia care that is sought in professional care. In Belgium, such sensitivity is encountered accidentally or is only found in Christian-inspired services. This means that religion-inspired needs of Christian older migrants with dementia are likely to be met, while those of other religious groups, especially Muslims, are left unaddressed. Awareness of these voiced needs and the benefits of religious practices offer opportunities for more effective professional care. And yet inclusion of religious sensitivity in dementia care can only be beneficial when professional care providers are aware of implicit individual and societal biases and their impact on the accessibility and suitability of care for older migrants with dementia. These biases must be addressed in order to see all persons with dementia in their complexity as human beings. In other words, provision of suitable dementia care for an ethnically diverse population means more than consideration of their religion-inspired needs. Religion sensitivity can therefore be an optimization of a holistic, comprehensive intersectional person-centered dementia care

References

- Agli, O., Bailly, N., & Ferrand, C. (2015). Spirituality and religion in older adults with dementia: A systematic review. *International Psychogeriatrics*, 27(5), 715–725.
- Ahaddour, C., van den Branden, S. & Broeckaert, B. (2016). Institutional elderly care services and Moroccan and Turkish migrants in Belgium: a literature review. *J Immigr Minor Health*, 18(5),1216-1227.
- Ahaddour, C., & Broeckaert, B. (2018). “For every illness there is a cure”: attitudes and beliefs of Moroccan Muslim women regarding health, illness and medicine. *Journal Relig Health*, 57, 1285-1303. <https://doi.org/10.1007/s10943-017-0466-1>
- Ahmad, M., van den Broeke, J., Saharso, S., & Tonkens, E. (2020). Persons with a migration background caring for a family member with dementia: challenges to shared care. *Gerontologist*, 60(2),340-349. DOI: 10.1093/geront/gnz161.
- Assad, T. (1986). *The idea of anthropology of Islam*. Washington: Center for Contemporary Arab Studies, Georgetown University
- Berdai Chaouni, S., Claeys, A., & De Donder, L. (2018). How to (qualitatively) involve older migrants with dementia and their informal carers with a migration background in research? Insights from a longitudinal project in Brussels. In Hannes K, Dierckx de Casterlé D, Heylighen A, Truyen F (Eds.), *ECQI 2018 Proceedings*. (pp 63-71). ISBN 9789067842082_
- Berdai Chaouni, S., & De Donder, L. (2019). Invisible realities : Caring for older Moroccan migrants with dementia in Belgium. *Dementia*, 18(7-8), 3113-3129
- Berdai Chaouni S, Smetcoren A-S, & De Donder L. (2020). Caring for migrant older Moroccans with dementia in Belgium as a complex and dynamic transnational network of informal and professional care: a qualitative study. *Int J Nurs Stud*. DOI:10.1016/j.ijnurstu.2019.103413.
- Beyers, J. (2017). Religion and culture: Revisiting a close relative. *HTS Theologiese Studies/Theological Studies*, 73(1), a3864. <https://doi.org/10.4102/hts.v73i1.3864>
- Brotman, S., Ferrer, I., & Koehn, S. (2019). Situating the life story narratives of aging immigrants within a structural context: the intersectional life course perspective as research praxis. *Qualitative Research*. DOI: 10.1177/1468794119880746
- Canevelli, M., Lacorteb, E., Cova, I., Zacharias, V., Valletaa, M., Raganatoa, R., Bruno’s, G., Bargagli, A.M., Pomati, S., Pantani, L., & Vanacoreb, N. (2019). Estimating dementia cases amongst migrants living in Europe. *European Journal of Neurology*, 26, 1191-1199.
- Daly, L., Fahey-McCarthy, E., & Timmins, F. (2019). The experience of spirituality from the perspective of people living with dementia: A systematic review and meta-synthesis. *Dementia*, 8(2), 448-470.
- Charmaz, K. (2011). Grounded theory methods in social research. In Dinzin N. and Lincoln, Y. (eds.), *The SAGE handbook of qualitative research*. (pp 359-81). Thousand Oaks: SAGE Publications, Inc.

- Cohen, A. (2009). Manu forms of Culture. *American Psychologist*, 64(3), 194 –204.
- Crenshaw, K.W. (1991). Mapping the margins: intersectionality, identity politics and violence against women of color. *Stanford law review*, (43)6, 1241-1299.
- Dierckx de Casterleé, B., Gastmans, C., Bryonc, E., & Denier, Y. (2012). QUAGOL: A guide for qualitative data analysis. *International Journal of Nursing Studies*, 49, 360-371.
- Erol, R., Brooker, D., & Peel, E. (2015). *Dementia and Women: an international review*. Londen: Alzheimer’s Disease International (ADI)
- Epps, F. & Williams, I.C. (2018). The importance of religiosity to the well-being of African American older adults living with dementia. *J Appl Gerontol*. DOI: 10.1177/0733464818820773
- Epps, F., Choe, J., Alexander, & K. Brewster G. (2020). Designing Worship Services to Support African-American Persons Living with Dementia. *J Relig Health.*, <https://doi.org/10.1007/s10943-020-00993-x>
- Eurostat. (2019). Migrant integration, employment rates. <https://ec.europa.eu/eurostat/web/products-eurostat-news/-/DDN-20190529-1?inheritRedirect=true&redirect=%2F%2Fec.europa.eu/eurostat%2F>. Accessed 04 March 2020
- Fadil, N. (2019). The Anthropology of Islam in Europe : A Double Epistemological Impasse. *Annual Review of Anthropology*, 48(1),117-132.
- Ferrer, I., Grenier, A., Brotman, S., & Koehn, S. (2017). Understanding the experiences of racialized older people through an intersectional life course perspective. *Journal of Aging Studies*, 41, 10–17.
- Gove, D., Plejert. Ch., Georges, J., Rauf, M. A., Rune Nielsen, T., Lahav, D., Jaakson, S., Parveen, S., Kaur, R., Golan-Shemesh, D., Herz, M., & Smits, C. (2018). *The development of intercultural care and support for people with dementia from minority ethnic groups*. Alzheimer Europe.
- Gove D., Georges J., Rauf M.A., van den Broeke J., Jongasma K., Claeys A., Berdai Chaouni S., Hellstöm I., Tromp K., Porteri C., & Watchman K. (2019). *Overcoming ethical challenges affecting the involvement of people with dementia in research : recognising diversity and promoting inclusive research*. Alzheimer Europe.
- James, W. (1997). *Varieties of religious experience: A study in human nature*. New York: Touchstone.
- Kevern, P. (2015) The spirituality of people with late-stage dementia: a review of the research literature, a critical analysis and some implications for person-centred spirituality and dementia care. *Mental Health, Religion and Culture*, 765-776
- Keenan, P.M. & Kirwan, M. (2018). Nurses’ Understanding of Spirituality and the Spirituality of Older People with Dementia in the Continuing Care Setting. *Religions*, 9(2), 50. <https://doi.org/10.3390/rel9020050>
- Koenig, H.G. (2009). Research on religion, spirituality and mental health: a Review. *Can J Psychiatry*, 54(5), 283-291.
- Koenig, H. G., King, D. E., & Carson, V. B. (2012). *Handbook of religion and health* (2nd ed.). New York: Oxford University Press

- Lafleur J-M., Marfourk A., & Fadil N. (2018). *Migratie in België: 21 vragen en antwoorden*. Leuven: University Press.
- Laurijssen, I., & Glorieux, I. (2015). Early career occupational mobility of Turkish and Moroccan. *Journal of Youth Studies*, 18(1),101-117.
- Lee, Y-S., Park, S-Y., Roth, S., Koenig, H.G., & Yoo G.J. (2017). The role of religiousness/spirituality and social networks in predicting depressive symptoms among older Korean. *American J Cross Cult Gerontol*, 32, 239–254.
- Lodewijckx, E. (2014). Ouderen van vreemde herkomst in Vlaanderen anno 2011: een korte demografische schets. In De Kock, C, Vens, E., Beljoudi, Y., Van Kerckhove, C. (eds), *Ouder worden in een veranderende samenleving*. (pp. 77-95). Antwerp/Apeldoorn: Garant Publishers.
- Martens, A. (1973). *25 jaar wegwerparbeiders: het Belgisch immigratiebeleid na 1945*. Leuven, Neth.: KUL Sciol. Onderzoeksinst.
- Monsees, J., Schmachtenberg, T., Leiz, M., Cardona, M.I., Stentzel, U., van den Berg; N., Hoffmann, W., Thyrian J.R. (2021). *EU-Atlas: Dementia & Migration - Estimated number, care situation, and policies regarding people with a migration background with dementia in the EU, EFTA, and UK*. Rostock/Greifswald: Deutsches Zentrum für Neurodegenerative Erkrankungen (DZNE). ISBN: 978-3-9823426-0-3
- Moriarty, J. (2015). Accessing support and services. Botsford J. & Harrison Denning K. (Eds.) *In Dementia, culture and ethnicity*. (pp 85-107). London/Philadelphia: Jessica Kingsley Publishers
- Monteiro, A.M.F., Santos, R.L., Kimura, N., Baptista, M.A.T., & Dourado, M.C.N. (2018). Coping strategies among caregivers of people with Alzheimer diseased: a systematic review. *Trends Psychiatry Psychother*, 40(3), 258-268.
- Mukadam, N., Cooper, C., & Livingston, G. (2013). Improving access to dementia services for people from minority ethnic groups. *Current Opinion in Psychiatry*, 26(4), 409-414.
- Nagpal, N, Heid, A.R., Zarit, S.H., & Whitlatch C.J. (2015). Religiosity and quality of life: a dyadic perspective of individuals with dementia and their caregivers. *Aging Ment Health*, 19(6), 500-506.
- Nazroo, J. (2006). Demography of multicultural Britain. In Nazroo, J. (ed.), *Health and Social Research in Multiethnic Societies*. (pp.1-19). Abingdon: Routledge
- Nielsen, T.R., Vogel, A., Riepe, A.M., de Mendonça, A., Rodriguez, G., Nobili F, Gade, A. & Waldemar, G. (2011). Assessment of dementia in ethnic minority patients in Europe: a European Alzheimer's disease consortium survey. *International Psychogeriatrics*, 23(1), 86-95.
- Parlevliet, J.L., Uysal-Bozkir, O., Goudsmit, M., van Campen, J.P., Kok, R.M., ter riet, G., Schmand, B., & de Rooij, S.E. (2016). Prevalence of mild cognitive impairment and dementia in older non-western immigrants in the Netherlands: a cross-sectional study. *Int J Geriatr Psychiatry*, 31,1040–1049.
- Petty, S., Harvey, K., Griffiths, A. Coleston, D.M., & Denning T. (2018). Emotional distress with dementia: a systematic review using corpus-based analysis and meta-ethnography. [*Int J Geriatr Psychiatry* 33\(5\), 679-687.](#)

- Plunkett, R., & Chen, P. (2016). Supporting healthy dementia culture: an exploratory study of the church. *J Relig. Health*, 55(6), 1917-28.
- Rathier, L.A., Davis, J.D., Papandonatos, G.D., Grover, C., & Tremont G. (2015). Religious coping in caregivers of family members with dementia. *J Appl Gerontol*, 34(8), 977-1000.
- Regan, J.L., Bhattacharyya, S., Kevern, P., Rana, T. (2013). A systematic review of religion and dementia care pathways in black and minority ethnic populations. *Mental Health, Religion & Culture*, 16(1),1-15.
- Regan, J.L. (2014). Redefining dementia care barriers for ethnic minorities: the religion–culture distinction. *Mental Health, Religion & Culture*, 17(4), 345-353.
- Reimer-Kirkham, S., Sharma, S., Smith, B., Schutt, K., & Janzen, K. (2018). Expressions of Prayer in Residential Care Homes. *Journal of Health Care Chaplaincy*, 24(2), 67–85.
- Sagbakken, M., Spilker, R.S. ,& Ingebretsen, R. (2017). Dementia and Migration: Family Care Patterns Merging With Public Care Services. *Qualitative Health Research*, 28(1), 16-29.
- Snyder, C.M., Fauth, E., Wanzek, J., Piercy, K.W., Norton, M.C., Corcoran, C., & Tschanz, J.T. (2014). Dementia caregivers' coping strategies and their relationship to health and well-being: the Cache County Study. *Aging & Mental Health*, 19(5), 390-399.
- Statbel. (2021). <https://statbel.fgov.be/nl/themas/bevolking/herkomst>
- Torres, S. (2019). *Ethnicity and old age: Expanding our imagination (Ageing in a Global Context)*. Policy Press. ISBN 1447328124,9781447328124
- Wilks, S.E., Spurlock, W.R., Brown, S.C., Teegen, B.C., & Geiger J.R. (2018). Examining spiritual support among African American and Caucasian Alzheimer's caregivers: a risk and resilience study. *Geriatr Nurs.*, 39(6), 663-668.

"I claimed the right to find out my history, myself! To study people, their attitudes and their discourse. People like me have been a study object, long enough. We were dissected, described, analyzed and turned inside out. Our skulls were collected and measured and our brains and genitals were put in strong water, as with Saartjie Baartman...Even now I regularly show the door to researchers who want to know how I think, how I love and who my acquaintances are. Always good for statistics, reports and doctorates. I, the stranger, explained to people who are the norm, the eternal observers. This time I am the mirror to these staring eyes. I will study them. This book is the result of that search process."

Rachida Aziz, pp. 15-16. Niemand zal hier slapen vannacht, 2017. Antwerp, EPO

Chapter 5: How to (qualitatively) involve older people with dementia and their informal carers with a migration background in research? Insights from a longitudinal project in Brussels⁴

Abstract

Representation of vulnerable groups and ethnic cultural minorities is inadequate in scientific studies. Aiming to include older people with dementia and a migration background in longitudinal research requires careful preparation to succeed. Based on this hypothesis we investigated what this good preparation means. What are do's and don'ts in the recruitment and retention of these older people and their carers? Based on insights acquired from the literature, interviews with ten experts with experience in involving older migrants and their close environment in their (research) projects we formulate six points of attention and possible success factors in involving the intended target group. Findings demonstrated 6 key-areas for consideration when developing a research design for older migrants with dementia: 1) investing in sustainable relationships with the respondents, beyond the traditional researcher-respondent relation; 2) collaborating with community key-figures for the recruitment of respondents; 3) focus on qualitative research methods; 4) investing in transparent communication techniques; 5) 'ethnic matching' by recruiting bicultural, bilingual researchers; 6) reflection on researchers' own societal position. There's a need for specific, customized and flexible research design.

⁴ Published as: Berdai Chaouni, S., Claeys, A. & De Donder, L. (2018). How to (qualitatively) involve older people with dementia and their informal carers with a migration background in research? Insights from a longitudinal project in Brussels. *Proceedings European Congress of qualitative inquiry*

1. Introduction

In 2017 the Flemish governmental Research Centre estimated that in Flanders, the Dutch-speaking region of Belgium, 6% of all people aged 65 and older had a migration background (Lodewijcks, 2017). The number is much higher in those cities and regions that hosted the majority of migrants who came to Belgium during the nineteen-sixties and seventies (Lodewijcks, 2014, 2017) . Moreover, this share of older persons of diverse ethnic background will continue to grow in the future: by 2020, nearly half of the older people living in Brussels will have a migration background (Lodewijcks, 2017) .

In 2016 the Flanders Government estimated that 122 000 people in the region had dementia. This prevalence of dementia is expected to increase by 25% by 2030 (Actualised Flemish Dementioplan, 2016) . Given the difficulty of diagnosing dementia in ethnic minority seniors, it remains a challenge to accurately estimate the prevalence of dementia amongst such groups (Nielsen et al., 2010). Recent research by Parlevliet et al. (2016) in the Netherlands using culturally sensitive diagnostic tools shows a higher prevalence of dementia among non-European older people. The prevalence of dementia among older people with a Moroccan background in the Netherlands was fourfold more than among native-born older people. In addition to differences in prevalence, also the experiences might differ: researching how ethnic minorities in Belgium face dementia experience and manage the condition is important because (even when the clinical manifestations of dementia may be similar across different countries), migration and cultural background can influence the experience of the condition (Parlevliet et al., 2016).

With the research project Diverse Elderly Care – funded by European funding for regional development we want to fill some of the research gaps and answer the following questions: how do migrant older persons and their informal and professional caregivers experience the dementia caring process and how can we work towards more suitable dementia care for these migrant older people in Brussels. This project runs over five years (2016-2021) giving the opportunity to follow participants over several years. Inclusion of participants with migration background, including the older people with dementia, during this research project is essential to answer the research questions. However, research has shown that involving ethnic minority older people in studies comes with methodological challenges, explaining the underrepresentation of these specific older people in scientific studies (Feldman et al., 2008; Low et al., 2009). Based on these insights, we can also expect methodological challenges in including older migrants with dementia and their family caregivers in our study. Careful preparation of the methodological approach is needed to guarantee an inclusion and retention of older migrants with dementia and their family caregivers. This article will therefore give an overview of the lessons learned during our search process of the do's and don'ts in including our target population and how we incorporated these insights into our methodological approach.

2. Methods

This study aims to answer the question of how to include older migrants with dementia and their family caregivers in a qualitative (longitudinal) study. What is a successful methodological approach and which pitfalls should be avoided? The study is built upon two methodological steps: first a narrative review of the existing literature, followed by qualitative, individual interviews with ten acknowledged experts, who have experience in the inclusion of vulnerable groups.

To conduct the literature review we used Web of Science, Medline, Cinahl, Science Direct and Psycinfo as search databases. Combinations of the following search terms were used: ethnic minorities, migrants, elderly, family caregivers, informal caregivers, dementia, (longitudinal) qualitative research, inclusion, recruitment and retention. A selection of the articles was made based on the relevance for our research purpose.

The second step was interviewing ten experts using qualitative, individual interviews. The experts were researchers or health care- or social care workers in Belgium (n=3) or in Europe (n=7). They were selected, based upon their research publications or from their well-known experience in working with vulnerable and hard-to-reach groups (older people, older migrants, family carers). The interviews had a duration ranging from 60 to 180 minutes and were conducted by two researchers. Minutes were taken during the interview. Minutes of both researchers were put together afterwards and were the basis of a thematic analysis (Braun & Clarck, 2006).

The last step was the translation of the insights from the first two steps into a research methodological approach suitable to our research goals. The team of three researchers discussed the insights from the first two steps in three meetings and developed a research action plan that was presented and discussed with the steering committee (n= 8) of the research project, consisting of experts in the field of ageing, dementia, care and migration.

3. Results

This study's aim was to determine what could be a successful approach to include older migrants with dementia and their family caregivers into a longitudinal qualitative study. Neither literature, nor the experts examples could answer the research question to a full extent. This means that the results are based upon experiences with either older people or family carers from ethnic minorities, either older people with dementia and within other study designs than merely longitudinal research. Based on the insights gained from the literature review and interviews we made an overview of successful factors that will be elaborated on in the next sections.

Insights from the literature review?

Longitudinal qualitative research has gained interest in the domain of the health sciences. Using such a research design is considered useful to better understand the nuances of experiencing a condition and providing care over time (Carduff et al., 2015; Thomson & McLeod, 2015). Qualitative research provides - in general - different possible design approaches where the choice of approach is linked to the goals of the study (Carduff et al., 2015; Thomson & McLeod, 2015).

Inclusion of (families from) older persons with dementia

In general, including older people in a longitudinal study involves a number of challenges (Marcantonio et al., 2008). The first question that can be posed is which research method is best suited. In this case, Bond and Corner (Bond & Corner, 2001) advise the use of qualitative research in which the perspective of the older person with dementia is mapped. Methods such as participatory observation for example are relevant when the objective is to study the complex interaction of diverse factors during the experience of dementia together with the participants. This inductive approach aims at a first-line

representation of the experience of the person with dementia in which general assumptions about these target groups and their experience are challenged. According to Bond & Corner (2001), this approach is relevant if no theoretical framework is set beforehand.

Second, working with people with dementia also requires several points of attention in the execution of the research. For instance, considering the social desirability of the answers is important. Developing a good relationship with the older person is also an important point for attention here to pinpoint the social desirability (Bond & Corner, 2001). This is also important in case of a conversation with a 'proxy'. Including proxies, such as (informal) carers, can even become a primary source of data during phases of dementia where the older person has lost their ability to communicate (Bond & Corner, 2001; Gibson et al., 2004).

Third, estimating the number of older people well before hand with strategies for the 'drop outs' are required. Integrating strategies in the research design that minimise the loss of the recruited participants throughout the research is important (Feng et al., 2006). These strategies concern conscious actions to make it as easy as possible for older people to participate, such as flexibility in follow-up times, developing a good relationship with the older person and their environment, continuation of the same researchers and creating a pleasant environment. In this way, Personen, Remes and Isola (2011) state that a combination interview of the older person with dementia together with his/her carer can give a better atmosphere of trust to the participants. In addition, it is also important to look at the effect of 'missing values'. Specifically, a lot of data is lost that could have influenced the results of the research. The collection of the reasons why older people withdraw can help when processing the results (Rabbitt et al., 2005).

Inclusion of older persons with a migration background

Several studies mention the difficulties of involving ethnic minorities in research. Areal and Gallagher-Thompson (1996) already warned about the challenges connected with the recruitment and retention of older people with a migration background so that they are underrepresented in research. They argued for specific strategies to tackle these challenges. Based on the same motivation, Dreer et al. (2014) argued for strategic planning in the recruitment and retention of older people with African American roots and by extension, with other roots. These strategies should take into account the multiple thresholds that hinder these older people and their environment from participating in studies: no trust in the researchers and health-related research, lack of cultural competencies and knowledge of native language in execution of the research, experience of racism, fear of being abused, lack of knowledge about the research process and fear or taboo around the research topic such as dementia (Dreer et al., 2014; Hinton et al., 2010). In addition, researchers can also be viewed as outsiders which causes a social disconnection (Dennis & Neese, 2000; Mwachofi & WaMwachofi, 2010).

However, Zubair and Norris (2015) warned for an essentialist research approach in studies including older persons in general and including ethnic minority older people more specifically. Focusing on a single aspect of the older people like their poor health condition or their ethnic background is a problematic, one-dimensional approach (Zubair & Norris, 2015). This essentialist approach has a one-dimensional unrealistic image of a group of older people and expects them to fit into a classic research paradigm. According to Zubair and Norris (2015), the current research criteria are not adjusted to the fieldwork reality. It is therefore necessary to question some assumptions and self-evidences within the

research protocols and methods. It is a necessary step if we truly want to include ethnic minority older people on an equal way. They argue that lots of research protocols and methods, like the written informed consent, are based on a Western middleclass logic. Looking further to the informed consent as an example, also other authors like Mazaheri et al. (2014) confirm the unsuitability of the written informed consent in a study involving older migrants, and use a recorded verbal consent instead. Their plea to broaden the more classic way of research with creative approaches as a way to include the underrepresented groups in research has also been supported by Swabrick (2016).

Suggested successful approaches

A first important success factor is building up and maintaining trust within the intended communities, in different phases. Researchers such as Dreer et al (2014), Hinton et al. (2010) and Romero et al. (2014) invested step-by-step in the development of the relationship with the recruiters, such as key figures or organisations which reach those communities, subsequently to develop a relationship with the older person and their environment, such as their children. Children after all appeared to be determining the participation of older people in the research (Hinton et al., 2010). When it comes to key figures, self-organisations, or other community leaders, it is important that the cooperation takes place respectfully and in (genuine) partnership (Dreer et al., 2014). This means also listening and formulating answers to the needs of these partners. This seems to increase the credibility of the researchers.

Second, several studies (Dreer et al , 2014; Hinton et al., 2010; Romero et al., 2014) also demonstrate the success of 'ethnic matching'. In this approach bi-cultural and bilingual researchers are members of the research team and are matched according to a shared ethnicity or language with the research participants. This approach however is challenged by Zubair and Norris (2015). Ethnic matching can become problematic when ethnicity of the researcher and the subjects is presumed the only way to avoid distance between a researcher and an ethnic group. The presumed proximity due to a shared ethnicity can be challenged by the distance resulting from other factors, like the social class that researchers represent. Another distance creating factor, they argued, is the use of the classic, not adapted research protocols and methods.

Third, active 'face-to-face', respectful communication is needed (Dreer et al , 2014; Hinton et al., 2010; Romero et al., 2014). This communication is supplemented with translated and image-recognisable flyers, posters, Being respectful means also being flexible as a researcher in collaboration with ethnic minority families. Adjusting to their reality is therefore a needed competence. In this approach, it is important that the older people and their family understand the relevance and purpose of the research and can preferably also see a visible return in it. For example, in the study of Hinton et al. [20] families of the older person appreciated the information they acquired about dementia through the researchers which they would not otherwise have received. Dennis and Neese (2000) also mention this 'reciprocity' as a success factor. The same study shows that ethnicity is not in itself a predictive factor. It is important for a researcher rather to know the historical and socio-economic context of the intended target group, the position of that group in society and what possible sensitivities must be taken into account. Furthermore, reflecting on the position of the researcher within this shared context is also necessary (Dennis & Neese, 2000; Mwachofi & WaMwachofi, 2010).

Insights from the expert interviews?

The experts interviewed were either researchers or practitioners working in Belgium or Europe. They were selected based on the expertise known through the literature or reputation in the field in involving the ethnic minority older persons and/or carers of family members with dementia.

These participants stressed first the importance of involving key figures and reliable networks or people in the recruitment of these older people and their environment. Key figures are people with a good reputation and an influence within particular communities. They also have broad networks and know from experience what does and does not work within those networks. In addition, it is important to work locally and to involve networks where the intended target groups may be in the recruitment and retention of participants. Being introduced as a researcher by these reliable people or key figures is important. This increases the chance that older people and carers agree to participate in the research.

Second, making the 'win-win' of their participation in the research clear to the intended target group appeared from the interview as important. In their opinion, the researcher must not only propose their 'win', namely finding respondents to answer his/her research question, but must also include, communicate and guarantee the 'win' for the participants in the research. Many ethnic communities have become distrustful of questioners (researchers and others). This is based on bad experiences in which the communities were often questioned without being informed of the result of that questioning or in which the results of the research were too little shown as an added value for themselves or for their own community. This results in a sense of 'being abused' which makes people reluctant to answer more questions. This 'win' for the community may only lead to access within the communities if it is sincere, visible and responds to a genuine need within the community.

Third, the respondents stressed that trust is a point of attention throughout the research. The carers and older people must trust the researcher concerned. Therefore, investing in a sincere relationship of trust in the execution of the research is important and that starts from contacting the key figures that lead you to the intended target group.

All of the above implies constant attention to the mode of communication, which is a fourth key recommendation the experts discussed. Tailoring the communication to the person in front of you is important. This implies attention to both non-verbal elements, such as posture and verbal elements in communication. For instance, a respondent suggested it is important not exclusively to use biomedical names for disorders, such as dementia, but to search for names used by the intended group, such as 'forgetting'. This increases the recognisability of the subject which reduces the distance in communication. It also requires dealing with communication tools consciously and in a targeted way. Experts recommend using different types of tools simultaneously, each time with a different objective. For instance, leaving behind an official folder will legitimize your research and make you seem more reliable to the participants, but the information about it should preferably be given verbally.

6. Discussion

This study is an attempt to formulate an answer to the following question: how to include older migrants with dementia and their family caregivers in an qualitative (longitudinal) study. We did not find any research that could respond to this question to a full extent, but researchers' experiences in performing dementia research on the one hand and research including ethnic minorities on the other hand provides valuable insights. Their experiences confirm that research including underrepresented target groups demands a careful preparation and execution. These suggested success factors will be included in our research. A phased action plan, in which flexibility is central and where evaluation of our methodological approach is included. These planned evaluations in the action plan gives us the opportunity to analyse our methodological approach and to adjust it to the experienced needs of that moment.

First, in terms of research design, we opt for a qualitative approach rather than a quantitative approach. In addition, based on the suggestions of the literature review we will supplement classical data collection methods such as interviews with an alternative creative approach such as participatory observations and collecting intermediate calls/texts/emails. In addition some aspects of standard research methodology are not included in our approach or will be adapted to the reality of the field. An example of this is the inclusion of an oral consent by the older person with dementia as a substitute for written informed consent.

It is also clear from both the literature and the interviews with experts that the communication approach in the study should be conducted in a thoughtful way. Good communication starts with a reflective, modest and open attitude (Johl et al., 2015; Mwachofi & WaMwachofi, 2010 ; Van Den Muijsenbergh et al., 2016). Every researcher involved in our research project reflects on how their background, approach, .can come across to the respondents and this during every step of the research. We also aim for sincere and honest communication with the older migrants and their family caregivers about the research and the goal of the study. The researchers are clear about their role and what they can or cannot expect from them. Building a relationship of trust is therefore sincere and not something instrumental. We also aim to communicate sincerely about the win-win for the community, and to explicitly search for a win for the older person and their carers. The respondents are not seen merely as subjects in our research but they should also experience short and long term benefits of our study and therefore should be seen as a partner in the research. Possible ideas are organizing information group sessions about dementia to the targeted community, or training social and health care professionals who work with our target group. In addition, this research should contribute to the improvement of care for the older people with a diverse background. This is a long term sincere goal of our research project. To realize this, we actively communicate about and valorize our¹ recommendations and examples of good practices to policy makers and the care sector.

The results indicate as well that in our communication strategy we have to pay explicit attention to the choice of verbal and non-verbal communication tools and accessible information, in which the different target groups could identify themselves. Language bridging is also a point of attention (Van Den Muijsenbergh et al., 2016) which is why we opt for multilingual researchers and communication tools. 'Ethnic matching' is a success factor that we carefully and critically approach. The research team is ethnically diverse but socio-economically homogeneous. Moreover we are also very keen not to

present ourselves as a researcher from a particular ethnic background, and to approach the older migrants and their family caregivers in a one-dimensional way. We are aware of several, intersectional nuances (Torres, 2015) and take these into the reflections and the team discussions.

Finally, collaboration with key figures within the various communities also appeared to be essential. They open the door to the different communities. We could benefit from the trust that the families have in such key figures. Recommendation of a key figure makes us a trustworthy person with whom to initiate contact. We want to further collaborate with the key figures during all phases of the study. Their critical feedback, from different perspectives, about our approach is an important added value for the research. This reflective and step-by-step approach will likely lead to the use of other (above-mentioned) methodological success factors. Because it is clear that in addition to traditional research skills, specific actions and skills are also required to conduct research successful in giving an underrepresented group like the ethnic minorities a voice (Shanley et al., 2013).

7. Conclusion

Both the experts interviewed and the literature emphasise that the involvement of older people with dementia of different origins and their environment requires a well-considered approach. Traditional research methods are inadequate to involve this population and to make their voice heard in the field of research. The results demonstrate a number of specific elements which research on older people with dementia, and with a migration background has to take into account: flexibility from the researchers and good listening abilities to listen carefully to those involved in our approach; investing in the trust and relationship with these target groups; building a relationship with the ethnic minority elders means also building a relationship with their gatekeepers: key figures and children of the older person with dementia. A relationship in trust is only sustainable when there is a transparent communication and partnership based on an equal and balanced 'win-win' for both sides. To achieve all these requirements researchers should have the time and resources to do so. To conclude, if we truly want to include underrepresented target groups into scientific research we should integrate tailored actions and move away from the 'one-size-fits-all' research approach.

References

- Actualized Flemish Dementia Plan 2016–2019. (2016). *Samen verder bouwen aan een dementievriendelijk Vlaanderen*. Department of welfare, government of Flanders
- Arean, P.A. & Gallagher-Thompson, D. (1996). Issues and recommendations for the recruitment and retention of older ethnic minority adults into clinical research. *J Consult Clin Psychol*, 64: 875-80
- Bond, J. & Corner, L. (2001). Researching dementia: are there unique methodological challenges for health services research?. *Aging and Society*, 2: 195-216.
- Braun V. & Clarck . V.(2006). Using thematic analysis in psychology. *Qualitative research in psychology*, 3 (2): 77-101.
- Carduff E., Murray, S.A.& Kendall M. (2015).Methodological developments in qualitative longitudinal research: the advantages and challenges of regular telephone contact with participants in a qualitative longitudinal interview study. *BMC Research Notes*, 8:142-52
- Dennis, B.P. & Neese, J..B. (2000).Recruitment and retention of African American elders into community-based research: lessons learned. *Arch Psychiatr Nurs*, 14(1),: 3-11
- Dreer, .L.E., Weston, J., Owsley, O. (2014). Strategic planning for recruitment and retention of older African Americans in health promotion research programs. *Journal of Health Disparities Research and Practice*, 7(2), (2014): 14-33.
- Feldman, S., Radermacher, H., Browning, C., Bird, S. & Thomas, S.(2008).Challenges of recruitment and retention of older people from culturally diverse communities in research” *Ageing and Society*, 28(4): 473-93
- Feng D., Silverstein M., Giarrusso R., Mcardle J.J., Bengston V.L.(2006). Attrition of older adults longitudinal surveys: detection and correction of sample selection bias using multigenerational data. *J Gerontol Psychol Sci Soc Sci*, 61: 323-8
- Gibson G., Timlin A., Curran S. & Watts J.(2004) The scope of qualitative methods in research and clinical trials in dementia. *Age and aging*, 33: 422-6
- Hinton L., Carter K., Reed B.R., Beckett L., Lara E., De Carli C., Mungas D.(2010). Recruitment of a community based cohort for diversity and risk of dementia. *Alzheimer Dis Assoc Disord*, 24 (3): 234-41
- Johl, N., Patterson, T., & Pearson,L.(2015) What do we know about the attitudes, experiences and needs of black and minority ethnic carers of people with dementia in the united kingdom? A systematic review of empirical research findings. *Dementia*, 15(4): 721– 42
- Lodewijcks, E.(2017) *Huishoudens van ouderen. Verschillen naar herkomst*. SVR. study service gouvernement of Flanders.
- Lodewijcks, E. (2014). Ouderen van vreemde herkomst in Vlaanderen anno 2011: een korte demografische schets. In De kock, C., Vens, E.,Beljoudi, Y. & Van Kerckhove, Ch. (eds.), *Ouder worden in een veranderende samenleving*. (pp 77-95) Apeldoorn/Antwerp:Garant Publishers
- Low, L.F., Draper, B., Cheng, A., Cruysmans, B., Hayward-Wright, N., Jeon, Y.H., Logiudice, D., Wu, H.H., Zogalis, G., Grodaty, H.(2009).Future research on dementia relating to culturally and linguistically diverse communities. *Australasian Journal on Ageing*, 28(3): 144-8

- Marcantonio, E. R., Aneja, J., Jones, R. N., Alsop, D. C., Fong, T. G., Crosby, G. J. & Inouye, S. K. (2008) Maximizing clinical research participation in vulnerable older persons: identification of barriers and motivators. *Journal of the American Geriatrics Society*, 56(8):1522–7
- Mazaheri, M., Eriksson, L. E., Nasrabadi, A. N., Sunvisson, H., & Heikkilä, K. (2014) Experiences of dementia in a foreign country: qualitative content analysis of interviews with people with dementia." *BMC Public Health*, 14:794-803
- Mwachofi, A. & Wamwachofi, N. (2010). Modelling health inequities research in context and the minority researcher's role. *Journal of Health Disparities Research and Practice*, 3(3): 21-42
- Nielsen, T.R., Vogel, A., Phung, T.K.T., Gade, A., & Waldemar, G. (2010). Over- and under-diagnosis of dementia in ethnic minorities: a nationwide register-based study. *Int. J Geriatric Gsychiatry*, 26: 1128–35
- Parlevliet, J.L., Uysal-Bozkir, Ö., Goudsmit, M., Van Campen, J.P., Kok, R.M., ter Riet, G., Schmand, B., & De Rooij, S.E. (2016). Prevalence of mild cognitive impairment and dementia in older non-western immigrants in the Netherlands: a cross-sectional study. *Int J Geriatr Psychiatry* 31(9): 1040–49
- Pesonen, H.M., Remes, A. M., & Isola, A.(2011). Ethical aspects of researching subjective experiences in early-stage dementia. *Nursing Ethics*, 18(5):651–61
- Rabbitt P., Lunn M., Wong D.(2005). Neglect of dropout underestimates effects of death in longitudinal studies. *J Gerontol Psychol Sci Soc Sci*, 60: 106-9
- Romero, H.R., Welsh-Bohmer, K.A., Gwyther, L.P., Edmonds, H.L., Plassman, B.L., Germain, C.M., Mccart, M., Hayden, K.M., Pierper, C., Roses, A.D.(2014). Community engagement in diverse populations for Alzheimer's disease prevention trials. *Alzheimer Dis Assoc Disord*, 28(3):269 – 274
- Shanley, C., Leone, D., Santalucia, Y., Adams, J., Ferrerosa-Rojas, J. E., Kourouche, F., Gava, S. & Wu, Y.(2013). Qualitative research on dementia in ethnically diverse communities. *American Journal of Alzheimer's disease & Other Dementiasr.*, 0:1-6.
- Swabrick, C.(2016). Visioning change: co-producing a model of involvement and engagement in research. *Dementia*, 0 :1-8
- Thomson, R., & Mcleod, J. (2015). New frontiers in qualitative longitudinal research: an agenda for research. *International Journal of Social Research Methodology*, 18(3): 243–50
- Torres, S. (2015). Expanding the gerontological imagination on ethnicity: conceptual and theoretical perspectives. *Ageing and Society*, 35: 935-960
- Van Den Muijsenbergh, M., Teunissen, E., Van Weel-Baumgarten, E., & Van Weel, C.(2016). Giving voice to the voiceless: how to involve vulnerable migrants in healthcare research. *British Journal of General Practice*, 66(647): 284–285
- Zubair, M., & Norris, M. (2015). Perspectives on ageing, later life and ethnicity: ageing research in ethnic minority contexts. *Ageing and Society*, 35: 897-916

Chapter 6: Doing research on the intersection of ethnicity and old age: Key insights from decolonial frameworks⁵

Abstract

Population aging and international migration are two of the most critical social trends shaping the world today. As a result, scholars across the globe have begun to investigate how to better incorporate ethnicity into gerontological research. The integration of insights from life-course theory, post-colonial, and feminist theories have resulted in valuable attempts to tackle issues related to ethnicity and old age. Inspired by these bodies of research, this paper explores how decolonial perspectives can strengthen social gerontological research at the intersection of ethnicity and old age.

This theoretical paper advances four key insights drawn from decolonial perspectives that expose some current blind spots in gerontological research at the intersection of aging and ethnicity. Through a process of awareness and resistance decolonial perspectives reveal that: 1) colonial thinking is deeply embedded in research; 2) critical reflection about who is considered the “knower” in research is warranted; 3) alternative ways to generate, analyze, and publish knowledge exist; and 4) the places and systems of knowledge production are not neutral. To address these issues empirically, decolonial frameworks call us to actions that include decolonizing the conceptual underpinnings of the research enterprise, scholars themselves, research-in-action (through “epistemic disobedience”), and current knowledge systems and structures that reflect and reinforce colonialism. Potential applications of these insights are explored, but acknowledged as an essential first step on a nascent path.

This paper concludes by arguing that decolonial perspectives offer a more genuine gaze by demanding nuanced reflections of the contemporary realities of aging persons embodying the intersection of aging and ethnicity, like racialized older migrants and ethnic minorities, while simultaneously revealing how historically-rooted power hierarchies that are often invisible constrain their aging experiences.

⁵ Published as: Berdai Chaouni, S., Claeys, A., van den Broeke, J., & De Donder, L. (2021). Doing research on the intersection of ethnicity and old age : Key insights from decolonial frameworks. *Journal of Aging Studies*, 56(November 2019), 100909. <https://doi.org/10.1016/j.jaging.2020.100909>

1. Introduction

Population aging and international migration are two of the most crucial societal trends in the world. These societal trends contribute to an increasing visibility of the diversity in the ethnic, religious, and cultural composition of the aging population, especially in the West. This has led to debates about the intersection of ethnicity and old age. Although these societal trends have ushered in attention to this intersectionality within gerontological research over the last few decades (Karl & Torres, 2016; Torres, 2019), scholars have increasingly come to question how gerontological research has historically addressed the issue (Torres, 2015; Torres, 2019; Zubair & Norris, 2015) and have identified several challenges. These authors argue, for example, that scholarship on older ethnic minorities reproduces societal inequalities in and of itself. The vast majority of this work is subjected to hidden obstacles, resulting in questionable assumptions being made about the older ethnic “other” that obfuscate crucial questions about old age and ethnicity (Torres, 2019; Zubair & Norris, 2015).

This theoretical paper starts by describing these “ethnicity blind spots” facing gerontological research at the intersection of ethnicity and old age; it then addresses the current paths to move forward that are being explored (intersectionality, life course perspective, and postcolonialism), and concludes with a section arguing why it is important to explore decolonial perspectives as a path to address issues of ethnicity in later life. By critically exploring insights from decolonial frameworks, we can provide an overview of key considerations to improve our understanding of and approach to (researching) the intersectionality of ethnicity and old age: 1) colonial thinking is deeply embedded in (gerontological) research; 2) there is a need for a critical reflection about who is considered the “knower”; 3) epistemic disobedience is needed to generate, analyze, and publish (gerontological) knowledge; and 4) the place and system of knowledge production are not neutral. Against this backdrop, we discuss the call to decolonize research by decolonizing the mind-frame of knowledge, the researcher, the research methodology, and the scientific structures and systems, and we explore their possible application for future research on the intersection of ethnicity and old age. We then discuss the potentials and limitations of decolonial perspectives. We conclude with a call to explore and employ these perspectives in gerontological research practice, as decolonizing research on ethnicity and old age is not merely another research methodological approach or simply a rhetorical discussion; rather, it is an ethical, ontological, and political exercise that can have wide-ranging practical and political implications.

2. “Ethnicity blind spots” challenge gerontological research about ethnicity and old age

After reviewing the last two decades of gerontological research on the intersection of ethnicity and old age, Torres (2019) concludes that gerontological research must still overcome five challenges, also raised by other gerontologists (e.g. Ivey et al., 2012; Johl et al., 2016; McDonald, 2011; Phillipson, 2015; Shanley et al., 2012; Zubair & Norris, 2015), in order to more effectively address this intersection.

First, the reviewed research is based mainly on literature from the United States, which tends to include only a narrow sample of ethnic diversity (Black and Hispanic groups), mostly in reference of

the majority group (Whites) (e.g. Ivey et al., 2012; Johl et al., 2016). Second, a vast majority of research practices address limited topics (such as health inequalities, health and social care, intergenerational relationships, and caregiving) not guided by any clear research agenda in addressing the intersection of ethnicity with these aging-related topics (e.g. McDonald, 2011; Phillipson, 2015). In other words, aging-related topics such as health inequalities were the focus of the research, not questions related to ethnicity. A third challenge is that studies often begin from a rather essentialist understanding of ethnicity that assumes that ethnic (and racial) groups are homogeneous and fixed “beings” that are easily identified (Johl et al., 2016; Shanley et al., 2012). This stagnated understanding of ethnicity informs the non-differentiation between ethnicity, race, minority, and culture in such research. The terms are conflated and used in a semantically ambiguous way that reflects how such groups are predominantly seen – namely, as the “other,” with an ethnicity – without recognizing key differences, such as that between an ethnic minority status and a race status, or between an ethnic minority with immigration experience versus one without. Ethnicity is often viewed as something only the “others” have, where problems that have been experienced are often explained as something specific due to their ethnicity (race, minority status, and/or culture) and/or compared to the normative group of older persons, who are “autochthonous”, white, and western (Torres, 2015; Torres, 2019; Zubair & Norris, 2015). Fourth, in addition to the conflation of ethnicity, race, and culture, gerontological studies about the intersection of old age and ethnicity seldom operationalized their angles of investigation. The found differences between white and colored age groups are attributed to either cultural values or ethnicity/race, without actually studying this angle.

A fifth challenge is that research often appears to rely upon a small number of methodological approaches (Zubair & Victor, 2015). Two shortcomings were identified. First, a large number of studies rely upon narrow study designs, mainly quantitative, that were not actually designed to study the intersection of old age and ethnicity. They also do not address contextual questions (Zubair & Victor, 2015) known to be important for most ethnic groups, such as the effects of discrimination. It is therefore argued that gerontological research could not grasp either the effects of ethnicity and immigration, on a structural level, or its implications for the aging experience, on the individual level (Jutla, 2013; McDonald, 2011). The second identified methodological shortcoming relates to the use of a narrow approach to the social positions studied. Most studies lack intersectional approaches (Zubair & Norris, 2015) and rely on “one variable at a time approach,” thereby disregarding other societal positions – such as gender, class, and historical and regional differences – as influencing aspects on the topic addressed in the intersection of aging and ethnicity. Ethnicity is assumed to be solely crucial to the circumstances of the ethnic “other,” an assumption that is exacerbated when scholars regard these groups as ethnic “beings” and are oblivious to how other societal positions affect the situation of this older “other.”

These five challenges lead to two negative outcomes. First, a reproduction of narrow assumptions about ethnic “others” and old age “that are passed on as ‘research findings’ by sheer virtue of the fact that we have attached a reference to them and made them seem like they are evidence-based understandings” (Torres, 2019: 3062). Torres (2019) therefore urges us to be critical about what we actually know about ethnicity and old age and what we still need to learn concerning different ethnic and racial groups’ values, attitudes, and preferences. Such reproduction leads to creation of one-sided stories about ethnic groups, often negative and far from the complex image of how these groups define themselves. There is thus a need for counter-narratives (Croom and Marsh, 2016; Merriweather-Hunn, Guy & Manglitz, 2006) to adjust this deformed image about the ethnic “other.” Second, researchers

(Zubair & Norris, 2015; Zubair & Victor, 2015) argue that the way current gerontological research involving older persons from ethnic minorities is conducted reproduces societal inequality in and of itself. The previously noted challenges in current research on ethnicity and old age render us oblivious to certain lines of oppressions associated with an “ethnic” societal status; in not properly addressing these lines in research about old age and ethnicity we contribute, often unconsciously, to this system of oppressions. Torres (2019) even argues that, in conflating ethnicity with race and culture and using “Whiteness” as the master category against which ethnic groups are compared, social gerontology contributes to constructions and maintenance of a racial hierarchy system “wherein different groups are labelled, ordered and rewarded or penalized according to a racial classification system developed and substantially maintained by whites” (Elias & Feagin, 2016: 95). In other words, due to this “White” framing, where ethnicity is considered a feature only of the “other,” researchers remain unaware of this system of subordination of ethnic minorities and how it disadvantages some groups and privileges others and what this implies for the older “other.”

3. Explored paths to move forward

In the last decade, intersectionality (Hulko, 2009; O’Connor, Phinney & Hulko , 2010; Torres, 2015, 2019a), life course perspective (McDonald, 2011), and postcolonial perspectives (van Dyk & Küpper, 2016) have been explored as three possible paths by which gerontological research can include this ethnicity perspective (Phillipson, 2015; Torres, 2015).

Originally inspired by the influences of critical race and feminist theories, intersectionality offers an analytical lens looking at the convergence of key social statuses such as age, class, gender, sexuality, and ethnicity (Crenshaw, 1991). It also focuses on how intersection of structural lines of oppressions/subordination such as sexism, racism, and ageism affects the individual position and experience (Ferrer et al., 2017). It reveals that this impact may vary depending on its combination with other sources of subordination or privilege (Denis, 2008; Torres, 2019a). As concerns the topic here, it informs us about how one social position or identification ground (e.g. ethnicity) in combination with another social position or identification ground (e.g. gender) can inhibit or facilitate the experience of the older ethnic “other.” Intersectionality allows inclusion of ethnicity in gerontological research without promoting cultural essentialism (Torres, 2015). The multiple positioning that characterizes power relations between people, and that is inherent to intersectionality, provides an opportunity to address the complexities that different backgrounds entail both on individual and on structural levels. Intersectionality draws attention to the complexity of ethnic diversity with differences and similarities between and within ethnic groups (Zubair & Victor, 2015).

Besides intersectionality, some scholars argue that gerontological research addressing ethnicity can benefit from a life course perspective that examines different structural sources of inequalities and (dis)advantages across a lifetime, such as the cumulative advantage and disadvantage model (Dannefer, 2003; Ferraro & Shippee, 2009), and how such sources affect an individual’s aging experience (McDonald, 2011; Phillipson, 2015). Ferrer et al. (2017) integrated both these perspectives into their theoretical analysis model of “intersectional life course perspectives.” This model tries to grasp the interplay of structural, personal, and relational processes experienced by racialized older persons across a life course. The authors state that this model has the potential to provide deeper

understanding about the complexity of the effect that different lines of oppressions can have on older migrants. Initial steps have been taken to examine how this model can be applied as a framework for analysis in research about ethnicity and old age (Brotman, Ferrer & Koehn, 2019).

A third explored path of inspiration was found in certain concepts of postcolonialism. A special issue in the *Journal of Aging Studies* in 2016 explored how postcolonial concepts can be applied to later life. Key postcolonial concepts such as (affirmative) othering, subalternity, exile, and colonial mimicry (Kunow, 2016; van Dyk & Küpper, 2016) were explored as new lenses by which to address questions relating the representation of old age as the “other”: for example, affirmative othering as a lens to see the double othering of the third and fourth age (van Dyk, 2016) and age mimicry of young-old of midlife norms as an extent of colonial mimicry (Küpper, 2016). However, in this special issue these postcolonial concepts were not used as analytical gazes for questions related to the intersection of age and ethnicity. The concepts were not applied to older persons embodying this intersection, such as aging ethnic “other,” aged people of color, older migrants, etc. Rajan-Rankin (2018) did explore the postcolonial concepts of exile and otherness as conceptual lenses to understand racialized aging bodies. The concept of exile, for example, explored how aging bodies of color are viewed through a dominant (white, youth-centered, masculinist) gaze. This dominant gaze limits at an epistemological level “the understanding of lived experiences of racialized ethnic minorities in old age” (Rajan-Rankin, 2018, p 32). However, the author also points to the limitation of postcolonial concepts such as exile and otherness to capture the multiple layers of difference, age, race, gender, and class, and the intersections of these various axes of difference. The author argues that decoloniality “can help to challenge the western canon and produce alternate epistemologies and ways of knowing” (Rajan-Rankin, 2018, p 37).

4. Decoloniality as a new path to explore the intersection of ethnicity and old age

This paper aims to explore decolonial perspectives in an extensive way, as a means to recognize the intersection of aging and ethnicity not as an intersection of two separate entities but as one embodied by persons, more particularly racialized older migrants and ethnic minorities, and colored and Black older persons. It is difficult to demarcate a strict line between postcolonialism and decoloniality, and there remains debate about their similarities and differences. We tend to follow a dynamic perspective, to regard these scholarly traditions as being in dialogue, as suggested by Bhabra (2014): postcolonialism and decoloniality are diverse scholarly traditions with shared concerns resulting from their contestations of territorial colonialism and its impact on knowledge production. These shared concerns include questioning the idea of universality and exposing the ways power relations define how knowledge is produced and which narratives are visible. However, they are different disciplines, not only because of their geographically different “origins” but also because of the contrasting focus of their studies. Postcolonialism emerged from the work of diasporic scholars from the Middle East and South Asia, such as Said, Bahaba, and Spivak. They introduced important concepts, including otherness and subalternity, to capture the reality of the colonized during and after the territorial colonization of the Middle East and South Asia by Europe (mainly France and the United Kingdom). Decoloniality arose from the work of diasporic scholars from South America, such as Quijano, Lugones, and Mignolo, who expanded the temporal and geographical focus of colonization to the fifteenth

century and to Spain and Portugal. They introduced concepts such as “coloniality” and “coloniality of power” as a “way to discuss the more profound realities of colonialism, especially ‘after’ the event” (Bahambra, 2014, p 119). Decoloniality recognizes that colonial thinking and colonial logic did not cease after territorial colonialism.

Decoloniality also expands and heightens postcolonial concepts such as subalternity and othering (Bahambra, 2014), in particular by challenging epistemologies used in colonial means of knowledge production (Bahambra, 2014, Grosfoguel, 2011; Rajan-Rankin, 2018). Decoloniality agrees with the post-colonial perspective that centralizes the possibility for the subaltern to speak, but argues that we can hear them only if we dismantle our thinking and epistemological approach from colonial influences. This more complex view of power hierarchies allows decoloniality to avoid alleged shortcomings of postcolonial perspectives, such as culturalism (Bahambra, 2014, Kunow, 2016) and excessive focus on binary categories of difference such as male/female, white/black (van Dyck, 2016).

We argue therefore that decolonial perspectives informed by intersectionality, life course theory, and postcolonialism provide a new potential path forward in studying the intersection of aging and ethnicity. Decolonial perspectives show that colonialism, in leading to the coloniality of knowledge production and education, still influences what is considered “good science,” and that this leads to blind spots in knowledge and contributes to the marginalization of unheard voices from different groups. Recently, scholars inspired by societal movements initiated by activists, artists, students, etc. (Rutazibwa, 2019) have begun exploring what this means for their research fields. Increasingly, scholars in the global north and south, and from disciplines such as psychology, pedagogy, cultural studies, nursing studies, and sociology, have sought to question these often invisible biases in science that silence marginalized groups based on their ethnicity or gender, for example, and to call for decolonialization of knowledge production and education (Al-Hardan, 2018; de Jong, Icaza & Rutazibwa, 2019; Dutta, 2018; Kessi & Boonzaier, 2018; Withaekcx & Essed, 2017). Inspired by the cross-disciplinary and international aspects of these works, this article explores what these decolonial insights may mean for gerontology and gerontological research, in particular research concerning the intersection of aging and ethnicity.

5. Key insights to be applied from decolonial perspectives

In this section, we discuss four key insights that we identified from decolonial perspectives as being relevant to gerontological research. These insights are interlinked and should be considered as a whole. Figure 1 presents these four insights and their corresponding call to action. Through a process of awareness and resistance, decolonial perspectives reveal that: 1) colonial thinking is deeply embedded in research; 2) critical reflection about who is considered the “knower” in research is warranted; 3) alternative ways to generate, analyze, and publish knowledge exist; and 4) the places and systems of knowledge production are not neutral. To address these issues empirically, decolonial frameworks call us to actions that include decolonizing the conceptual underpinnings of the research enterprise, scholars themselves, research-in-action (through “epistemic disobedience”), and current knowledge systems and structures that reflect and reinforce colonialism.

The following sections will discuss each of these key insights, offer suggestions about how the insights can be applied in (gerontological) practice, and consider how these insights can inspire and guide future gerontological research on the intersection of ethnicity and aging.

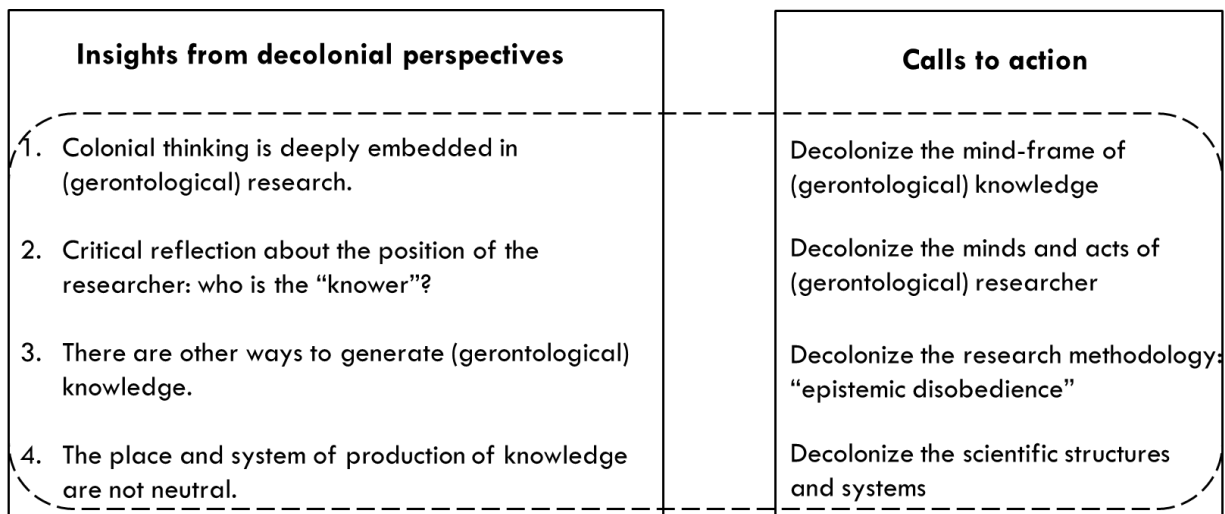


Figure 3: Key insights from decolonial perspectives, with calls to action.

Insight 1: Colonial thinking is deeply embedded in (gerontological) research

Decolonial frameworks inform us about how colonial thinking is deeply embedded in (gerontological) research and thereby call us to decolonize this mind-frame of knowledge. Coloniality refers to an invisible structuring force engrained in our mind-frames that shape power structures, knowledge, and individual experiences. It is the continuity of colonial forms of domination after the end of colonial administration (Grosfoguel, 2011). Coloniality of knowledge continues to shape knowledge through a binary power division of “us” versus “them,” even decades after direct colonialism (Mignolo, 2011). The “us” is the “Western” academy at the center of production of knowledge and theory about “others.” In gerontological research, the “others” can be indigenous (older) people or (aging) original inhabitants of colonized territories; they are also mainly non-Western (older) immigrants in current super-diverse Western cities and regions (Grosfoguel, Oso & Christou, 2014). These colonial mind-frames take for granted that European and Western concepts are not only normative and an ideal and global human system of knowledge, but also transferable to all. The West holds economic, political, technological, and normative dominance, enabling it to produce knowledge – including on ethnicity and aging – which is considered neutral, authoritative, and scientific, in which the “others” are viewed as sources of data (Mignolo, 2011).

Decolonial scholars such as Mignolo (2009) critique this assumption of neutrality and universality in knowledge production, as it has led to a distorted and incomplete image of what is considered “reality” (ontology) in various sciences. Scholars refer to such images – for example, the exclusivity of culture as a motivation to provide family care for older migrants – as “myths” (Grosfoguel & Cervantes Rodriguez, 2002; Rutazibwa, 2019), and call to “de-mythelise” this “reality” (Rutazibwa, 2019). As such, it is important to be critical about *what* is considered knowledge and “evidence” in academia (Ramos, 2018; Rutazibwa, 2019). This means questioning the positivistic preference of doing research where

the “subjects” are objectified and categorized, quantified, labelled, and compared by the researcher from an observational position assumed to be neutral and distant (McDowall & Ramos, 2011). Such research reflects the process by which people were classified into racial categories during territorial colonialism, so as to give scientific justification for racialization of the inhabitants of colonized territories, thereby inferiorizing them as less human and less rational (Grosfoguel, Oso & Christou, 2014; Smith, 2012). Several decolonial scholars have noted that positivistic scientific work is not only an underlying constructor of racial categories and justification of (biological) racism, but also observable in gerontological research. They alert us to how this mode of research can reproduce racialization, especially of indigenous people, ethnic minorities, and immigrants (Chalmers, 2017; Smith, 2012).

Researchers, including gerontologists, should be aware of this invisible reproduction and maintenance of racism: it is a global hierarchy of human superiority and inferiority that has been produced and reproduced politically, culturally, and economically by institutions of the capitalist, Western-centric colonial world system (Grosfoguel 2011, 2013). During territorial colonization, positivistic science initially helped to categorize people according to skin color. Current research, however, reproduces cultural racism (Grosfoguel, Oso & Christou, 2014), by which people are similarly divided and subordinated not only by skin color but also by cultural and religious backgrounds. In this division, the Fanon model of racism (1967), with zones of being and non-being, is still reproduced for the “cultural other” in super-diverse Western cities (Grosfoguel, Oso & Christou, 2014). This division means that older ethnic “others,” especially those of non-Western background and non-Christian religion, are lower on the hierarchy; they are in the zone of non-being and therefore considered less human. For such minorities, being in the zone of non-being entails that they face more barriers to basic rights, including human, civil, women’s, and/or labor rights. Moreover, their subjectivities, identities, epistemologies, and spiritualities are less recognized, and are inferiorized, as compared to those of people in the “zone of being” (Grosfoguel, Oso & Christou, 2014).

In the same line of reasoning, Quijano’s concept of (2000) “coloniality of power” argues that colonial frameworks continue to shape different power relationships, expressed through political and economic spheres, with racism being “the transversal dividing line that cuts across multiple power relations such as class, sexual and gender relations on a global scale” (Grosfoguel, Oso & Christou, 2014, p3). This coloniality of power is strongly associated with and manifested in the coloniality of knowledge, thereby empowering and privileging Euro-American knowledge systems that are regarded (often unintentionally or unconsciously) as being entirely rational and universal in determining our understanding of the world.

Call to action 1: Decolonizing the mind-frame of (gerontological) knowledge

Because coloniality of knowledge similarly informs the structure and fabric of scientific disciplines (Grosfoguel, 2011), colonial thinking remains deeply embedded also in gerontological research. This has led to a limited and biased understanding of the “reality” of the aging ethnic “other.” This insight offers an extra layer in better understanding the effects of structural oppression on the aging experience of older ethnic “others,” especially in the West. It is imperative to cease conducting research about “the other” (Cole & O’Riley, 2010) and instead highlight relationships and similarities,

rather than differences and categories regarded from a distant position of discovery. Decolonial perspectives not only support critiques of the imposition of “White” templates in social gerontology, as formulated by social gerontologists such as Phillipson (2015) and Torres (2018); they also invite us to examine the roots of such impositions. Such perspectives situate this formulated concern of “White” framing into a broader context of “colonial thinking” that results from the colonial consequences of power relationships (Braun et al., 2014). For gerontology, decolonial questions include: How can normative standards be beneficial or harmful to different ethnic groups of older adults? How do such norms reproduce inequality? Are there alternative gerontological norms and standards, that can be used and constructed that include the voices of people who embody the intersection of age and ethnicity? For gerontology, as in other fields, decolonizing the mind-frame of knowledge entails being aware of the coloniality of knowledge and finding ways to resist the invisible influences of “colonial thinking” on epistemology. These measures will advance a more holistic epistemology that offers space for other forms of knowledge production.

Insight 2: Critical reflection about who is the “knower”

Decolonial frameworks invite gerontological researchers to decolonize our mind-frame by critically reflecting upon who is considered the “knower” in a research relationship. Decoloniality highlights the importance of the researcher’s position and how it influences knowledge production. Researchers, regardless of ethnic background, should examine their position from a colonial lens: this entails developing awareness of one’s own colonial mindset, and striving both to resist colonial thinking and to avoid reproducing it in one’s research (Chalmers, 2017). There is debate about the position of researchers from minority backgrounds. Most agree that it would be beneficial for academia to have more researchers from ethnic minority backgrounds; however, there is a dual perspective in considering their added value as decolonizing forces in academia. Some argue that inclusion of such researchers is an act of decoloniality of academia and that these researchers can articulate critiques, from their positions as “outsiders-within” (Zavala, 2013), of the marginalized position of a migrant or ethnic minority in the West (Smith, 2012; Zavala, 2013). Others suggest that this is not always the case, as many of these researchers have also incorporated dominant epistemologies and tend to reproduce Western-centric knowledge (Grosfoguel, 2013). Including these marginalized and silenced voices should not be a “multiculti-plussing-up exercise of inviting more of the silenced voices around the existing table” (Rutazibwa, 2019: 169); rather, it should be a profound engagement to de-silence such voices by displacing current power hierarchies.

Call to action 2: Decolonizing minds and actions of (gerontological) researchers

An important step towards the decolonization of the (gerontological) researcher involves becoming familiar with works of decolonial, anti-racist scholars and adapting a fuller concept of what knowledge is (Datta, 2018). Equally important in this process is a critical examination of one’s own position as a researcher and how this position manifests itself in relation to the “research population.”

Decolonial frameworks hold that (gerontological) researchers are accountable for their actions and required to “give back” to the community involved with the research (Chalmers, 2017). This requires an alternative attitude towards research topics and research participants. As a researcher, one must

be a humble actor in the research relationship, such that the goal, the approach, and the results are co-defined by the engaged community (in this case, older ethnic minorities) and are not harmful to their situation (Chalmers, 2017; Datta, 2018). According to Chalmers (2017), the researcher becomes an “ally” to these silenced voices but does not speak on their behalf. These silenced voices are viewed as a knower who we as researcher are learning from as opposed to discovering about (Datta, 2018). The most important aspect of this learning is that it improves the situation of these silenced voices. This also requires another orientation as a researcher: from a “science-oriented researcher to a participant-oriented researcher,” as formulated by Datta (2018, pg 15). Although a researcher’s intentions in a more power-balanced co-operation with these silenced communities may not be harmful, researchers should always be careful about the remnants of power imbalances in such research relationships: as long as one person is a “researcher” and another a “participant,” power imbalances, as well as ethical complications, will continue to exist (Chalmers, 2017), even when the established agency of the participant (Zubair & Victor, 2015) has been taken into consideration. In gerontological research, reflecting on the position of the researcher and who is considered “the knower” are therefore important steps, especially in a context where researchers have been trained to prioritize an academic agenda over participants’ interests. It is therefore necessary that our academic training broadens the current research-oriented training, shifting it towards participant-oriented training (Datta, 2018), which will allow for us to truly engage in ethical relationships with research participants. In this respect, the science-oriented curiosity of “doing some research about older ethnic/racial/migrant group” is problematic and something to avoid. Decoloniality considers the study sample not “participants” but “knowers.” Fadil (2019) argues that the added value of a researcher is synthesizing knowledge that is shared by these “knowers,” thereby rendering shared authorship of publications inevitable.

Decolonial frameworks hold researchers accountable for any adversity respondents may face as a result of research practices and force researchers to examine their position and responsibility at a much deeper level. This aligns with the suggestion of Torres (2019) about incorporating “reflexivity” into gerontological research on ethnicity and old age. Inspired by the racial theoreticians Emirbayer and Desmond’s (2012) definition of reflexivity, Torres (2019) sees in reflexivity a means to uncover the hidden assumptions of our scientific unconsciousness and their effects. In doing so, we “develop deeper insights into the workings of a social and power order” and can strive to undo the negative effects of this unconsciousness.

Decolonial scholars emphasize that we are operating in a context that is influenced by invisible colonial mechanisms and that this leads us to reproduce (usually unconsciously and without negative intention) colonial frameworks (Chalmers, 2017). Understanding the invisible mechanisms behind the reproduction of these frameworks (Grosfoguel, 2013) allows researchers to become more aware of their own biases and to critically examine their positions through a decolonial lens (Chalmers, 2017; Datta, 2018; McDowall & Ramos, 2017). From what place and perspective do we, as gerontological researchers, observe and analyze? How is our thinking shaped by global power hierarchies? Which position do we take along these different axes of hierarchies and how do these positionalities influence our thinking and research? How colonized is our thinking and how does this influence how we regard aging ethnic “others”? Do we consider ourselves accountable for potential harm induced by our research, such as psychological distress triggered or exacerbated by a participant’s testifying about the impact of migration on the aging experience, and if so, what actions do we take to avoid or ease such

distress? Decolonization of one's mind-frame is therefore a long and continuous learning process, with space for mistakes. Indeed, challenging this internalized superiority of white Euro-American-centric structures requires lifelong commitment (DiAngelo, 2018).

Insight 3: There are other ways to generate (gerontological) knowledge

Decolonial perspectives make us aware not only that there are other, neglected sources of knowledge but also that there are other ways to produce knowledge. Other means of generating knowledge are required if we wish to achieve a research praxis in which silenced voices can truly speak and be heard. The decolonial perspective creates space for different pathways by which to pursue more effectively engaged research, without being dictated by one epistemic approach. Decolonizing research means decolonizing methodology, not methods, although some methods are more favorable in a decolonized research. Whereas "method" refers to a particular mode of data collection and analysis, "methodology" refers to a broader framework that sets the research parameters and guides the overall research process. Methodology determines not only the purpose of research and the research question, but also one's approach to the research, how the results are disseminated, and who owns the data. It is thus more sensitive to reproducing the colonial way of research (Chalmers, 2017; Datta, 2018; Smith 2012), or "epistemic racism," as formulated by Grosfoguel (2013). Decolonizing research is also an invitation to learn about and from "epistemologies of the South" that are often unknown or overlooked due to "Epistemicide", the colonial erasure of alternative ways of knowledge production, as conceptualized by Santos (2014).

Call to action 3: Epistemic disobedience

This calls for "epistemic disobedience" through "de-linking" (Mignolo, 2009) from the dominant way of doing research – which is historically interlocked with Western colonial, imperial, capitalistic, Eurocentric, Christian influences and assumed to represent a neutral and detached observational position over the world. Such de-linking fosters "epistemic affirmation" of people who have been historically silenced and excluded from knowledge production (Mignolo, 2009). This is in line with Chalmers's (2017) process of "decentering and recentering" as a means to decolonize epistemologies: decentering Western epistemologies and recentering marginalized ones (Chalmers, 2017). Of course, this should not be read as a suggestion that Western methods and theories should be wholesale rejected (Datta, 2018). Rather, these methods and theories should be considered as one possibility in the pluri-versality of methods, with caution not to reproduce colonial thinking. According to decolonial frames, knowledge can also be found in non-academic sources (Smith, 2012; Weiner & Carmona Baez, 2018) such as oral stories, dreams, and objects; likewise, we can employ different approaches, such as working through art, to capture emotionality in knowledge (Ramos, 2018). The decolonial lens can be applied to the classic phases of research, from the definition of the research question through final publication. In defining the research question, it is critical to ensure that it will have no harmful impact on the people involved in the research (Chalmers, 2017) and that it will not contribute to othering or silencing the participants (Chalmers, 2017; Datta, 2018).

Within the dominant set of Western methodologies, several methodologies can be used, but there is preference for more qualitative research approaches, especially participative action research (PAR) (Braun et al., 2014). These approaches intrinsically strive for nuance and endeavor to remain close to the narratives of the participants. More participatory approaches such as PAR and co-creation are preferred, as it is thought that they afford the participant equal power to define the methodology and that the participant can thereby assist in countering the (usually invisible) power relationship between researchers and participants (Datta, 2018). The participant from the minority group is a valued co-producer of knowledge in each step of the research process, with great emphasis on the participant's narrative (Zavala, 2013). The participant's lived experience and knowledge are valued as she or he works collaboratively with the researcher in co-constructing knowledge about these experiences (Ramos, 2018). However, a decolonial lens should also make us vigilant as to how these epistemic templates (of participatory action research) remain "White" templates and that participative and co-creative research can still reproduce unequal power relationship between researchers and participants. Moreover, these participative approaches, as with any (qualitative) methodological approach, can be considered "decolonial" only when the research question addresses an actual need of the ethnic minority, if the pace and process of the research are determined by the participants and not by the researchers, policymakers, and funding providers, and if the research results are used to improve the situation of the ethnic minority group (Smith, 2012; Zavala, 2013).

For gerontology, development of decolonial awareness is important during the analysis of results: researchers must consider the visible and invisible frameworks from which they analyze these results and whether their approach reproduces, to some degree, a colonial order (Chalmers, 2017), such as by disempowering and stigmatizing the ethnic older groups considered in the research. Datta (2018) argues that the way in which researchers explain participants' lives, culture, and values can contribute to this invisible power over such groups. It is therefore important to be aware of the dominant Western-centric, essentialist discourse in analysis of the research topic. Awareness of this mechanism is achieved both by looking for nuances in a broader spectrum of analytical frameworks and by maintaining awareness of the structural mechanisms that lead to reproduction of stereotypical thinking about minorities (Braun et al., 2014).

Decolonial perspectives also highlight that the way we write is not neutral. As McDowall and Ramos (2017: 6) state, "Academic writing has been instrumental in the construction and distribution of positivist colonial logics, with its oppressive and exclusionary parameters that continue to guide how we classify, categorize, what we write about and most importantly, who 'can' write." The positivistic Western tradition reduces the worlds of others into determinable and predictable patterns of behavior, whereas decolonial writing seeks to render space for the story of the "participants" along with their emotions, relationships, and tensions. Such writing addresses the inconsistencies of the positioning of the researcher, using a type of writing that reflects this complexity. Inspired by feminist scholars, McDowall and Ramos (2017) illustrate this type of writing as being a hybrid form of art and science. Inclusion of creative and art-based methodologies in research has already been proposed (Rajan-Rankin, 2018) and used by scholars in various disciplines, including sociology (Erel et al., 2017), psychology (Fox, 2015), and gerontology (Zeilig et al., 2018), all driven by the question of how to increase participation of marginalized voices.

This third call to action makes us aware that in order to centralize marginalized voices as “knower,” other ways are needed to generate, analyze, and publish knowledge; it also calls us to “epistemic disobedience.” This can be inspiring as a way to fulfil the need for other methodologies by which to broaden our thinking concerning scholarship at the intersection of old age and ethnicity. Decolonial frameworks compel us to continually ask what strategies we might use to conduct gerontological research that effectively speaks to the needs of the people embodying this intersection. How can we set research conditions that allow racialized older persons to express their agency to the fullest? How can we avoid knowledge extraction from these older persons, even in well-intended participatory methods? Answering these questions means flexibility in communication and in the decision-making process to build a trust relationship between researchers and “participants.” This enables a partnership in which “participants” can co-define the research goal, what and how data is gathered, how the results will be disseminated, and where the “participants” will be acknowledged for their contribution as “knowers” (e.g. co-authorship, a clear return for the community, etc.) (Tucker, 2018). This also means that non-participation of marginalized voices in gerontological research (Gove et al., 2019) is read not simply as a sign that the group is “inherently hard to reach” but also as evidence of agency on the part of these older persons and their communities, thereby informing us that we should reconsider our epistemology.

Insight 4: The place and system of production of knowledge is not neutral

Decolonial thinking makes us mindful of the importance of place in the production of knowledge. According to these frameworks, knowledge is influenced by its “place” of production, or “locus of enunciation” (Mignolo, 2009), and therefore cannot be “universal” (Chalmers, 2017; Smith, 2012). Universities are key places where knowledge is produced under the dominance of Euro-American-centric positivist epistemology that claims to be universal. Universities have traditionally afforded space for critical ways of thinking and innovation in academic research, and thus can provide space for decolonial ways of knowledge production. Yet, the norms of what is considered good research – produced through logic, abstract reason, and measurement (Chalmers, 2017) – can narrow this space of creativity in which new forms inspired by decolonial thinking can arise (McDowall & Ramos, 2017). Decolonial frameworks require that we maintain a critical perspective towards ethical boards and research funders. These bodies tend to prefer positivistic research, in which researchers should be distant from the research subjects and whose objectives do not question the research’s impact on the participants (Chalmers, 2017). This concern has also been raised by gerontological researchers such Zubair and Victor (2015).

Call to action 4: Decolonize the scientific structures and systems

This fourth insight makes us aware that, like place, the structures and systems of knowledge production are not neutral, and calls us to decolonize them. Gerontological research about the intersection of aging and ethnicity should, therefore, resist the restrictions imposed by the dominant knowledge institutions, in particular by encouraging us to conduct research beyond the physical and psychological walls of academia (Gove et al., 2019; Zubair & Victor, 2015). This is a call for a pluri-versal academia that includes a diversity of epistemic particularities. These particularities have been shaped

by different decolonial epistemic and ethical responses of subaltern groups from various locations of world power hierarchies (Grosfoguel, 2011). The ultimate goal for some scholars is the “decolonization of academia,” and decolonization of epistemology is considered a valuable first step towards such transformation of academia (Chalmers, 2017). A path to this transformation is still being paved and is context dependent (de Jong, Icaza & Rutazibwa, 2019). However, it is clear that this path should be established via collaboration across disciplines that strive to incorporate the intersection of marginalized voices such as feminist, anti-racial, queer, and other epistemologies (Chalmers, 2017; de Jong, Icaza & Rutazibwa, 2019; Weiner & Baez, 2018). Weiner and Carmona Baez (2018) go further in their advocacy for multi-disciplinarity in the struggle for decolonized research by illustrating the critical importance and added value of knowledge generated from the practice and experience of decolonial and minority activists and artists. An illustration of this tendency is the incorporation of non-academic and marginalized voices, such as through the creation of space in which forms that are considered non-academic (poems, testimonies, photographs, etc.) can function to generate academic knowledge (Cornell, Mkhize & Kessi, 2019; de Jong, Icaza & Rutazibwa, 2019).

Because individual researchers have limited power in the institutions of academia, decolonizing such institutions is probably the most difficult aspect for researchers to address in this call to action. However, researchers can use “tactics” such as epistemic disobedience to “gradually contribute to a weakening of the wall and open up possibilities for transformational change” (Withaekx, 2019, pg 38). Profound transformative change towards an equity-oriented gerontological research requires actions from powerful actors within both academia and funding bodies.

6. Conclusion: Potentials and limitations of decolonial perspectives

This paper illustrates the need for gerontology researchers to maintain a critical perspective about how their research on ethnicity and old age is conducted. From the literature we have identified four “ethnicity blind spots” that obfuscate crucial questions about this matter: focus on the United States; focus on aging-related topics; non-differentiation between ethnicity, race, minority, and culture; lack of operationalization of ethnicity, race, minority and culture; and the prevalence of mainly narrow (quantitative) study designs that do not address contextual questions. In addressing these blind spots and moving the discussion forward, social gerontologists have found inspiration in intersectionality, life course perspective, and postcolonialism.

We argue that additional, and necessary, inspiration can also be found in insights drawn from decolonial frameworks. These insights make us more aware that the consequences of colonial trauma are not only still present but also continue to define, often imperceptibly, our research, policy, and practice. The decolonial invitation for us to examine the roots of things historically, structurally, institutionally, and individually gives opportunity to engage with this topic more profoundly, while embracing the diversity of insights already generated from gerontological, feminist, postcolonial, and other studies. An awareness of how coloniality remains present in our mind-frames, in our research practices, and in our scientific structures, and thereby leads to the reproduction and maintenance of

subordination, silencing, and deforming of realities of people who embody the intersection of aging and ethnicity, spurs us to seek ways to resist these conditions.

Decolonial frameworks call us to engage at a deeper level, questioning our accountability as gerontological researchers in the reproduction of biased knowledge and power hierarchies. Such questioning is facilitated through decolonization of the mind-frame of research, the researcher, the epistemology and scientific systems and structures. This decolonization process refines what is considered to be knowledge and leads to a more ethical way of conducting research. To achieve this goal, decolonial scholars provide concrete epistemological suggestions, such as engagement in more participant-centered research that highlights the voice and narrative of people who typify the intersection of aging and ethnicity, engagement that allows for equal collaboration with persons whose expertise is based on experience (e.g. family carers of older migrants) or in other fields (e.g. art), and for co-authorship with these “knowers.” According to Ramos (2018), decolonial thinking gives us a critical language and a variety of analytical tools for reading and interpreting the micro and macro levels in an individual’s personal narrative. Incorporation of decolonial frameworks thus provides a broader analytical framework to understand ethnicity and old age research themes such as the reasons for professional care use by the ethnic “other,” and avoids essentialist explanations of such topics. By linking the impact of (invisible) power structures on individual lives, decolonial frameworks provide a wider analytical lens to examine why, for example, some professional carers are oblivious to certain power structures and how these carers contribute to inaccessible and lower quality care to aged ethnic minorities, even when they have positive intentions to provide good, effective care. Being aware of our structural “cultural archive,” itself based on colonial frameworks that shape individuals’ everyday thinking, feelings, and social practices (Wekker, 2016), extends our perspective so as to examine such topics beyond the individual level.

However, applying decolonial frameworks also entails potential pitfalls and limitations. The first such obstacle is the absence of strict definitions about what a decolonized epistemology should look like. What is considered decolonized research is based on a set of principles and can come across as vague. The second limitation involves the term “decolonization” itself, as there is risk that the vast theorizing related to decolonial thinking, including the intersections of marginalized voices due to racism, sexism, ageism, ableism, and culturalism, will be narrowed in its understanding and application to issues related only to territorial coloniality. This notion of “territorial coloniality,” along with the understanding that decoloniality of research means thinking about changing the status quo in academia, may lead to resistance against considering the possibilities of such a framework. Other potentials and limitations will surely be encountered in the process of applying these insights to gerontological research. Further research and theorizing on the potential of decolonial frameworks in gerontology and other sciences is therefore needed.

Decolonial perspectives provide a more open mode of evaluation and engagement, with room for complexity that reflects the contemporary reality of older persons who embody the intersection of aging and ethnicity, such as racialized older migrants and ethnic minorities, colored and Black older people. They also make us aware of how invisible, historically rooted power hierarchies continue to impact the aging experience. It is crucial that these principles and epistemological suggestions be translated into action in the gerontological field. They offer a pathway that can, together with other attempts, lead us to the next steps in constructing gerontological research that is better suited to

address questions at the intersection of aging and ethnic diversity within the trends of population aging and international migration.

References

- Bhambra, G. K. (2014). Postcolonial and decolonial dialogues. *Postcolonial Studies*, 17(2), 115–121. <https://doi.org/10.1080/13688790.2014.966414>
- Braun, K. L., Browne, C. V., Sue, L., Kim, B. J., & Mokuau, N. (2014). Research on indigenous elders: from positivistic to decolonizing methodologies. *Gerontologist* 54(1), 117–126. <https://doi.org/10.1093/geront/gnt067>
- Brotman, S., Ferrer, I., & Koehn, S. (2019). Situating the life story narratives of aging immigrants within a structural context: the intersectional life course perspective as research praxis. *Qualitative Research*. <https://doi.org/10.1177/1468794119880746>
- Chalmers, J. (2017). the transformation of academic knowledges: understanding the relationship between decolonising and indigenous research methodologies. *Socialist Studies / Études Socialistes*, 12(1), 97-116.
- Crenshaw, K. (1989). Demarginalizing the Intersection of Race and Sex: A Black Feminist Critique of Antidiscrimination Doctrine, Feminist Theory and Antiracist Policies. *The University of Chicago Legal Forum*, 1989(1), 139–167. [10.1525/sp.2007.54.1.23](https://doi.org/10.1525/sp.2007.54.1.23).
- Crenshaw, K.W. (1991) Mapping the margins: intersectionality, identity politics and violence against women of color. *Stanford law review*, 43, 6, 1241-1299
- Cornell, J., Mkhize, L., & Kessi, K. (2019). Envisioning photovoice as decolonial feminist praxis. In F. Boonzaier, T. van Niekerk (eds.), *Decolonial Feminist Community Psychology, Community Psychology* (pp 59-74). Springer Nature, Switzerland AG https://doi.org/10.1007/978-3-030-20001-5_5.
- Croom, N.N. & Marsh, T. (2016). Introduction: Envisioning critical race praxis in higher education through counter-storytelling. In Croom N.N. & Marsh T. (Eds.) *Envisioning critical race praxis in higher education through counter-storytelling*. Information Age Publishing USA. ISBN: 978-1-68123-405-2 2016
- Dannefer, D. (2003) Cumulative advantage/disadvantage and the life course: cross-fertilizing age and social science. *Theory Journal of Gerontology*, 58B(6), S327–S337.
- Datta, R. (2018) Decolonizing both researcher and research and its effectiveness in Indigenous research. *Research Ethics*, 14(2), 1-24. <https://doi.org/10.1177/1747016117733296>
- de Jong, S., Icaza, R., & Rutazibwa, O.U. (2019) *Decolonization and feminisms in global teaching and learning*. Routledge. Abingdon, Oxon/New York, NY. ISBN:9780815355946
- DiAngelo, R. (2018) *White fragility: why it's so hard for white people to talk about racism*. Beacon Press, USA.
- Dutta, M.J. (2018) Autoethnography as decolonization, decolonizing auto-ethnography: resisting to build our homes. *Cultural Studies vs. Critical Methodologies*, 18(1), 94-96.
- Elias, S. & Feagin, J.R. (2016) *Racial theories in social science: a systematic racism critique*. New York/London: Routledge.
- Emirbayer, M. & Desmond, M. (2012). Race and reflexivity. *Ethnic and racial studies*, 35(4), 574-599.
- Erel, U., Reynolds, T., & Kaptani, E. (2017). Participatory theatre for transformative social research. *Qualitative Research*, 17(3), 302–312. <https://doi.org/10.1177/1468794117696029>
- Fadil, N. (2019) It's not possible for me to be objective: on decolonisation in social sciences <http://www.dewereldmorgen.be/artikel/2019/04/10/over-de-dekolonisatie-van-de-sociale-wetenschappen-%c2%93it-is-not-possible-for-me-to-be-objective%c2%94/> Accessed 20 May 2019.

- Ferraro, K.F. & Pylypiv Shippee T. (2009). Aging and cumulative inequality: how does inequality get under the skin? *The Gerontologist*, 49 (3), 333–343, <https://doi.org/10.1093/geront/gnp034>
- Ferrer, I., Grenier, A., Brotman, S., & Koehn, S. (2017). Understanding the experiences of racialized older people through an intersectional life course perspective. *Journal of Aging Studies*, 41, 10–17. <https://doi.org/10.1016/j.jaging.2017.02.001>
- Fox M. (2015). Embodied methodologies, participation and the art of research. *Social and Personality Psychology Compass* 9, 321–332.
- Gove D., Georges J., Rauf M.A., van den Broeke J., Jongasma K., Claeys A., Berdai-Chaouni S., Hellstöm I., Tromp K., Porter C., & Watchman K. (2019). *Overcoming ethical challenges affecting the involvement of people with dementia in research: recognising diversity and promoting inclusive research*. Alzheimer Europe.
- Grosfoguel, R. & Cervantes-Rodriguez, A.M. (2002); Introduction: unthinking twentieth century Eurocentric mythologies: universal knowledge, decolonization and developmentalism, In Cervantes-Rodriguez, A.M. et al. (Eds.) *The modern/colonial/capitalist world-system in the twentieth century: global processes, antisystemic movements, and the geopolitics of knowledge?* Westport, CT: Praeger Publishers (pp. xi-xxix). ISBN:0027597197X
- Grosfoguel, R. (2004). Race and ethnicity or racialized ethnicities: identities within global coloniality. *Ethnicities*, 4(3), 315-336.
- Grosfoguel, R. (2011). Decolonizing Post-Colonial Studies and Paradigms of Political-Economy: Transmodernity, Decolonial Thinking and Global Coloniality. *Transmodernity: Journal of Peripheral Cultural Production of the Luso-Hispanic World*, 1(1), 1–38.
- Grosfoguel, R. (2013). The Structure of Knowledge in Westernized Universities: Epistemic Racism/Sexism and the Four Genocides/Epistemicides of the Long 16th Century. *Human Architecture: Journal of the Sociology of Self-Knowledge*, XI (1), 73–90.
- Grosfoguel R., Oso L., & Christou A. (2014). Racism, intersectionality and migration studies: framing some theoretical reflections identities: *Global Studies in Culture and Power*: <http://dx.doi.org/10.1080/1070289X.2014.950974>
- Hulko W. (2009). From ‘not a big deal’ to ‘hellish’: experiences of older people with dementia. *Journal of Aging Studies*, 23(3), 131-144. <https://doi.org/10.1016/j.jaging.2007.11.002>
- Ivey S.L., Ladtko S.B., Price A.P., Tseng W., Beard R.L., Liu R., Fetterman D., Wu B, & Logsdon R.G. (2012). Experiences and concerns of family caregivers providing support to people with dementia: a cross-cultural perspective. *Dementia*, 12(6), 806-820.
- Johl, N., Patterson, T., & Pearson, L. (2016). What do we know about the attitudes, experiences and needs of Black and minority ethnic carers of people with dementia in the United Kingdom? A systematic review of empirical research findings. *Dementia*, 15(4), 721–742. <https://doi.org/10.1177/1471301214534424>
- Jutlla K. (2013). Ethnicity and cultural diversity in dementia care: a review of the research. *Journal of Dementia Care*, 21(2), 33-39.
- Kessi, S., & Boonzaier, F. (2018). Centre/ing decolonial feminist psychology in Africa. *South African Journal of Psychology*, 48(3), 299–309. <https://doi.org/10.1177/0081246318784507>
- Kunow, R. (2016). Postcolonial theory and old age: an explorative essay. *Journal of Aging Studies*, 39, 101-106.

- Küpper, T. (2016). Age mimicry. A perspective on the young-old. *Journal of Aging Studies*, 39, 121–128. <https://doi.org/10.1016/j.jaging.2016.06.006>
- Maldonado-Torres, N. (2011). Thinking through the decolonial turn: post-continental interventions in theory, philosophy and critique, an introduction. *Transmodernity: Journal of Peripheral Cultural Production of the Luso-Hispanic World*, 1(2), 1–15.
- McDonald, L. (2011) Theorising about aging, family and immigration. *Ageing & Society*, 31(7), 1180-1201. <https://doi.org/10.1017/So144686X11000511>
- McDowall, A. & Ramos, R. (2017). Doing decoloniality in the writing borderlands of the PhD. *The Australian Journal of Indigenous Education*. <https://doi.org/10.101017/jie.2017.13>
- Merriweather-Hunn L., Guy T., & Manglitz E. (2006). Who can speak from whom? Using counter-storytelling to challenge racial hegemony. *Proceedings of the 47th Adult Education Research Conference* (pp: 244-250).
- Mignolo, W. (2009). *Epistemic disobedience, independent thought and decolonial freedom*. *Theory, Culture & Society*, 26(7–8), 159–181. <https://doi.org/10.1177/0263276409349275>
- Mignolo, W. (2011). Decolonizing western epistemology: Building decolonial epistemologies. In A.M. Isasi-Diaz (Ed.), *Decolonizing epistemologies: Latina/o theology and philosophy* (pp. 19–43). New York, NY: Fordham University Press.
- O'Connor D., Phinney A., & Hulko W. (2010). Dementia at the Intersections: A unique case study exploring social location. *Journal of Aging Studies*, 24(1) 30-39. <https://doi.org/10.1016/j.jaging.2008.08.001>
- Phillipson, C. (2015) Placing ethnicity at the centre of studies of later life: theoretical perspectives and empirical challenges. *Ageing & Society*, 35, 917-934 DOI: 10.10117/SO144686X14001032
- Quijano, A. (2000). Coloniality of power, Eurocentrism and Latin America. *Nepantla*, 1(3), 533–580.
- Ramos, F. (2018) Opening-up entangled conversations: Engaging with the stories of refugee-background students in Australia. <https://doi.org/10.14264/uql.2018.375>
- Rajan-Rankin, S. (2018). Race, embodiment and later life: Re-animating aging bodies of color. *Journal of Aging Studies*, 45, 32–38. <https://doi.org/10.1016/j.jaging.2018.01.005>
- Rutazibwa, O.U. (2019). On babies and bathwater: decolonizing international development studies. O.U. Rutazibwa. In de Jong S, Icaza R, Rutazibwa O.U. (Eds.) *Decolonization and feminisms in global teaching and learning* (pp. 158-180).Routledge. Abingdon, Oxon/New York, NY. ISBN:9780815355946;
- Santos, B. d. S. (2014). *Epistemologies of the South: justice against epistemicide*. New York: Routledge.
- Shanley, C., Boughtwood, D., Adams, J., Santalucia, Y., Kyriazopoulos, H., Pond, D., & Rowland, J. (2012). A qualitative study into the use of formal services for dementia by carers from culturally and linguistically diverse (CALD) communities. *BMC Health Services Research*, 12, 354. <https://doi.org/10.1186/1472-6963-12-354>
- Smith, L. T. (2012) *Decolonizing methodologies research and indigenous people*. Second edition. Zed books Ltd. London and New York.
- Tucker, K. (2018). Unravelling coloniality in international relations: Knowledge, relationality, and strategies for engagement. *International Political Sociology*, 12(3), 215–232. <https://doi.org/10.1093/ips/oly005>

- Torres, S. (2015). Expanding the gerontological imagination on ethnicity: conceptual and theoretical perspectives. *Ageing & Society*, 35(7), 935-960. <https://doi.org/10.1017/So144686X14001030>
- Torres, S. & Karl, U. (2016). A migration lens on inquiries into aging, old age and elderly care: carving space while assessing the state of affairs. In Karl U. & Torres S. (Eds.) *Ageing in contexts of migration (pp 1-12)*. Routledge, New York, USA.
- Torres, S. (2018). Cultural Values and the Nature of Successful Aging. In *Oxford Research Encyclopedia of Psychology*. <https://doi.org/10.1093/acrefore/9780190236557.013.343>
- Torres, S. (2019). Ethnicity and old age: Expanding our imagination (Ageing in a Global Context). Policy Press, 2020. ISBN 1447328124,9781447328124
- van Dyk, S. (2016). The othering of old age: Insights from postcolonial studies. *Journal of Aging Studies*, 39, 109–120.
- van Dyk, S. & Küpper, T. (2016). Postcolonial perspectives in Aging Studies: Introduction. *Journal of Aging Studies*, 39, 81-82.
- Weiner, M. F. & Carmona Báez, A. (2018). *Smash the Pillars*. Lexington Books, London.
- Wekker, G. (2016). *White innocence, paradoxes of colonialism and race (pp 19-20)* Duke University Press, United States of America. ISBN 9780822360599
- Whitaeckx, S. & Essed, P. (2017). Two steps forwards, one step back: a conversation with Philomena Essed on difference and decolonisation of academy and beyond. *Tijdschrift voor Genderstudies*, 20(3), 275-285.
- Whitaeckx, S. (2019) Weakening the institutional wall: reflections on race, gender, decolonisation in Belgian academy. *Journal of Diversity and Gender Studies*, 6(1), 25-44. <https://doi.org/10.11116.612>
- Zavala, M. (2013). What do we mean by decolonizing research strategies? Lessons from decolonizing Indigenous research projects in New Zealand and Latin America. *Decolonization: Indigeneity, Education, and Society*, 2(1), 55–71.
- Zeilig, H., West, J., & van der Byl Williams, M. (2018). Co-creativity: possibilities for using the arts with people with a dementia. *Quality in Ageing and Older Adults*, 19(2), 135–145. <https://doi.org/10.1108/QAOA-02-2018-0008>
- Zubair, M. & Norris, M. (2015). Perspectives on ageing, later life and ethnicity: ageing research in ethnic minority contexts. *Ageing & Society*, 35, 897-916.
- Zubair, M. & Victor, C. (2015) Exploring gender, age, time and space in research with older Pakistani Muslims in the United Kingdom: formalised research ‘ethics’ and performances of the public/private divide in ‘the field’. *Ageing & Society*, 35 (5), 961-985. 10.1017/So144686X14001030

Chapter 7: General Discussion

Abstract

This closing chapter provides a General Discussion on the main findings of this dissertation. Drawing back on the results of five conducted studies (see Dissertation Outline pg. X), we answer the four formulated questions of this doctoral thesis described in the Introduction. We learned that the experience of dementia and dementia care among migrants families has some points that are shared with the majority population with dementia. And yet having a migration background adds nuances and extra challenges to the experience of dementia and dementia care provision. We also learned that dementia care provision is determined by the unique societal position of migrant families and by overlooked structural mechanisms leading to inaccessible and poor-quality dementia care for older migrants. Still, other solutions to the unmet needs are found in the transnational capital of family caregivers. Lastly, we discuss the potential of decolonial frameworks for gerontological research concerning topics related to older migrants. Against this backdrop, a conceptual lens to examine dementia care provision for a diverse population is presented and linked to possible implications for policy and practice. This is followed by a discussion on the limitations of this dissertation, with suggestions for further research. The chapter closes with a general Conclusion.

1. Introduction

Belgium has a growing ethnic diversity among its older population, with Moroccan migrants as the largest group of non-European migrants. Although exact numbers on dementia prevalence among ethnic minority populations in Belgium are missing, there is a hypothesis that dementia is higher among this subpopulation. Older migrants with dementia seem to follow a specific dementia care trajectory with diagnostic challenges, preference for family care and under-use of professional care. Gerontological research on this topic seems to be biased, however, resulting in the reproduction of narrow assumptions about this population and of societal inequality within and throughout research itself.

The Introduction identified three research gaps: limited knowledge about dementia and older migrants in Belgium, culture as a dominant one-sided perspective on the situation of older migrants with dementia, and limited knowledge on how to conduct ethical research on dementia among older migrants. The dissertation aimed to address these research gaps and explore: 1) a multilayered image of the dementia experience and dementia care provision among labor migrant families, and 2) methodological pathways to contribute to more ethical research involving this population. The goal was to move beyond the essentialist and culturalist gaze on this topic and therefore avoid a single story. Understanding this complexity can advance the provision of better dementia care for older migrants with dementia.

The two research aims were translated into four research questions:

1. How are dementia and dementia care provision experienced by Moroccan families in Belgium?
2. How is dementia care currently provided to older Moroccan migrants?
3. Which factors influence the dementia care provision?
4. How can we improve gerontological research on older migrants and their family caregivers?

2. Discussion of the main findings in relation to the research questions

This section provides an answer to the four general research questions formulated in the introductory chapter. While the specific results are discussed in each of the separate chapters, this section offers a general overview of the main results, bringing together insights from the five conducted studies.

Research question 1: How are dementia and dementia care provision experienced by Moroccan families in Belgium?

Although every experience of dementia and dementia care is unique and depends on a complexity of personal and contextual factors (Parland, Kelly & Innes, 2017), this dissertation provides insights into three common threads, three patterns of experiences as put forward in the testimonies of the respondents: 1) dementia as an elusive, difficult-to-grasp condition, 2) family caregivers' experience of

dementia care provision as a dynamic and challenging process underlying a multilayered care burden, and 3) professional caregivers' experience of dementia care provision as demanding, underscoring various challenges influenced by their own ethnic background.

1) Dementia: an elusive condition

In general, dementia is experienced by family caregivers and Moroccan migrants with dementia as a difficult-to-grasp and challenging condition due to its changing manifestations and the diversity of symptoms over the course of the disease trajectory (studies 1, 2 & 3). Although this reflects a general feeling of uncertainty and a shared sentiment of the majority of individuals facing dementia (Van Wijngaarden et al., 2018), regardless of migration background, our studies also show that the course of the dementia trajectory contains some elements specific to older migrants and their families: dementia being invisible (study 1) and dementia having a specific meaning (studies 1 & 2).

Invisibility of dementia

There is an accumulation of factors rendering dementia a present yet invisible condition that is not recognized, fails to be diagnosed in time, if at all, and has various co-existing labels or no label at all (study 1). The invisibility of dementia can be explained by the specific position of these families in our society due to the interplay of their migration history and their cultural and religious background (studies 1 & 3). Being a first-generation migrant family means being a pioneer (Segers et al. 2013) in dealing with ageing-related conditions and issues, and explains these families' unfamiliarity with dementia. The condition of dementia was not common in Morocco because of its young population, therefore it was rarely encountered via transnational family ties. Dementia is currently an emerging ageing-related condition in Morocco, reflecting the recent ageing of its population, and will rapidly increase in the upcoming years (Bhalla et al., 2018; Prince et al., 2013). Symptoms are often misinterpreted as "a result of different cultural backgrounds" of non-European migrants (Sagbakken et al., 2018). In addition, the absence of adequate assessment tools alongside the existence of a language and communication barrier (study 1) disallow a diagnosis of dementia among older migrants (insensitivity of diagnostic tests to people's literacy, educational system of the country of origin, cultural background) and lead to delayed diagnoses or misdiagnoses (Nielsen et al., 2011a,b; Segers et al., 2013; Goudsmit et al., 2017). All these factors contribute to the lack of recognition and consideration of dementia – either by the persons themselves, their surroundings or professional caregivers – as an option when symptoms manifest.

Various labels, various meanings

Having a diagnosis does not mean that dementia has become visible. Even in cases of an established diagnosis, communication aspects contribute to the difficulty of grasping dementia as a condition. Our results show that the diagnosis is not always communicated to the person with dementia by professional or family caregivers, nor is it communicated with a label that is culturally recognizable, reassuring or acceptable for the person with dementia (study 1). While professional caregivers mainly use biomedical diagnostic terms to communicate the diagnosis, family caregivers use a culture- and religion-specific combination of social and biomedical labels to communicate about the condition (studies 1, 3) amongst themselves and to the person with dementia. These coexisting labels enhance the fluidity of dementia as an elusive condition. Dementia has been labelled differently over time and geographic location, reflecting the feeling and meaning given to the condition and to persons who

have it (Thomas & Milligan, 2017). This is illustrated in the findings of study 3, where having a religious background co-defines the meaning of dementia going from divine gift to divine punishment. This aligns with Hulko's (2009) findings, claiming that intersectional social location of a person with dementia defines the fluid meaning dementia gets and questioning the universality of the negative views associated with dementia. Our studies add religious background to the intersections of race, ethnicity, class and gender as determinants of this intersectional social location in Hulko's research (2009).

It is generally argued that there is still stigma associated with dementia as a condition (Swaffer, 2014; World Alzheimer Report, 2019). However, studies focusing on ethnic minorities seem to emphasize the link between the stigmatization of dementia and the different cultural backgrounds (Mukadam, Cooper & Livingston, 2013; Sayegh & Knight, 2013; Gove et al.; 2018). This dissertation rejects that stereotypical perspective and portrays a more nuanced image (study 1). Not talking about dementia in a dominant biomedical label does not mean that it is silenced, nor is it proof of a higher stigma. Furthermore, the presumed neutrality linked to the biomedical term(s) of dementia is questioned, as this represents the "tragedy discourse" of dementia, emphasizing loss of function, loss of cognition, decline and death, and is therefore argued to be avoided (Parland, Kelly & Innes, 2017). Using the different labels of dementia simultaneously (studies 1 & 3) can in some cases reflect a stigma. However, it can also reflect a way to process a fluid and complex condition using tools found within the personal social archive (as personal and collective experiences, knowledge, practices and tools), to give dementia a place in life, visible or invisible. Some scholars (Grenier et al., 2017; Parland, Kelly & Innes., 2017) argue that this use of multiple labels better reflects the complexity, fluidity and multiple realities – both positive and negative – of dementia, and therefore actually contributes to acceptance of the paradoxical nature of this condition and to the social inclusion of persons with dementia.

2) Experience of dementia care provision by family caregivers

Studies 1, 2 and 3 show that family caregivers experience dementia care provision as a dynamic and challenging process with various obstacles to overcome and where family caregivers have to rely on their agency and possibilities to face this process. There is susceptibility to a multilayered care burden, despite the resilience of family caregivers.

Dementia care provision as dynamic and challenging

The search process was dynamic because of the need to continuously adjust to the changing symptoms and the growing and differing care needs of persons with dementia (Zwaanswijk et al., 2013). Family caregivers experienced dementia care provision as challenging, with accumulations of challenges related to 1) dementia's dynamic manifestation, 2) their own dementia care provision practice, and 3) professional care help-seeking obstacles (studies 1, 2 & 3).

First, it was hard for family caregivers to see that their loved one with dementia is changing as a person. This contributed to emotional and psychological distress, triggering feelings of losing the person with dementia while they are still alive. This aligns with previous findings about multiple losses in caregiving experienced by family caregivers, including the increasing disconnectedness of the person with dementia while anticipating their physical death, resulting in feelings of loss and pre-death grief (Liew et al., 2019).

Second, related to their own dementia care practice, family caregivers found it challenging having to maneuver between different levels:

- the personal level (assessing one's own competences and possibilities to provide care, feelings of responsibility to guarantee best possible care),
- the interpersonal level, with the person with dementia and with other family caregivers (finding a balance between siblings, family quarrels);
- the meso level: the community (fear of condemnation for choices made), other actors in their life like their employer, and professional care services (e.g. filling the gap of lack of sensitivity toward the specific needs of the person with dementia);
- the macro level: mechanisms related to social location as migrant (experiencing racism, dealing with disadvantaged financial position) (studies 1, 2 & 3).

These findings confirm that family care extends beyond practical hands-on care or merely physical support. And yet family caregivers have to deal with the complexity of dementia care provision using different competences for anticipating, monitoring, supporting and supervising care needs (Farina et al., 2017).

Lastly, family caregivers also experienced the limitations of family care, which moved them to search for solutions in professional care that required them to navigate a complex and fragmented professional care system (Stephan et al., 2015). Professional care is experienced as inaccessible (Lopez-Hartmann, 2020) and insensitive (Ahaddour, van den Branden & Broeckaert, 2016), and a paradoxical partner in dementia care provision (studies 1, 2 & 3). On the one hand, family caregivers experienced professional care as a needed partner in dementia care provision because of its technical expertise and as a care relief source. And yet they questioned the limited room for human, relational person-centered aspects and the burden relief impact of professional care (study 2). This is challenging and can cause emotional and psychological distress (Gilhooly, Gilhooly & Sullivan, 2016). Moreover, our findings add the cumulative, adverse impact of structural mechanisms like facing discrimination and racism to the equation, which have also been proven to adversely impact psychological and physical health (Chillunga et al., 2019; Pascoe & Smart Richman, 2009).

Susceptibility to a multilayered care burden

All of the above indicates that facing these discussed challenges with limited support from one's own community and professional care leads to a multilayered care burden as well as to the activation of personal agency that relies on individual coping styles and the transnational possibilities offered by a migration background (studies 1, 2 & 3). Multilayered care burden refers to family caregivers' experience of stress, tension and anxiety resulting from the increasing actual caregiving provision and its subjective impact on the caregiver (Cao & Yang, 2020; Van der Lee et al., 2014). Our studies add the impact of the racism experienced in professional care on established caregivers' dissatisfaction with the collaboration with care professionals as contributing factor to the care burden and to dropping out from service duties (Wittenberg et al., 2017). Study 3 also elaborated on religion as a dual mediator of the dementia/dementia care experience, as a possible source of both relief and care burden. The beneficial and adverse effects of religion on the dementia care experience were confirmed (Fider et al. 2019; Monteiro et al. 2018; Rathier et al. 2015). Religious coping has been predominantly associated as a way to mediate care burden and improve caregivers' resilience (Mahdavi et al. 2017; Wilks et al.

2018). Religious coping could help accept dementia, find strength to deal with dementia care burdens, and experience feelings of pride, fulfillment and reward. However, it could also enhance the dementia care burden when family caregivers feel they are failing to measure up to the high religious standards of caregiving or when they prioritize the rewards of the afterlife above self-care.

3) Professional caregivers' experience of dementia care provision

Provision of dementia care to older migrants is also experienced as demanding by professional caregivers (studies 1 & 2), who share a number of challenges, some of which are dependent on their ethnic background. Formulating diagnoses (study 1), collaboration with family members and lack of structural support measures to deal with the ethnic diversity of care recipients (study 2) were challenges shared by professional caregivers regardless of ethnic background. Our results confirm the challenges related to diagnosing dementia in migrant populations discussed in the introductory chapter (pp. 18-19), stressing the insensitivity of diagnostic tests to the literacy, testing savvy and cultural background of this population in addition to communication barriers (Goudsmit et al., 2017; Nielsen et al., 2011a,b; Segers et al., 2013). The results also confirm that caution is advised when relying on diagnostic tests and our respondents' voiced need for tailored diagnostic tools (Nielsen et al., 2018). Some professional caregivers found it difficult to engage with the various family members involved in caring for an older Moroccan relative with dementia and preferred instead to deal with one contact person from the family (study 2). Conversely, professional caregivers who anticipated this reality of care networks could turn the collaboration into something positive. Professional caregivers with a Belgian background added dealing with 'nonstandard' care requests and accusations of racism (study 2) to the list of challenges. These findings align with the need of professional care to find ways to deal with the complex and dynamic nature of informal care networks (Broese van Groenou & De Boer, 2016) or convoys (Lambotte et al., 2019) surrounding older persons with dementia.

In summary, dementia is experienced by Moroccan families as a fluid and elusive, difficult-to-grasp condition, which is a common image of dementia regardless of ethnic background. However, the unique societal position of having a migration background adds other aspects (unfamiliarity with dementia, labels of dementia) to the fluidity of dementia. Both family and professional caregivers agree that providing care to older migrants with dementia is challenging, but for different underlying reasons. The challenges experienced by family caregivers reflect the complexity and accumulation of faced challenges related to the nature of dementia, to the changing and increasing care needs, and to their societal position as family caregivers with a migration background. The latter alludes to skills required to align personal, interpersonal and community expectations in an unfamiliar professional care context. Additionally, professional care does not always provide the needed support and sometimes even adds to the care burden due to encountered racism. The challenges faced by professional caregivers (inadequate instruments, lack of structural support, nonstandard care requests and anxiety from being called racist) reflect structural issues when attempting to provide adequate dementia care to a diverse population.

Research question 2: How is dementia care currently provided to older Moroccan migrants?

Our studies show that dementia care is mainly provided by family caregivers, with limited use of professional services. Alternative transnational external care options are considered as a solution for the inadequacy of professional care to meet all the needs of older migrants with dementia (studies 1, 2 & 3). Care provision for older labor migrants with dementia is a dynamic, continuous, transnational search process across the three stages of dementia (study 2). In each stage, various constellations of informal and external help are engaged. Our results support the notion of complex care networks or care convoys, composed of informal and formal caregivers that change over time to support frail older persons, adding alternative and transnational care solutions to this concept. Our results also emphasize the importance of relational and social aspects of care within care convoys as definers of the extent of quality of the provided care. Equally crucial is considering the multidimensional identity of older migrants with dementia in care provision, which seems to be lacking.

1) Leading position of family care

Family care leads the care provision to older migrants with dementia. Our findings show that family care 1) results from a dynamic and continuous search and decision-making process by a complex set of motivators reflecting the unique pioneer position of family caregivers of migrant descent, 2) is provided by a dynamic transnational composition of female and male family caregivers' network that changes over time, and 3) is person-centered and culture-/migration-/religion-sensitive with possible risks of negative outcomes.

Family care: dynamic and continuous search and decision-making process

At first glance family care seems like the natural thing to do, a continuation of a mutual care relationship before the development of dementia, confirming Tronto's statements that care relationships often have a murky beginning (Tronto, 2014 a). However, behind this "evident" finding, providing family care to a migrant with dementia is a dynamic and continuous search and decision-making process. This process is influenced by a complex set of motivators that reflect the unique social position of family caregivers of migrant descent – therefore family care provision varies depending on personal motivations, possibilities, and the presence and availability of external support (studies 1 & 2).

The initial religion- and culture-inspired values to provide family care commingle with more emotional and practical reasons as equal motivators to provide family care (study 1). This motivation is also reinforced by the barriers to find adequate professional care such as lack of person-centered care; absence of sensitivity to cultural, religious and migration background; and fear of gossip and disapproval by the Moroccan community (studies 1, 2 & 3). An additional motivation is fueled by the migration history of the person with dementia. Against this background, family care is perceived as the only care path that can guarantee the best care for a migrant with dementia and a concession to balance the sacrifices made by this first generation to give their offspring a better future (studies 1, 2 & 3). All these different motivators have an impact on how family care is shaped.

Family care: a dynamic, transnational composition of a family caregivers' network changing over time

The family care network is dynamic and changes composition over time, depending on the care needs of the person with dementia and the continuous assessment of the possibility to provide family care (studies 1 & 2). Study 2 shows, for example, that family caregivers were involved in a continuous search and adaptation process to divide and balance informal care responsibilities across the three stages of dementia – early, middle and late (Reisberg et al., 1982) – with increasing care needs and the correlated need of support as each stage reflects different care and relational challenges. A more complex and dynamic picture is that of rotational family care (Nielsen & Waldemar, 2020), only one of the found formulas to temporarily provide dementia care among migrant families. Families with multiple siblings strive for equivalent care task divisions, which is not always achieved (study 2). The long duration of the dementia care trajectory with its increasing needs seems to defy the fragile balances of care responsibilities found between family members (study 2). This aligns with studies arguing that providing sustainable family care for persons with dementia is challenging due to the higher care burden, lower quality of life and excessive hours spent on care compared to other conditions (Bleijlevens et al., 2015; Cès et al., 2016; Farina et al., 2017).

Family care: by local and transnational family

Family care is not only provided by local relatives, it also includes transnational family care with involved relatives living in other European countries or in Morocco (study 2). This expands transnational agency, leading to transnational care arrangements like care circulation (circulation of family between different countries to provide care) and distance care (Ciobanu, Fokkema, Nedelcu, 2017) in the context of family care provision to first-generation migrants with dementia. Hence the migration-related specific social position of these family caregivers influences the care potential of their social network, shaping the actual informal care provision (Broese van Groenou & De Boer, 2016). The locality of the social network is thus extended with transnational options searched and found in Morocco and with relatives outside Belgium. Family caregivers will also rely on the Moroccan community to facilitate finding external care options as alternatives to professional care (study 2).

Family care: not only women, also men

Family care is provided by a dynamic (transnational) network, which is often female-driven but not solely composed of women. This network embodies different informal care roles of family caregivers like coordinator, main caregivers, assistant and/or legally responsible (study 1). The female face of family care in non-EU migrant families as perceived by professional caregivers (study 1) and confirmed by literature (van Wezel et al., 2016; Ahmad et al., 2020) is nuanced by our respondents (studies 1 & 2). Although family care is predominantly female-driven, men are also involved, in some cases even as main caregivers (study 1), yet they remain invisible to the outside world (study 1). This concurs with the invisibility of subnetworks of caregivers and their important contribution to informal care (Jacobs et al., 2015), and with the general invisibility of male informal caregivers in research (Milligan & Morbey, 2016). This finding should be acknowledged as a valuable part of informal care and receive more attention in future research.

The female face is not a unique trait of informal care among migrant families, but a global phenomenon (Azzurra, Bhattacharya & Frazer, 2019; Erol, Peel & Ratcliff Brooker, 2015; Tronto, 2014 a). In Belgium too, informal care is predominantly given by women (Cès et al., 2016): 54% of live-in informal

caregivers and 71% of non-live-in informal caregivers are women. Keady and Elvish (2019) speak of family care for persons with dementia as a gendered experience. This broader perspective is missing in the image held by professional caregivers among our respondents and also in certain literature, which risks placing this phenomenon within a rather culturalist frame when it comes to families with a migration background. Ahmad et al. (2020) even warns of gender norms within Turkish, Moroccan and Surinamese culture as unique sources of pressure to provide family care in families with this migration background in the Netherlands. Attention to the overrepresentation of women as informal caregivers is needed, and the influence of culture- or religion-inspired values to take on this caring role is also important. And yet the discussion about this topic should be seen from a broader perspective and consider the complexity of factors leading to this global overrepresentation (Azzurra, Bhattacharya & Frazer, 2019; Tronto, 2014a), countering the culture of non-EU migrants as only explanatory factor for family care (Tronto, 2014a).

Family care = person-centered and culture-/migration-/religion-sensitive with possible risks

Family care is provided with sensitivity to the older adult with dementia as a complex person. The care needs are met with recognition and validation of care wishes associated with the unique composition of the cultural and religious background and migration history of the person with dementia (study 1). Study 3 showcases, for example, how family caregivers try to be sensitive to the religious background of the person with dementia even when they are not religious themselves. Achieving this sensitivity in a context that is not sensitive to this multi-layered identity of the person with dementia is demanding for family caregivers. It requires devotion and creativity within family care provision, which was shown by our respondents. This supports the call of Keady and Elvish (2019) to value the invisible creativity of family caregivers in handling the daily challenges associated with dementia care and to acknowledge this expertise as professional caregiving. However, the demanding character of family care also risks self-neglect and the development of long-term physical afflictions and mental health issues.

2) Limited use of professional care services

Dementia care is provided with limited use of regular professional care services. Underlying factors to this limited use are the complementary status of professional care to family care, migrant families' extent of familiarity with aged care, and the perception that professional care is inadequate in meeting the needs of older migrants with dementia.

Professional care is complementary to family care

Good working family care solutions underlie the limited use of professional care. Professional dementia care services are a presumed substitute for or complement to informal care (Bremer et al., 2017). In case of our respondents, the main role attributed to professional care services is that of complementing family care. Engaging predominantly high-skilled healthcare professionals during all stages of dementia aligns with findings of Bremers et al. (2017) that restorative care with highly skilled professionals, like general practitioners, complement informal dementia care, while low-skilled professionals targeting maintenance of the care receiver's quality of life, like those providing home care, engage in a substitutional relationship with informal care. However, formal services fail to some extent to complement family care due to the lack of sensitivity to migration, religious and cultural background. This narrows care options with family care as the only option in some cases (Broese van Groenou & De Boer, 2016). On the other hand, superiorization of family care as perceived norm within

migrant communities informed by certain religious and cultural values (studies 2 & 3; Ahmad et al., 2020) also excludes to some extent the complementary role of professional care as an option.

Familiarity/unfamiliarity with professional care

Our studies show that family care was part of a dynamic, broader transnational care network with limited use of professional care and alternative external care resources. Professional care options were considered at all stages of dementia (study 2). Some forms of professional care were used more than others, reflecting the familiarity with these care options. Familiarity can be interpreted as knowing and/or having experience with the care option but also as emotional familiarity. The latter reflects the acceptance of some professional care options depending on their accordance with personal, cultural and religious values (studies 1, 2 & 3). This was reflected in the used and unused care options. Professional medical care (GP, hospital visits, home nursing, physiotherapist) was used in all stages of dementia (study 2), with limited use of supportive home care (cooking, cleaning) (study 3). As the care needs and care burden increased, nursing homes were also considered yet weren't always used, for various reasons such as lack of sensitivity to the older person's migration, cultural and religious background, negative experience with (residential) care (personally or through acquaintances), the high costs of a nursing home, inconsistency with one's definition of good care and/or fear of condemnation by the community (studies 1 & 3). These results confirm the underuse of aged care by older migrants due to its unfamiliarity (Ahaddour, van den Branden and Broeckaert, 2016). On the other hand, our results add that dementia-associated care needs and the longitude of family care push family caregivers to overcome this unfamiliarity and to consider care options, even those that are distant from the ideal.

Inadequacy of professional care

The inadequacy of professional care in meeting the needs of older migrants with dementia and their caregivers is put forward by our studies as underlying reason for the limited use of professional dementia care. Professional care is perceived as inadequate by its inaccessibility, lack of person-centered care with insensitivity to the specific background of older migrants with dementia, and its exclusionary mechanisms, resulting in experiences of discrimination and racism for these families (studies 1, 2 & 3).

Professional caregivers were oblivious to experiences of discrimination and racism as contributors to inaccessibility of care (study 2). This fits with previous studies highlighting the negative impact of racism on access to health care (Hamed et al., 2020). Although gerontological research is very limited on this matter, more evidence points to a similar impact of racism on aged care (Torres, 2020). Racism is institutionalized and invisible through repetition and routinization which lead to unequal access and subtle racism that damages care users through silencing of suffering or erosion of dignity, resulting in loss of trust in health care (Hamed et al., 2020).

3) Alternative external care sources

In addition to family care and professional care services, older migrants with dementia and their families also appeal to alternative transnational external care sources to provide dementia care. Study 2 portrays how family caregivers face the need for sensitivity for the multi-layered identity of the person with dementia, financial prudence and increasing care burden by considering alternative

external care options. These are found outside traditional Belgian professional care services and can include undocumented domestic helpers, temporary relocation to Morocco and care marriages. These alternative external care sources reflect 1) the transnational care agency of family caregivers to seek solutions for their unmet needs and 2) current needs of aged care, while 3) remaining under the radar of mainstream professional care, with limited awareness of its existence by professional caregivers with a migration background.

Alternative external care sources: a reflection of transnational care agency

On an individual and family level these solutions provide relief to the care burden. They also identify the agency of family caregivers to use all options they have, which are also found transnationally thanks to their migration background. In these cases the care provided by transnational relatives can be seen as social capital and as part of care circulations within transnational families (Merla & Baldassar, 2016). Care circulations refer to forms of care that are provided over time and distance, which continue to exist with adapted care practices when a person in the family becomes dependent. The increasing mobility and technological possibilities (Merla & Baldassar, 2016) strengthen the integration of relatives in Morocco in the remote care of persons with dementia. This makes it possible to follow up the care in Morocco while the main family caregiver is in Belgium (studies 1 & 2). Our studies confirm and broaden this concept of care circulation. With care marriages the families extend their social capital to the community surrounding their family in Morocco.

Alternative external care sources: a reflection of current gaps in aged care

From a broader perspective, engaging mainly socially vulnerable women from the global south, through care marriages or as undocumented helpers (studies 1 & 2), as a solution to the professional care gaps in the West is a variant of a global phenomenon called “global care chains” (Azzurra, Bhattacharya & Frazer, 2019; Merla & Baldassar, 2016). This care practice of including migrant women from Eastern Europe and Africa to provide domestic care for older persons is increasingly used in Western Europe (Life & Author, 2019; Schwiter et al., 2015). Also in Belgium, autochthonous Belgians rely on live-in migrant care workers to guarantee the availability of permanent care 24/7 (Hoens, Smetcoren & De Donder, 2019). This option, still rather invisible in Belgium, fills some of the care gaps in current Belgian aged care such as limited person-centered care and continuity of care providers. The practice is seen as a consequence of austerity measurements and neo-liberalization of care that results in it being provided by private intermediaries, which raises concerns about these women’s employment conditions (Hoens, Smetcoren & De Donder, 2019; Life & Author, 2019; Schwiter et al., 2015).

Alternative external care sources: under the radar of professional caregivers

Mainly professional caregivers with a migration background among our respondents seem to be aware of these alternative external care sources (studies 1 & 2). Some of them also try to actively engage in such transnational care networks by having direct contact with professional and informal caregivers in Morocco, and follow up on the contribution of the undocumented helpers and care marriages. A possible explanation for this finding is that caregivers with a migration background are attentive to these practices (Carlsson et al., 2020). Another reason is that they are trusted (Kirmayer & Jarvis, 2019) with this information by the families, who assume that these caregivers will understand and not condemn them for their choices. This hypothesis is still to be researched though, as ethnic concordance

does not always mean enhanced trust and open communication between healthcare providers and care receivers (Mujica & Cruz-Gonzalez, 2020).

In summary, current dementia care provision among Moroccan migrant families goes beyond the binary division of family vs. professional care. Rather, dementia care is provided by a complex and dynamic network that includes alternative care forms and caregivers within a transnational context. This picture of care provision is sought by family caregivers as an answer to unmet needs that can fall under “complexity-sensitive person-centered responsive care”, which considers the multilayered identity of the older migrant with dementia. The picture also reflects professional care gaps to provide suitable, sustainable, affordable and inclusive dementia care.

Research question 3: Which factors influence the dementia care provision? (RQ 3)

In order to answer this research question, this section first highlights the interplay of migration, culture and religion as influencing factors of dementia care provision for older migrants with dementia and how this interplay co-shapes the dementia care provision. Several hidden mechanisms influencing the care provision (neutrality, otherness, racialization) are discussed. This section closes by looking at various macro-level aspects influencing care provision (neoliberalism & globalization, coloniality/decoloniality of care).

1) The interplay of migration, culture and religion

The first three studies show that migration, culture and religion influence care provision dynamically, with unclear and fluid borders between these three influencers, often intertwined with other personal, socioeconomic and contextual aspects. It is therefore difficult to disentangle the three influencers from each other and from other influencers. An attempt has nonetheless been made aimed at better capturing and understanding the complexity of the realities of migrant families dealing with dementia. The interplay of migration, culture and religion influence dementia care provision via the following aspects: 1) migration as a significant life event influencing the meaning of family care and the constellation of dementia care networks; 2) cultural and religious values and practices that are expected in informal and formal dementia care; 3) cultural and religious values that also co-shape the provision of family care, and 4) the interplay of migration, culture and religion as axes of marginalization underlying the inaccessibility and unsuitability of professional dementia care for older migrants with dementia. Each of these four aspects are explained in more detail below.

Migration as significant life event influencing dementia care

Migration can be considered as an important life event in the life history of a person with dementia, and it affects the dementia care for a number of reasons. Migration as a life event determines the social position of older migrants with dementia and their descendants. It also influences the meaning of family care as a migration-inherited responsibility, and defines the constellation of the dementia care networks.

Being part of the labor migration wave in the 1960s has shaped the position of older persons with dementia and their families socioeconomically (e.g. they are often in a vulnerable position). It also underlies their position as unheard voices in research (under-researched, biased research approaches (studies 4 & 5)) and in professional care (formulation of care needs due to language barriers, lack of suitable care (studies 1, 2 & 3)). Additionally, the history of labor migration defined the collective societal position of the migrant community, which explains why issues related to ageing are not prioritized while other challenges related to the disadvantaged position of migrants (education gap, discrimination, racism) are addressed. Migration defined the dyadic and collective pioneer position to face and deal with dementia (unfamiliarity with dementia and with dementia care, the community's dementia-unfriendly attitude).

Migration also co-sets the conditions for family care as continuation of the supporting role most second-generation migrants have toward first-generation older migrants. Moreover, this is the "first" generation of the family that has to provide family care in the Belgian context, shaping its unique pioneering position. This position adds complexity to the process. Informal carers have to juggle between various tensions of their own expectations and hidden and pronounced expectations of the older person with dementia, the rest of the care collective, other relatives, the community, and professional care providers and institutions. Family care in this case is framed as a responsibility to guarantee good care for older migrants with dementia in a professional care context that lacks sensitivity to their needs, which supports Tronto's view on care (2014, a) as reciprocal responsibility. Responsibility in this case is often given an additional interpretation by second-generation family caregivers: responsibility to ensure dignified ageing as an appreciation for the first generation's sacrifices. This nuances the dominant image of family care within migrant families solely as filial piety (Brooke et al., 2017) or a moral duty (Ahmad et al., 2020).

Having a migration background likewise co-defines the constellation of the care networks with transnational external care opportunities (p. 136) and attitudes toward dementia care. The latter often means that family caregivers have embraced the professional care possibilities but with a critical mind. They often keep searching for professional care that is sensitive to the migration history of the person with dementia, while educating and challenging regular professional dementia carers to provide care that is responsive to the multidimensional identity of these older persons with dementia (studies 1, 2 & 3).

Cultural and religious values and practices are expected in informal and formal dementia care

Responsiveness to the multidimensional identity of older migrants with dementia also means that certain cultural and religious values and practices are expected in the provision of dementia care, both informal and formal (studies 1, 2 & 3). Study 3 further shows that religion-inspired values of care (respect, patience, compassion) set a high bar for how family care and care in general should be provided. Family caregivers integrated cultural and religious practices into their care practice. They often continued to do so when using professional care services, in collaboration with or complementary to professional caregivers. Cultural practices integrated and expected in dementia care practice were: continuation of communication in the mother language, provision of recognizable food/dishes prepared following familiar recipes, and integration of recognizable music or entertainment options (e.g. TV channels) as daily activities. Culturally-specific day care centers in the

Netherlands incorporate these aspects in their care provision, thus increasing not only their responsiveness to the needs of migrant families but that of the entire care landscape (Carlsson, Pijpers & Van Melik 2020). Family caregivers incorporated religious practices into their care practice (prayer, holy books recitations, mosque/church visitations, Halal food) and searched for professional care that supported the continuation of these practices, which were often lacking, especially for Muslims (study 3).

Cultural and religious values also co-shape the provision of family care

Our studies also showed that cultural and religious values were additional motivators next to emotional and pragmatic motivators to provide family care (study 3). Family care can become part of a religious devotion with rewards here and in the afterlife, and therefore a source of positive feelings about family care. However, religious arguments (like responsibility of males to financially provide for the household or responsibility of females to take care of husband and children) were used too, often pragmatically and alongside other arguments, to evade the provision of family care (study 2). This nuances the image of family care as a moral duty with little room for negotiation as something that caregivers undergo (Ahmad et al., 2020). Additionally, religious coping has been proven to influence the dementia care provision both positively and negatively: as a source of resilience to sustain the straits associated with dementia and family care provision or as a care burden intensifier (study 3).

Migration, culture and religion as axes of marginalization underlying the inaccessibility and unsuitability of dementia care

Professional care is perceived as inadequate because of its inaccessibility and unsuitability. The inaccessibility of professional care is already present during the diagnostic phase of the dementia care trajectory, as the unsuitable diagnostic tools lead to misdiagnosis and define the rest of the care path. Unsuitability refers to the lack of sensitivity to the multifaceted identity of older migrants with dementia, including their migration, cultural and religious background (studies 1, 2 & 3). The inaccessibility and unsuitability are both linked with the interplay of migration, culture and religion as axes of marginalization, as they are often positioned at the deprived side of the axes as learned from intersectionality (Carbado et al., 2013; Crenshaw, 1989) and decoloniality (study 5). Study 3 illustrates differences in experience and encountered challenges between older persons with an Italian background and those with a Turkish and Moroccan background based on their position on these axes. This confirms the notion that different intersectional positions on these axes lead to different individual experiences and different manifestations of marginalization (Carbado et al., 2013; Crenshaw, 1989). Moreover, European migration and Christianity are more in the “zone of being” (Fanon, 1952/2008) in Belgium, thus leading to a slight advantage in suitability of care compared to non-European and Muslim counterparts.

2) Hidden mechanisms in professional dementia care: assumed neutrality, otherness and racialization

Our studies indicate that dementia care provision is also influenced by hidden mechanisms in professional dementia care:

- a. Assumed neutrality sets the norms of what is considered as good professional dementia care and therefore something to fit in with while alluding to be inclusive;

- b. Older migrants and their descendants have to face cumulative and intersectional "otherness" with consequences at the individual and societal level;
- c. Racialization as a specific "othering" mechanism faced by our respondents, adding up to different manifestations of exclusion of older migrants with dementia from good-quality care.

Assumed neutrality

Informal care provision is influenced by a complexity of factors, as is professional dementia care provision. Although the latter is often presented as neutral (Ahaddour, van den Branden & Broeckaert, 2016 & study 3) and sometimes even universal, our studies evidence the opposite. Professional dementia care is rather oblivious to how cultural norms, biomedical dominance and a White Eurocentric gaze shape the diagnostic and other instruments used, care norms and standards, and the definition of what is considered as "good" dementia care. This aligns with Carlsson and Pijpers' findings (2020) about the expected assimilation of older migrants in aged care even in cases where culturally and linguistically sensitive care is provided. An example is the resistance against religious sensitivity in care, especially of non-Christian religions, by services that argue neutrality (study 3).

Drawing on the lessons learned from decolonial frameworks (study 5), we can question the assumptions of neutrality, universality and standardization of care approaches and methods. The care methods and standards used are based on science that is neither neutral nor universal, with blind spots about marginalized and unheard voices like older migrants. This implies a risk of imposing "White templates" such as active aging and person-centered care as universal frames (Kitwood, 1997, 2019; Phillipson, 2015; Torres, 2019a) without addressing the blind spots. It invites us to look carefully at the assumed universality in dementia care models, like Kitwood's person-centered care: are the identified psychological needs in the model universal? If we reexamined the needs of marginalized groups, like people in the global south, would we come up with the same needs or are there other needs, nuances or prioritizations?

The flag of neutrality, universality and standards in care implicitly implies that this care is good for everyone, including marginalized groups. The decolonial gaze helps us see and understand the often-hidden adverse outcomes behind the dominance of White norms in care. An example is the inferiorization of these migrant families due to their position in the zone of non-being, leading to deprioritization of their needs and experiences compared to the dominant group. As discussed in study 5, being in the zone of non-being entails that older migrants with dementia and their families face more barriers to basic rights like the right to accessible and good-quality care; this is established by proven inequalities in health care for ethnic minorities (Nazroo, 2006). Moreover, their subjectivities, identities and spiritualities are less recognized and subordinated, often unconsciously, compared to those of people in the "zone of being" (Grosfoguel, Oso & Christou, 2014; study 2 & 3). Lastly, we can presume that a care organization – which is an institution within a system that is influenced by dominant societal views about migrants, Muslims and ethnic minorities – can never be neutral or universal. Health care in European welfare states, for example, is assumed to be universal, yet it is normative, expecting gratitude from underserved marginalized groups like migrants, as shown by Bradby, Humphris & Padilla (2018). Moreover, care organizations are built on various sets of values that are influenced by the dominant cultural (e.g. autonomy) and religious values (Christianity) associated with care. These values are present in care practices that speak to the dominant ethnic and

cultural group. Whereas ethnocultural values are hyper-visible in care for older migrants, dominant cultural values are rarely considered in either care or research. Or, as Torres stated (2019a, pp. 3056-62): “Failing to design studies that aim to break out of this ‘national container’ understanding of ethnocultural values means not only failing to seriously acknowledge that national, societal and socio-cultural contexts matter to the values people hold, but also failing to explore how they actually matter.”

Otherness

A second hidden mechanism in professional dementia care is “otherness”. The presence of multiple forms of otherness is highlighted (studies 2, 3 & 5). This can be seen as cumulative and/or intersectional, influencing the experience of dementia and dementia care provision.

Professional caregivers with a Belgian background mentioned dealing with nonstandard care requests as care challenges. In study 5 we saw that professional caregivers are not aware that what they consider as “deviating from the norm” or “normal” is influenced by a White, Western and Belgian cultural template (Phillipson, 2015; Torres, 2019a) that is considered a “neutral” standard, often leading to an ethnocentric care approach (Forsell, Torres & Olaison, 2015). This approach is also fueled by implicit biases like the assumed “sameness” and “otherness” toward older migrants in care provision (Mildberg, Torres & Ågård, 2016; Torres, Ågård & Mildberg, 2016). Our studies showed that care professionals categorize migrant care recipients based on their assumption on how “same” or how “other” this person is perceived compared to themselves. Both assumptions lead to a homogenous image about the caregiver influencing the care attitude toward the care receiver, positively for highly assumed “sameness” and negatively in case of highly assumed “otherness”.

Otherness can be seen as a result of the process of othering, defined by Chimakonam (2019, p. 2) as “the stratification of identities into in-group and out-group by the norm and the consequent marginalization of the out-group”. Different scholars from different disciplines (feminist, post-colonial, decolonial, aging studies, psychology) have conceptualized othering (Chimakonam, 2019). A connecting thread in all these definitions is that people are binarily divided – self vs other, sameness vs difference – by the dominant, powerful group based on social constructs of identities like age, gender, ethnicity, socioeconomic status, ability and religion (Fadil, 2019; Torres, Ågård & Mildberg, 2016, Powell & Menendian, 2016). The “other” is inferiorized, marginalized and powerless in an asymmetric hierarchical system. This categorization into the “other” therefore leads to a set of dynamics, processes and structures that reproduce marginality and inequality. It can be described as different forms of “isms”, such as sexism, ableism, ageism, orientalism, cultural essentialism, elitism, racism. These are structural mechanisms influence our daily lives, more specifically the balance of privilege versus deprivation based on these categorizations.

Our results (studies 1, 2, 3 & 5) show that older migrants with dementia and their family caregivers are considered as the “other” in our society based on different aspects: old age, having dementia, being a migrant, having a migration background, being female in the case of family caregivers, providing care, having a non-dominant ethnicity, having colored skin, being from “another” culture and having a different religion (Muslims). Challenges named by native Belgian professionals (study 2) – language barrier, difficult interaction with families, hesitation to act driven by the perceived cultural distance between them and migrant families, fear of being accused of racism or discrimination, standardization

or centralization of a care approach – can be seen as a manifestation of the othering of older migrants with dementia and their family caregivers as an invisible mechanism. This results in inaccessible and poor care provision at the individual level, as voiced by family caregivers (studies 1, 2 & 3). The othering was also clear in the essentialization of older migrants and their family caregivers to their “different” culture. This different culture was also seen as the source of and the answer to their challenges when interacting with these other categorized care receivers (like the suggestion to learn about the different culture of the older migrants). On the other hand, the impact of one’s own cultural background on the care provision is neither seen nor examined. This supports the finding that “culture” is viewed as a feature of the “other” and not of the dominant cultural group (Torres, Ågård & Mildberg, 2016; Torres, 2019 a).

The hierarchical aspect in the process of otherness was seen in problematization, de-normalization and sometimes even inferiorization of a care recipient’s requests when estimated as deviating from what is considered “normal” (study 2; Sagbakken et al., 2017). Our results also highlight the intersectionality of otherness as a complex concept (Norris, 2015): “othering” is not based on one single social identity construct. Study 3 shows an interesting example of the complexity intersectional otherness. Whereas older Moroccan and Turkish Muslim migrants with dementia are perceived as the ultimate “other” (Claeys et al., 2020; Fadil, 2019), older Christian migrants with an Italian background are seemingly considered within the “in” group. The estimated “sameness” was based on their religion and shared European culture. However, respondents with an Italian background testified about experiences of otherness based on their culture (cultural racism) and dementia-related loss of the dominant Belgian languages. The discrepancy between the perception of older Italians and their experiences remains an illustration of othering dynamics, as it is the dominant group which portrays an essentialized homogenic image of an Italian migrant. Such an image neglects “different” care needs.

Our studies point to the accumulation of otherness experienced by older migrants with dementia and their descendants – otherness related to having dementia (Parland, Kelly & Innes, 2017; Van Wijngaarden, Alma & The, 2019), being old (Fret et al. 2019; van Dyk, 2016), being a migrant (Rast & Gorashi, 2018), having a minority ethnicity (Grosfoguel, Oso & Christou, 2014), having “another” culture (Said, 1978; Zubair & Norris, 2015), having dark skin (Fanon, 1952/2008; Rajan-Rankin, 2018), having “another” religion (Claeys et al. 2020, Fadil, 2019) and providing care (Tronto, 2014). Moreover, the decolonial gaze discussed in study 5 invites us to look at the entanglement of these different layers of otherness intersectionally and within a broader global (Powell & Menendian, 2016) and historic (Chawla, 2017) hierarchical system based on aspects like race, gender, ability and class. This intersectional approach adds to the growing body of evidence looking at otherness based on intersections of age and ethnicity (Rajan-Rankin, 2018; Torres, Agard & Milberg, 2016; Zubair & Norris, 2015) and dementia and ethnicity (Hulko, 2009). As Powell and Menendian (2016) state, that othering is a problem of the 21st century, where every seemingly overwhelming challenge is wrapped within one or more dimensions of group-based differences.

Consequences of otherness on dementia care provision

The presence of othering and otherness in the dementia and dementia care trajectory of older migrants with dementia and their families has consequences for the provision of dementia care at the individual and societal level. At the individual level, otherness shapes the experience of dementia and dementia care. For example, caregivers with a Belgian background systematically did not propose

professional care options based on their assumption that “these” families will not use professional care, because of “their” culture. With these actions the dominance of the image of family care as the only “cultural” care preference by non-EU migrants is perpetuated and these families are kept from making a well-informed care decision. Othering and a culturalist gaze was also experienced as discriminatory and racist by our respondents through uncaring encounters (Söderman, Rosendahl & Sällström, 2018). This gets in the way of building a good relationship with the person with dementia, which is primordial for a person-centered practice (Kitwood, 1997, 2019). However, professional caregivers who are committed to engage in caring encounters with persons with dementia and their relatives and who are flexible to adapt to the situation, succeed in learning and meeting care recipients’ needs even when there is a language barrier (study 2; Söderman, Rosendahl & Sällström, 2018). Another example of the impact of othering mechanisms on professional care provision is the felt hesitation and insecurity to act as professional caregiver, described in study 2 and in compliance with other studies (Claeys et al., 2020; Sagbakken et al., 2017).

Looking at otherness from an intersectional lens explains the contextual and temporal variability of our respondents’ experiences of otherness. The used axes of othering can be different during an encounter at the hospital (intersection of migration background, language, “other” culture) than at the mosque (e.g. having dementia) on the same day. This intersectional lens draws our attention to the variety of configurations and accumulations of negative experiences of otherness (Bürkner, 2012), where some accumulations can be sometimes bearable and sometimes intolerable. Hulko (2009) states that the wide range of experiences of dementia from “not big deal to hellish” is linked to the social location of the person with dementia. Hulko argues that multiply-othered/marginalized persons are more resilient to dementia-related othering and marginalization, compared to multiply-privileged persons. On the other hand, experiencing otherness has been shown to intensify psychological stress (De Wilde et al., 2019), which in turn enhances the care burden (Gilhooly et al., 2016). Another consequence of otherness is dehumanization (Grosfoguel, Oso & Christou, 2014), which can jeopardize good care provision by not seeing the person; this is essential in professional dementia care, as described by Kitwood and others (Kitwood, 1997, 2019; Dely, Verschraegen & Steyaert, 2018).

The reproduction of positions of domination and subordination (Chimakonam, 2019) co-sustains the otherness of care and care providers (informal and formal) also at the societal level (Tronto, 2014). According to Tronto (2014), care has been “othered”, marginalized and gendered by those in power (White, male). She therefore calls for centralization of care as a sophisticated human interdependence that guarantees human existence. We learn from Tronto’s work that care is provided by those who have less power in Western society, starting with females, and when White, highly educated women are “liberated” by their inclusion in the labor market and the care work is done by less privileged (based on other axes of otherness) individuals. Or as Tronto (2014, p.11) states: “in order to fulfil caring duties, other lower-class, racialized, ethnic women and men would have to step in to complete the caring work”. This is illustrated by the global care chains (Azzurra, Bhattacharya & Frazer, 2019; Merla & Baldassar, 2016), as discussed in studies 1 and 2. In relation with our results (studies 1, 2 & 3), providing care is generally valued by the person with dementia, family caregivers, and Moroccan and religious communities. Conversely, the choice to provide family care had adverse financial and career outcomes for some family caregivers, as they had to quit their job or work part-time. Family care bonuses were inaccessible and/or too small to meet needs (Lopez-Hartmann, 2020). This was one of the reasons to look for alternative care solutions engaging others, often females in less favorable social positions

(undocumented helpers, care marriages), as discussed in RQ2. Also at the level of professional care we notice this phenomenon in the recent policy campaigns trying to attract ethnic minorities/migrants, mostly females, to work in care (Saeyen et al., 2020) or, as seen with the high ethnic diversity of care staff in residential facilities of Belgian cities, predominantly in lower-educated positions (Berdai-Chaouni, Van Thiel & Vanmechelen, 2020).

Racialization

Our respondents experienced painful discrimination and various forms of racism. This induces diverse reactions such as lower expectations from professional care, avoidance actions toward such situations, preventive actions like mediating and bridging, and educating professional caregivers to meet the needs of older persons with dementia without engaging in discriminatory, racist behavior (studies 1, 2 & 3). It is generally well-established how racism can be a traumatic experience (Kilomba, 2020), with adverse psychological and physical outcomes even when it is experienced in its subtle forms (Essed, 1991; Fanon, 1952/2008; Kilomba, 2020). Moreover, bringing up racism is not welcomed by healthcare organizations and can even lead to more adverse outcomes for those who label an experience as racist (Ahmed, 2012), as experiences of racism are often silenced (Ahmed, 2012; Ahlberg et al., 2019).

These experiences of racism (studies 1, 2 & 3) can be seen on the foreground as an outcome of a specific form of othering: racialization, which we consider as the third hidden mechanism in professional dementia care. Racialization refers to the process of giving racial meaning to groups that were previously not classified as racial, based on the original Black/White binary conception of racism (Gans, 2017; Gonzalez-Sobrinio & Goss, 2019). This means that groups that do not have Black skin, like migrants and non-black-Muslims, can also be discriminated, marginalized and oppressed based on a set of deviating characteristics set by the dominant powerful group (Gans, 2017; Gonzalez-Sobrinio & Goss, 2019, Grosfoguel, 2016). Furthermore, racialization as a process can be a temporary phenomenon or last permanently by continuous reproduction, in which case it becomes institutionalized (Gans, 2017). An example of temporality of racialization is found in our results (study 3) when we look at the position of older Italian migrants and their descendants. This group is currently “less” othered based on their ethnic and migration background, as discussed in pg. 145. However, this was not the case right after they migrated to Belgium, when they did face intense discrimination and racism (Morelli, 1988). Gans (2017) conceived this process as “de-racialization”. It illustrates the dynamic character of racialization for some groups, also pointing to “re-racialization” of previously deracialized groups.

Racialization is helpful to understand why our respondents, who are not Black, spoke of experiences of racism (studies 2 & 3). The importance of looking at those experiences at the intersectional, individual and institutionalized level is highlighted (studies 2, 3 & 5). First, the intersectional approach make us aware of the diversity of experiences of different forms of racism (cultural racism, islamophobia) that can be influenced by other aspects, like class (study 5). For example, it is the poorest migrants who would likely undergo racialization (Gans, 2017). As intersectionality examines how crossroads of the different axes of our social identity determine our privileged and/or oppressed position in society (Crenshaw, 1989), Bourabain & Verhaege (2020) argue for an intersectional lens to examine racism in health care and state that following the intersectional tradition will more accurately estimate the effect of racism on certain groups with room for heterogeneity between and within groups.

Second, our research underpins the presence of racism at both the individual and institutional level (studies 1, 2, 3 & 5). This aligns with the micro-macro relationship of racism as put forward by post-colonial and decolonial researchers (study 5). A clear conceptualization of this micro-macro relationship and its impact on our daily lives is captured by Philomena Essed's concept of everyday racism (1991). This concept reinforces the idea that power structures related to "race" as a social construct influence individual prejudices and intergroup interactions. These structures also facilitate exclusionary and oppressive acts by the powerful/dominant group. On the other hand, this structural hierarchy is reinforced and reproduced through micro-interactions. The macro- and micro-level forces of racism are therefore intertwined. Racism-based inequality patterns are observed at the individual, institutional and societal level (Bourabain & Verhaege, 2020, study 5). Decolonial frameworks discussed in study 5 confirm the idea that racism is institutionalized and therefore also present in care institutions. Conversely, family caregivers voicing experiences of discrimination or racism are often not seen, understood or recognized, and are even considered unreasonable by native Belgian professional caregivers (study 2). This reaction denies the expertise to distinguish racist from non-racist events, labeled as "double consciousness" (Sue, 2010), and illustrates the invisibility of everyday racism in care provision at both the individual and the structural level. According to Ahmed (2012), the invisibility of racism to the dominant group is a form of reluctance to deal with the matter, as it is "uncomfortable" for institutions to face racism and silencing it may seem a better strategy. This strategy is reinforced by the "exceptionality" image of racism and the "happy diversity" approaches that "manage" ethnic-cultural diversity while reproducing a positive image about the organization. Gloria Wekker's concept of "White innocence" (2016) confirms the same beautifying mechanism of denial of racism as a societal and cultural manifestation by the dominant group to safeguard White privilege. Whether denial of racism may be more appealing in professional care provision because of the "non-harming" image of care remains an open question.

All of the above draws the hypotheses that different manifestations of otherness lead to poor care provision for older migrants with dementia. The impact of otherness on care provision nonetheless needs closer examination (study 5, De Wilde et al., 2019; Torres, 2019, 2020). Or, as stated by Zubair and Norris (2015, p. 911), "the multiple and interconnected dimensions of social inequalities, experienced by those within the particularly more disadvantaged social locations within ethnic minority groups and over the life course, need to be uncovered" – preferably in a way that does not reinforce otherness, as we learned in study 5.

3) Macro-level aspects influencing care provision

Our studies also indicate that dementia care provision to older migrants is influenced by macro-level aspects, namely neoliberalism, globalization and coloniality.

Neoliberalism & globalization

Neoliberalism and globalization are formulated as two major challenges for current and future general care provision (Azzurra, Bhattacharya & Frazer, 2019; Tronto, 2014 a,b). Tronto refers to neoliberalism as a force behind the devaluation and marginalization of care. It manifests as decentralization of the needs voiced by care recipients and providers (formal and informal) and as capitalization of care (Azzurra, Bhattacharya & Frazer, 2019). The latter emphasizes cost-effectiveness, technical skills and less favorable working conditions for professional care providers. This influence is also traced in our

studies with both professional and family caregivers. They referred to the performance pressures of professional caregivers with limited room for “human” aspects of care such as relationship-building and flexibility, alongside a lack of support measures and budget cuts (studies 1 & 2). Neoliberalism reinforces the inferiorization of care by framing it as a product that is not entitled to societies’ resources and investments to maintain its quality and existence. This leads to inequalities in accessible and affordable care and to poor working conditions for those who provide low-skilled care. The latter reinforces phenomena like global care chains and engagement of women with a vulnerable social position in care as a way to keep care affordable, as discussed in RQ2.

These phenomena are also situated within global power imbalances, as portrayed by decolonial frameworks (in study 5) together with care ethics and feminist theorists, shaping individual and family choices of dementia care provision. Our results confirm the notion that individual care choices are influenced by macro-mechanisms, like global power imbalances, although these imbalances are not on the foreground in every respondent’s testimony. However, looking at these testimonies collectively and through the decolonial lens (study 5), the experiences can be situated within broader global tendencies. The alternative care choices by family caregivers (like care marriages, respite care in Morocco) can be seen as a variant of global outsourcing of care to migrant care workers in the West (Horn et al., 2019; Schwiter et al., 2018) or as a variant of how Western families seek answers to their unmet care needs in middle- and low-income countries (Bilsen, 2020).

Coloniality/decoloniality of care

A second macro-influence is coloniality of care. Whereas generally coloniality of care has been associated with use of care as colonization tool in colonized regions (Tilley, 2016), our studies imply that coloniality influences care provision. A decolonial gaze provides an interesting angle on current dementia care provision for older migrants (study 5), questioning aspects like neutrality, normativity, universality, standardization of care approaches and methods. It also raises awareness around invisible mechanisms in care provision by professional caregivers and care organizations, such as otherness and racialization. It further offers a useful frame to look for solutions to guarantee equity in care for marginalized and racialized persons with dementia. Coloniality refers to an invisible structuring force ingrained in our mind frames that shapes power structures, knowledge and individual experiences (study 5). This means that decolonial frameworks invite us to examine how coloniality of mind is rooted in provision of care. It is achieved by dismantling our thinking and taking into account a complex view of power hierarchies. It invites us to look critically at concepts like culturally sensitive care. Does this approach have a harmful impact? Is the emphasis on “culture” by itself not a result of colonial thinking by attributing culture as a problematic characteristic of the “other” while being blind to how normative culture influences care provision? How does culturally sensitive care reproduce inequality? How does coloniality of mind influence the care relationship? Are the lower expectations of family caregivers not a continuation of internalization of coloniality of mind, for example? Are the expected assimilation of care needs not a sign of internalized superiority by White professional caregivers? Although sensitivity to minorities’ cultural, religious and migration background is a good first step to guarantee good care for these minorities, decoloniality of care challenges us to go further. It invites us to see how coloniality, as a shared history by minorities and the majority, has an harmful impact on dementia care provision and how can we work toward equal and suitable good-quality care for everyone, not only those who are privileged.

In summary, dementia care provision to older migrants is influenced by several factors with consequences at the individual, organizational and societal level. The interplay of having a migration background with an “other” culture and religious background co-shape current care provision. Cultural and religious values and practices are expected in dementia care but are almost exclusively fulfilled by family care. This interplay also determines the societal starting position of these families and co-sets the conditions of how care is currently provided. Dementia care provision is also influenced by hidden mechanisms like assumed neutrality, intersectional otherness and racialization, preventing access to and provision of good-quality care for this population. Lastly, dementia care provision is also influenced by neoliberalism, globalization and coloniality as global macro-level tendencies. Striving for dementia care equity for all people therefore means also striving for justice and for revaluation and decolonization of care.

Research question 4: How can we improve gerontological research on older migrants and their family caregivers?

Looking back at the individual learning process is required to answer this question. After reflecting on the search process, the author learned the following: 1) the merger of constructivist grounded theory and critical gerontology as gazes (see Introduction) formed a good basis to engage with this research topic; 2) this approach was confirmed, extended and deepened by decolonial frameworks in study 5; 3) and yet, this dissertation reflects the learned lessons only to a limited extent, as further future steps are needed to develop a decolonial-inspired research praxis.

1) Constructivist grounded theory and critical gerontology: a good starting point

When reflecting on the individual learning process during this dissertation, the emphasis on methodological self-consciousness and reflexivity drawn from the merger of constructivist grounded theory and critical gerontology (Introduction) formed a good starting point – a sound basis to shape the search process for a more ethical research practice on dementia among migrant families.

Study 4 puts forward that there is a need for a customized and flexible research design that takes into consideration the following aspects: 1) investing in sustainable relationships with the respondents, beyond the traditional researcher-respondent relationship; 2) collaborating with key community figures to recruit respondents; 3) focus on qualitative research methods; 4) investing in transparent communication techniques; 5) “ethnic matching” by recruiting bicultural, bilingual researchers; 6) reflection on researchers’ own societal position. These findings are valuable. They confirmed certain key aspects posited by constructivist grounded theory and critical gerontology (Introduction), such as adjusting the methodological approach to the reality, reflexivity on one’s own societal position (Charmaz & Thornberg, 2020), emphasizing a more equitable relationship with key persons from minority communities, and creating a “win” for the “researched” community. Still, these findings are rather superficial if we are to fully meet the goal of more ethical research. The findings give the impression that engaging with this underrepresented subgroup is a recipe with boxes to tick. Inspired by an initial critical skepticism of literature (Charmaz & Thornberg, 2020), study 4 centralized the practical experience of professionals from different disciplines who had succeed in including older

migrants or their descendants. And yet, that study lacked the voice of the considered persons (older migrants and their descendants) and confirms the limited knowledge (also by non-researchers) about this marginalized group. Alongside, it reflects the easily adopted superficiality (by the author too) in found “solutions” when considering hard-to-reach groups (Gove et al., 2019).

4) Decolonial frameworks as an extended and deeper framework

Decolonial frameworks in study 5 provided an extended framework requiring an in-depth approach/engagement to improve gerontological research on the intersection of age and ethnicity. Decolonial frameworks confirm various points portrayed by constructivist grounded theory, critical gerontology (Introduction) and study 4: methodological self-consciousness, equitable researcher-participant relationship and beneficial impact of research participation. However, these aspects were critically situated within a larger framework.

First, the decolonial gaze connects all these aspects as part of a bigger endeavor of the decolonialization of conceptual underpinnings of the research enterprise, of scholars themselves, of research-in-action through “epistemic disobedience”, and of current knowledge systems and structures that reflect and reinforce coloniality. Second, decolonial frameworks make us aware of the intertwinement of micro, meso and macro dynamics in knowledge production. On the one hand, decolonial frameworks situate research in a historically rooted global system of hierarchies. This system is enforced by institutions and is invisibly present in our thinking. It therefore defines our societal positions, shaping our interpersonal interactions at the individual level (study 5). On the other hand, individual researchers’ and institutional choices contribute to a systemic reproduction of marginalization of the unprivileged ones in this system of power hierarchies that is based on socially constructed features like age, migration background, color, religion, culture, and their intersections (study 5).

This framework therefore adds critical depth to the methodological self-consciousness and reflexivity discussed above. Methodological self-consciousness through a decolonial gaze requires not only a methodological adaptiveness but extends to epistemic disobedience: questioning every step of the research endeavor as described in study 5. Reflexivity through a decolonial lens entails continuous engagement of the researcher to reflect on various aspects. How does coloniality shape one’s own thinking and behavior? How is this reflected in the questions asked, in engagement with research participants, analysis of data, the used language about the topic? This reflects the decolonial process of awareness and resistance discussed in study 5, highlighting that: 1) colonial thinking is deeply embedded in research; 2) critical reflection about who is considered the “knower” in research is warranted; 3) alternative ways to generate, analyze and publish knowledge exist; and 4) the places and systems of knowledge production are not neutral. Moreover, according to decolonial scholars reflexivity is not only a deep psychological and continuous process, but one that should lead to action. Kilomba (2020) argues that giving a voice to racialized persons in research requires work on the ego defense mechanism that inhibits listening to the subaltern. Engaging in this psychological process – composed of denial, guilt, shame, recognition and reparation – is required to enable “listening” to the subaltern. This aligns with the emphasis on genuine commitment to decolonize one’s own thoughts of Moreno et al. (2021) as prerequisite to realize their suggested listening-based dialogue approach. It is an attempt to decolonize co-creative data-collection approaches. Again, reflexivity should lead to

actions invoking one's own agency to decolonize research (Grosfoguel, 2016), or to being an "agent of social change" (p. 28) as an important step in the 10 steps toward decoloniality as formulated by Maldonado-Torres (n.d.). These steps are inspired by the work of several decolonial voices like Franz Fanon, Aimée Césaire and Audre Lorde.

This is how decolonial frameworks add depth to the insights from study 4. For example, the aim to realize an equitable relationship with research participants becomes a continuous awareness of power dynamics in this relationship. It also means a continuous search for ways to resist these power dynamics, recognizing research participants as "knowers" and centralizing their questions in research. Another example is having the intention to conduct research that does not harm minority populations. This means following through a decolonial gaze: the researcher is accountable for striving for a research approach that does not reproduce forms of injustice, starting from project application (choice of research questions, choice of funding) to research execution (choice of methodology, avoidance of knowledge extraction and superior attitude) and knowledge dissemination (language use, beneficial impact on older migrants). All of this shows that decolonial frameworks require exhaustive engagement by individuals (researchers), institutions (academia), and by extension society (policymakers) to improve gerontological research on the intersection of age and ethnicity.

5) Reflection on the empirical papers of this dissertation

The empirical papers (studies 1, 2 & 3) only reflect these lessons to a limited level. For example, the three papers used constructivist grounded theory as a basis for the used qualitative methods and for the choice of centralization of the experiences of the respondents in the analysis. Also, intersectionality is implicitly used as a gaze in questions asked about the influence of migration, culture and religion (studies 1 & 2). It becomes more present in the focus of paper 3, on the intersection of religion and migration.

Moreover, elements of decoloniality were present in the research approach even before learning about decoloniality. Starting from a grounded approach is in a sense decolonial: the choice to centralize the voice of the persons experiencing the reality of the researched topic as guiding compass in this research. These voices were central in the observation of the impact on the author and in the navigation through the different theories to make sense of this reality. Other examples of a decolonial "spirit" in this dissertation can be found in the fact that this research was set up after observing an actual need through previous collaboration with older migrants and their family members. Safeguarding the ultimate goal of this dissertation – providing insights in order to contribute to better care for these older persons with dementia – can also be considered decolonial (Maldonado-Torres, n.d., study 5).

Other decolonial lessons learned were increasingly used in how the relationships were set with the respondents (developing long-term relationships, lending a listening ear when they need one, providing practical help), the cautious way of centralizing their narrative in the data analysis, the choice of words in writing, the advocacy work for equal access to care, and the continuous reflexivity on personal emotions, thoughts and actions as a researcher. However, these aspects are barely detectable in the published papers, if at all, and remain behind the scenes. The latent use of the lessons learned from the methodological search journey is twofold. First, it reflects the immaturity of the

learning process at the moment of execution of the empirical studies. Second, it mirrors the limited room in journals' criteria to support a decolonial approach, which is not considered a mainstream scientific approach (study 5). Further application of the lessons learned from the decolonial frameworks is still needed in the future. This can be part of the search for a decolonial praxis in gerontology (Moreno et al., 2021).

In summary, the search to improve gerontological research on older migrants and their family caregivers is still ongoing and various paths seem to point to the importance of reflexivity and methodological adjustment. However, decolonial frameworks provide a more open gaze, suggesting a pluriversity of knowledge and modalities of knowledge production challenging us to go deep as researchers into a process of awareness and resistance to the historically rooted coloniality of mind, to the hegemonic power mechanisms in knowledge production and knowledge production institutions/systems. This process results in a deeper, continuous process of reflexivity considering one's own intersectional position on the different hierarchal axes and how coloniality has impacted personal thoughts, emotions, behavior and role as researchers, plus how can we counter coloniality's negative impact on these aspects. This continuous awareness and resistance process should be translated into actions that are tangible during the whole research process, starting from the formulation of the research question.

3. Implications for practice & policy

1) A new conceptual lens on dementia care for a diverse population

Our studies indicate that we need to rethink the dominant care approaches, both person-centered care and culturally sensitive or competent care. The reasons are threefold. These current dominant care approaches 1) underline that dementia for older migrants care is determined by their ethnic-cultural background, 2) do not meet the complex interaction of personal, cultural and religious aspects in defining care needs of older migrants with dementia, and 3) fail to recognize the hidden structural and systemic exclusion mechanisms at the organizational and societal level shaping inequity in dementia care.

First, the presented dominant care approaches – person-centered care vs. culturally sensitive or competent care – evoke the impression that older persons with dementia need a totally different care provision approach based on their ethnic background. A divisive line seems to be drawn between older persons with dementia who have a non-EU migration background and older persons from the ethnically dominant group (studies 1, 2 & 3). Person-centered dementia care is generally perceived as something to strive for (Dely, Verschaegeen & Steyaert, 2018) in the case of ethnically dominant elders, whereas for cultural sensitivity competent care is the way to go when it concerns older migrants with dementia (Gove et al., 2018). On the one hand, person-centered care centralizes the individuality of a person, with a unique set of needs that should subsequently be met with a tailored care approach (Dewing, 2019; Kitwood, 1997,2019), yet culturally competent care positions older migrants with dementia within a group that has a “different” culture, requiring a care approach sensitive to their cultural needs. These needs are supposedly shared with other members of the same ethnic-cultural group. In other words, whereas individuality is emphasized in dementia care for the ethnically dominant group, sensitivity to a group’s trait – ethnic-cultural background – is accentuated for older migrants. Our studies indicate that both fail to meet the needs of older migrants with dementia. Where person-centered care is too individual (Dewing, 2019), culturally sensitive care is too group-oriented. Additionally, both are currently framed within a normative context and are susceptible to the above-mentioned colonial thinking and hidden mechanisms in their application.

Second, our research (studies 1, 2 & 3) stressed the interplay of migration, cultural and religious background as co-definers, alongside other factors (personal, relational, practical, economical), of the care needs of older migrants with dementia, and of the support needs of family caregivers. This requires complexity-responsive professional dementia care – a care that responds to the complex, dynamic and nuanced character of older migrants’ needs as relational older persons, considering their multidimensional identity in all its diversity and complexity. It entails a multilayered and intersectional sensitivity of professional care to current blind spots about culture, religion and migration without othering and essentializing the person with dementia to a stereotype of one’s own images about these migrant families. Complexity-responsive dementia care assumes adaptivity to what is agreed upon as “good care” through interaction between care givers and receivers (Tronto, 2014) engaged in a care relationship. This requires openness to other care practices (like inclusion of religious practices in dementia care, study 3) and true partnership in dementia care provision between informal and formal caregivers, which was often not the case (studies 1, 2 & 3).

Third, our studies point to hidden mechanisms at the individual, organizational and societal level (assumed neutrality, otherness, racialization) shaping dementia care that is normative, care with an essentialist static view of older migrants with dementia (mainly of non-European, Muslim background) that prevents them from accessing good-quality dementia care that considers their multidimensional uniqueness (studies, 1, 2, 3 & 5). These mechanisms confirm the increasing awareness to the existing inequity in healthcare provision to racialized groups like older migrants (Hardeman & Karbeah, 2020; Kierger, 2020). These hidden mechanisms can help understand why even when person-centered care is perceived as the road to provide good care to an ethnic-culturally diverse population (Epner & Baile, 2012), the expectation of “sameness” with the dominant group disallows person-centeredness in care provision (Torres, Ågård & Mildberg, 2016); or how ethno-specific aged care, designed to meet the cultural diversity of ethnic minorities in the Netherlands, does not meet the needs of these care users due to its assimilationist framing (Carlsson & Pijpers, 2020 b), expecting sameness instead of affirming differences.

This illustrates the need for a new conceptual lens for dementia care provision: one that is aware of its normativity; that takes into account the complex and dynamic character of influencing factors for dementia care needs and provision; and that includes mechanisms contributing to both equity and inequity in dementia care. Figure 1 provides such a new conceptual lens, which of course might benefit from further reflection and examination in future research. This conceptual lens is formed by the results of the studies of this dissertation and builds upon well-known models in care – Kitwood’s person-centered care (1997), Engels’ biopsychosocial model⁶ (1978) and Bronfenbrenner’s ecological model⁷ (1979) – plus other frameworks mentioned throughout this dissertation (i.e. Crenshaw’s intersectionality (1989) and decoloniality (study 5)).

The visualization of this conceptual lens (Figure 4) centralizes at the **micro-level** the care relationships between the person with dementia, the informal caregiver and the professional caregiver, abstractly visualized as part of a dynamic and transnational care network (studies 1, 2 & 3). These care relationships are influenced by needs that can be extended-biopsychosocial (i.e. inclusion of spirituality) for all individuals involved, and by an axe or an intersection of multiple axes of their multidimensional social identity (age, gender, ethnicity, ability, nativity, religion, class, language, sexual orientation, skin color) – this while acknowledging the structural macro-advantage or -disadvantage linked to different positions on the axes at that moment and in a specific context or situation. This also means recognition of the possible cultural needs associated with the different cultures a person relates to. Centralization of the care relationship affirms the focus of care upon older persons’ needs (person-centered care), simultaneously acknowledging the importance of the relational dynamics in care, which are also shaped by the needs of care providers.

⁶ The biopsychosocial model (1978) emerged from dissatisfaction with the biomedical model of illness. It is now generally accepted as a model indicating that illness and health are the result of an interaction between biological, psychological and social factors. The model is widely used as a structure for healthcare interventions, guidelines, management and research (Wade & Halligan, 2017).

⁷ Bronfenbrenner’s ecological model (1979) is a theory-based framework to understand the multifaceted and interactive effects of personal and environmental factors. It puts the individual at the center, which is influenced by various systems: microsystem (relationships with immediate surroundings), mesosystem (community), exosystem (institutions), macrosystem (societal influences) and chronosystem (time & historical content). It was initially introduced by Bronfenbrenner to understand human development but is widely applied and adapted to other fields such as understanding major contributors affecting health and health care (Kilanowski, 2017).

The **meso level** refers to the influence on dementia care provision of the communities of persons with dementia and the informal and professional caregivers and of the medical/care institutions, under the premise that individuals can be simultaneously part of different communities and that being part of a community is dynamic and multifaceted. For example, studies 1, 2 and 3 highlight the transnationality of these communities. They also show that ethnic-cultural and religious communities are crucial influencers (even in the case of remote connection) of dementia care provision. On the other hand, dementia care organizations or institutions are also crucial in defining the dementia care trajectory of persons with dementia. Individual professional caregivers shape the care provided in the organizations. Conversely, organizational structures also shape professional care provision at the individual level.

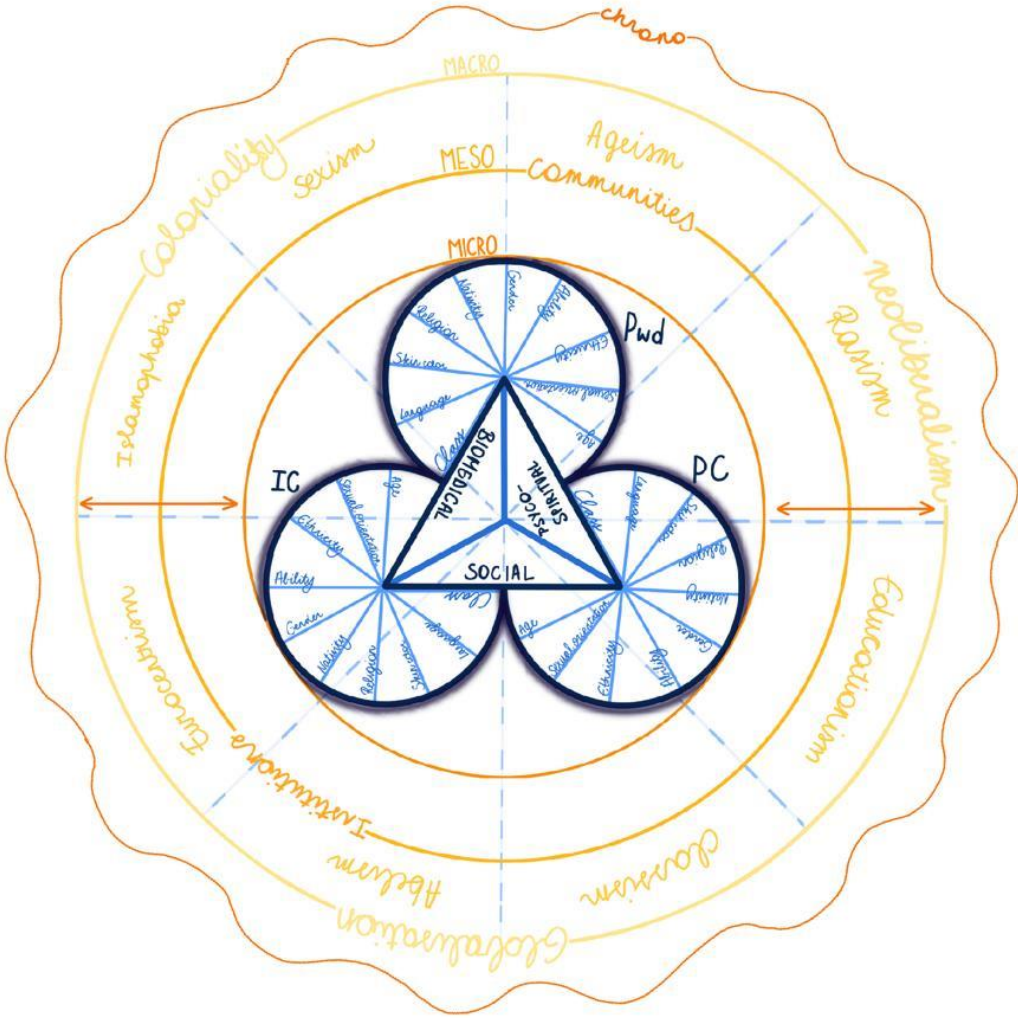


Figure 4: Conceptual lens of dementia care

At the **macro level** the conceptual lens involves structural societal mechanisms that are influencing the dementia care provision for individual older migrants. Our studies highlight the influence of neoliberalism, globalization and coloniality on dementia care provision, as discussed in Section 3 of RQ3. The underlying power structures (ageism, ableism, racism, sexism,...) in society define the axes of advantage/disadvantage at the individual level. They therefore shape the societal position

(marginalized or at the center of the power structure) from which each person interacts with the other. The conceptual model does acknowledge how actors at the micro and meso levels contribute to these structural mechanisms, explaining for example how hidden mechanisms like racialization and othering shape dementia care provision. From this perspective, tackling these structural mechanisms is equally important in addressing inequity in dementia care provision for marginalized groups such as older migrants with dementia.

The **chrono level** in the concept visualizes the importance of time in dementia care provision for older migrants. Drawing from our results, time can be manifested in the care process (dynamic change of care needs over time according to stages of dementia, the care relationship), in histories (persons with dementia experiencing a changed sense of time by going back to their past experiences and spaces, the importance of the life course in shaping the person, their needs and their societal positions, the historical embeddedness of power structures) and in temporality of aspects that can be of importance in care provision at some moments but not in others. Illustrating the latter is the dominance of certain aspects of one's own identity above others in shaping what is considered important in care: inclusion of religious practices in care can be considered important at a certain point in the dementia trajectory (initial, middle stages) but less of a priority at a later stage, which centralizes biomedical needs and bodily comfort.

The conceptual lens of dementia care also acknowledges the intertwinement and reciprocity of influences at the different levels, visualized by the double arrow. Taken together, this conceptual lens provides an innovative capturing of the dynamic complexity of influences, actors and localities within dementia care provision. It broadens the scope in the search for suitable and inclusive dementia care for a diverse population, suggesting that building blocks for this goal should be searched at the different levels (micro, meso, macro). By broadening this scope one-sided understanding of care needs of older migrants with dementia is avoided. For example, culturally influenced needs become one of the possible important needs of a person, that can be seen as an extension of social needs as part of biopsychosocial needs at a specific point in time, without being oblivious to other needs shaped by a person's multilayered identity. It further acknowledges the cultural needs or culturally colored behavior of everyone involved in a care relationship, also from the dominant culture. Against the shade of this conceptual lens, tailored care for older migrants with dementia involves the following building stones:

1. Centralization of the needs of older migrants with dementia without being oblivious to needs of informal caregivers (the need to be understood) and professional caregivers (the need to be reassured) that are present in the care relationship and which consequently influence the care provision.
2. Awareness that these needs are complex (biopsychosocial), dynamic (vary in time), situational, sometimes visible or invisible, and present at the individual level but reflecting gaps and challenges at the institutional (lack of tailored aged care organizations for ethnic minorities) and societal level (structural health disparities resulting from structural disadvantages based on one or an intersection of two or more lines of marginalization).
3. Accurately detecting, understanding and responding to these visible and invisible needs is required in order to move forward. This means that working toward dementia care that is inclusive for marginalized populations, like older migrants, is in need of actions at the micro, meso and macro levels.

2) Realization of multidimensional dementia care for older migrants

Drawing back on the conceptual lens described previously, realizing multidimensional dementia care for older migrants requires actions at the micro, meso and macro levels. This Section outlines a selection of possible policy and practical recommendations at these three levels.

Toward more agency for older migrants (with dementia), supported informal caregivers and agile professional caregivers (micro level)

To reinforce quality care relationships as a key shaper of dementia care provision on a micro level, actions leading to more agent older migrants, supported informal caregivers and agile professional caregivers are recommended. Although the wishes of older migrants with dementia may be considered by family caregivers, more opportunities to reinforce their full participation in the care relationship are needed. A way to achieve that is by strengthening their agency in order to voice their concerns (studies 1, 2 & 3). This can be achieved by investing in suitable and accessible information about dementia and the dementia care path and landscape for older migrants. It means that information resources and processes should reflect the circumstances and needs of these older migrants (Boughtwood et al., 2012). Situating existing information about dementia in a recognizable context for these older persons, conveyed in their language by knowledgeable, professional, trustworthy and respected individuals (Boughtwood et al., 2012; Schaffler et al., 2019) in familiar settings, have been put forward as successful approaches (Berdai Chaouni and Claeys, 2021; Boughtwood et al., 2012; Schaffler et al., 2019). This approach could diffuse the information gatekeepers' position of family caregivers as sometimes the sole information source for older migrants (Schaffler et al., 2019, study 1), contributing to better-informed older migrants and a more agent partner in discussions about the dementia care trajectory.

This dissertation also emphasizes the need for a transnational support system for family caregivers constituted by accessible information on dementia and the dementia care landscape, with guidance throughout the dementia care trajectory. Additionally, family caregivers' role and expertise need to be validated by care professionals. Further investment on centralization of information about dementia is needed, with attention for the specific needs of family caregivers with a migration background. Also in this case the information resources and processes should reflect the circumstances and needs of these family caregivers (Boughtwood et al., 2012). Inspiration can be drawn from tailored intergenerational information sessions like "dementia tea houses" in the Netherlands (Alzheimer Nederland, 2012) and "Faith groups dementia" resulting from a collaboration between Alzheimers UK and various religious communities (Alzheimers UK, 2021). As interpersonal aspects in information and support provision are important for ethnic minority communities (Boughtwood et al., 2012; Schaffler et al., 2019), further investment in personification of central information and support resources, such as dementia case managers, is warranted in Belgium. Case managers have been proven to contribute to a better quality of life of both persons with dementia and family caregivers (van Mierlo et al., 2016). However, this beneficial potential can only be achieved when case management is embedded in a well-functioning integrative care network (Khanassov & Vedel, 2016; van Mierlo et al., 2016) with notion of transnationality of the care network.

Professional caregivers should be more aware of and validate the extended role of family caregivers as guardians of a good relationship between them and the older migrants with dementia. Validation

of this role can be achieved by investing in a trusting relationship, by including them in care as creative experts with transnational resources (Wilding and Baldassar, 2018), by actively supporting their needs, and by being a challenging sparring partner in care when needed. The latter refers to the role that professional caregivers can have in discussing the care burden of family caregivers while inviting them to self-care and other alternative care solutions, always respecting the choices ultimately made by the family caregivers. To fulfill this role as professional caregiver requires flexibility and confidence to work outside the known paths. This can be linked to the concept of learning agility, which refers to the ability to learn from experience and the willingness to apply those lessons in a new and complex situation by pursuing self-directed learning, reflection, feedback-seeking and sensitivity to others' needs (De Meuse, 2017; Lee & Song, 2020). This can be achieved by creating a working environment that invests and supports the learning agility of each individual professional caregiver, with room for experimentation and feedback opportunities (Ghosh, Muduli & Pingle, 2020).

Toward an intersection-friendly environment (meso)

On the meso level, actions toward an intersection-friendly environment with communities and care organizations considering the multilayered and intersectional identity of older migrants with dementia, are recommended. Various policy guidelines have led to the development of age-friendly cities (WHO, 2007) and dementia-friendly communities (Flemish Government, 2016), often in separate policy guidelines followed by actions with a singular focus, targeting accessibility and social inclusion based on age or dementia. An intersectional approach strives for social inclusion of persons with disadvantaged inclusion based on the different identity axes and their intersections. This approach would better detect and understand why certain communities, like older migrants, are not reached by dementia-friendly initiatives, and set up remediating actions to include everyone with dementia. For migrant and religious communities unfamiliar with dementia, investing in actions promoting dementia-friendliness can enable them to become more supportive environments for persons affected by dementia and their family caregivers (study 3). Local governments can also collaborate with these migrant and religious communities to integrate their concerns and advice in order to build intersection-friendly municipalities and cities.

Inclusive care organizations are also an important part of an intersection-friendly environment. An inclusive care organization should target accessibility, provision of good-quality care and good outcomes, plus equity in medical/care provision for everyone with dementia (Lane et al., 2019). This means that every care provision should be person-centered and consider the intersectional identity of the person, meeting their bio-psycho-spiritual-social and cultural needs. In order to accomplish this, care organizations should be aware of, assess and tackle their Eurocentricity and the reproduction of coloniality of thoughts and actions, othering and racialization. The manifestation of the reproduction of these structural aspects is different for every care organization. For example, it is known that the form taken by everyday racism varies depending on organizational characteristics like workplace culture, policies, regulations and institutional hierarchy (Bourabain & Verhaeghe, 2021). Assessment of the situational, institutional manifestations of structural barriers to good care for older migrants should be followed by actions and strategies to tackle them. This requires a "deep structure" approach (Resnicow et al., 1999) with long-term organizational policies to profoundly dismantle those mechanisms that obstruct access and good-quality care provision to older migrants. This means that we should move beyond the current diversity policies, with their limited superficial achievements

(diverse workforce) that even reproduce exclusion (Ahmed, 2012; Carlsson & Pijpers, 2020 b), to decoloniality of care as a deep-structure approach.

Lastly, an intersection-friendly care environment is constituted by different decolonial care organizations. Movements encouraging optimization of integrated care through better collaboration of multidisciplinary care organizations like the “Primary Care Zones” should therefore be cheered. However, these locally organized zones poorly fit the transnational reality of the care networks of many older migrants (study 2). How these movements can also support better collaboration with transnational organized care networks while facilitating the goals set up by migrant families remains an issue to be addressed.

Toward an equitable society (macro)

The recommendations discussed above need to be embedded in a society that strives for equity and takes measures to provide its population with equal opportunities and outcomes during their entire life course. Hence a society should be aware of its structural systems leading to inequity for some population groups while advantaging others. In the shade of the mentioned conceptual lens, this confirms the need for actions that tackle ageism, disablism, racism, sexism, islamophobia and homophobia. It aligns with how equity is conceived as guiding principle in the “Decade of Healthy Ageing” action plan (WHO, 2020). However, actual policies to deal with these structural systems have a unifocal perspective – for example, policies only targeting ageism (e.g. “Decade of Healthy Ageing” action plan (WHO, 2020), WHO ageism report and guide (WHO, 2021 a,b)) or racism (the promised Belgian interfederal anti-racism plan (NAPAR coalition, 2021)). An intersectional approach would be more beneficial to tackle the intertwined reality of the different “isms”. To this end, intersectional policy guidelines with profound understanding of the mechanisms behind the different isms and their intertwinement with actions reflecting the voice of people embodying the impact of these isms are needed. We should accordingly rethink our participation flows and reshape them to guarantee fully-fledged participation of these marginalized people.

4. Limitations of the dissertation and directions for future research

In addition to limitations related to the content of each study, this dissertation is also subject to a number of general limitations informing pathways for future research. Drawing back on the conceptual lens (Figure 4), the following limitations and directions for further research are presented at the micro, meso and macro levels.

Toward intersectional and multi-perspective examination of the care relationship with inclusion of older migrants' perspective (micro)

This dissertation only included the perspective of family caregivers and professional caregivers cross-sectionally. Inclusion of older migrants with dementia in future research through observations and tailored interviews would be preferable. A longitudinal multi-perspective approach (chronological) following older migrants, family and professional caregivers would also provide a more in-depth understanding about the dynamics of this triangular care relationship.

Another limitation of this dissertation is the restricted intersectionality. Only study 3 zoomed in on the intersectionality of migration and religion. Issues related to gender are not on the foreground in this dissertation. Moreover, the engaged family caregivers were mainly female and highly educated. Future research on this topic should therefore not only involve caregivers from various socioeconomic profiles (Nazroo, 2006) and include a male perspective (Snyder et al., 2014; Ahmad et al., 2020), but also apply an intersectional lens. Using intersectionality as a lens in future research would better capture the complexity of the influence of factors like age, class, gender, sexuality and ethnicity on individual experiences (Torres, 2019a). As attempts including an intersectional approach (Brotman, Ferrer & Koehn, 2019) evidence its challenging character, more research searching for suitable methodologies to capture this complexity is warranted (Gove et al., 2019).

Toward research on manifestations of power structures in care organizations and transnational care communities (meso)

Manifestations of power structures in care organizations were only discussed in this dissertation as a result of the individual experiences of family and professional caregivers (studies 1, 2 & 3). However, close examination of how these power structures manifest on an organizational level is desirable in research about this topic, the more so given that this institutional meso-level angle in research on influences of exclusionary and advantaging mechanisms on care provision is limited in gerontological research (Carlsson & Pijpers, 2020; Torres, 2019a). Also from this angle, more research on the dynamics between the different transnational care communities (study 2) and their impact on dementia care provision is recommended. What is the construction of the care community in the country of origin? What visions on dementia care does this care community apply? How do they collaborate with care communities in Belgium? How is the dementia care landscape in this case shaped and extended, and how does it meet the needs of older migrants? These are possible questions that remain to be answered.

Toward research on the influence of power structures on the ageing experience and better understanding of the global care chains (macro)

This dissertation only incorporated a macro-lens when discussing its results. Drawing back on the insight of how macro-level structures and systems influence provision of care at the micro-level, research focusing on the macro-level is needed, especially since gerontological research on the intersection of ageing, migration and ethnicity lacks body of work from this perspective (Torres, 2019b). Research on how the influence of power structures (racism, ageism, sexism) and their intersections influence the ageing experience of older migrants is thus needed. Another example of research to set up from the macro-level angle is triggered by a micro-level finding of this dissertation: care marriages and undocumented care assistants (study 2). A better understanding of the various forms of global care chains and their impact on care providers, care receivers and the ones left behind (in case of migrant care workers) would likewise be welcome.

Toward developing a decolonial research praxis in research on the intersection of ageing and migration.

This dissertation underlines the need for decolonization of research on the intersection of ageing and migration (study 5). However, this awareness has organically grown into incorporation of insights from decolonial frameworks in its research approach. Deliberate application of these insights in the setup of future research is needed. This too can contribute to the collective learning about what a decolonial research praxis on the topic should look like.

5. General Conclusion

This dissertation shows that dementia and the dementia care trajectory as experienced by older labor migrants and their families is both a recognizable and an unknown story. It is recognizable when it entails issues related to the fluidity and course of dementia, the dementia care burden and the general inaccessibility to care. And yet the story is unknown when it considers the added layers resulting from the unique intersectional social position of older migrants and their families shaping these experiences. Moreover, this dissertation invites us to move beyond the binary division between migrants and non-migrants with “having a different culture” as the division line. This unifocal cultural lens to look at the dementia/dementia care experience of older migrants shapes a one-sided story a distorted story that does not capture the variety of influences shaping the diverse, dynamic and complex character of these experiences, a story that essentializes the persons and their experiences while overlooking other dimensions contributing to shared and unshared aspects in the dementia stories.

Our findings show that the specificity of the dementia care experience of migrant families mainly results from their unique intersectional social position, which is also shaped by having a migration background and a non-normative culture and religion. This position signifies a different starting point in the dementia care trajectory. For family caregivers with a migration background this means that they are pioneers in providing dementia care, with a trajectory that is influenced by multiple contexts, forces and hidden mechanisms like cumulative othering and racism. Family caregivers have to provide dementia care while navigating between numerous contexts (personal, interpersonal, transnational, community, professional care) shaped by multiple norms that do not always align (medical, religious, cultural, socioeconomic, gender). This accumulates challenges in addition to a lack of full support from the family, ‘community’ and professional care (such as insensitivity to the multilayered identity of older migrants and encountered racism), making for an extra heavy care burden. Our results do show that care burden protectors are also found in positive religious coping and transnational care networks by agent and creative family caregivers.

This dissertation includes the perspective of professional caregivers to understanding the dementia care trajectory of migrant families, an angle that is often overlooked in research about the topic. The findings illustrate how migration- and diversity-informed needs are considered as abnormal and even illegitimate, and how professional care operates within a White Eurocentric frame while assuming its own neutrality. Professional caregivers are thus unaware of how the coloniality of their thinking and institutional racism direct their actions. Moreover, they operate within an organizational context that lacks the adequate mind frame, knowledge and approaches to provide accessible and good-quality care to older migrants with dementia. A new way of looking at dementia care is needed that takes all of the above in account and that paves a path toward complexity-sensitive person-centered responsive care.

Hence this dissertation contributes to the debate about dementia care for older migrants by broadening the perspective to analyze this question, moving away from the culturalist frame where it is currently embedded both at the care provision and the research level. At the care provision level we suggest a new conceptual lens to examine dementia care for a diverse population. This lens highlights that dementia care provision should be seen in its global, colonial and neoliberal context with

structural mechanisms (e.g. ageism, ableism, racism) shaping this care provision – this while taking into consideration the specific intersectional position that older migrants with dementia and their family caregivers uphold in this context, with the risk of being intersectionally othered and racialized. On a research level this dissertation suggests further exploration of decolonial frameworks as compass for an ethical gerontological research praxis: a praxis that acknowledges the pluriversality of knowledge and knowledge production and which engages us into a process of awareness of and resistance to the historically rooted coloniality of mind in our own knowledge production. A praxis that truly enriches and broadens our gerontological knowledge while integrating various unheard voices and achieving this aim without reproducing inequality.

References

- Ahaddour, C., van den Branden, S., & Broeckeaert, B., (2016). Institutional elderly care services and Moroccan and Turkish migrants in Belgium: a literature review. *J. Immigr. Minor. Health*, 18(5), 1216–1227. DOI: 10.1007/s10903-015-0247-4
- Ahmad, M., Van Den Broeke, J., Saharso, S., & Tonkens, E. (2020). Persons with a migration background caring for a family member with dementia: challenges to shared care. *Gerontologist*, 60(2), 340–349. <https://doi.org/10.1093/geront/gnz161>
- Ahmed, S. (2012). Speaking about racism. .In *On being included racism and diversity in institutional life*. (pp 37–39) London: Duke University Press
- Ahlberg, B. M., Hamed, S., Thapar-Björkert, S., & Bradby, H. (2019). Invisibility of racism in the global neoliberal era: implications for researching racism in healthcare. *Frontiers in Sociology*, 4,1–9. <https://doi.org/10.3389/fsoc.2019.00061>
- Alzheimer Nederland (2012). Alzheimer Theehuis. <https://www.dementievriendelijk.nl/uploads/media/57d7ad35e698f/presentatie-alzheimer-theehuis-oktober-2012.pdf?v1> Retrieved on 05 June 21
- Alzheimers UK (2021) .<https://www.alzheimers.org.uk/get-involved/dementia-friendly-communities/dementia-friendly-faith-groups> Retrieved on 05 June 21
- Azzurra C., Bhattacharya T., & Frazer N. (2019). *Feminism for the 99 %: a manifesto*. London: Verso Books.
- Berdai Chaouni, S., Van Thiel, C. & Vanmechelen, O. (2020). *Is iedereen welkom? Onderzoeksrapport van het leertraject cultuursensitieve zorg in residentiële ouderenzorg*. https://www.kdg.be/sites/default/files/rapport_cszinwzc-sep2020-scherm.pdf
- Berdai Chaouni, S. & Claeys, A. (2021). *Dementie bij ouderen met migratieachtergrond*. Antwerpen: Garant
- Bhalla, D., Lotfalinezhad E., Amini, F., Salmannejad, M., Reza Borhani Nezhad, V., Rezai Kooshalshah, S.F., Delbari, A., Fadayeatan, R., Irmansyah, I., Abdelrahman, A., Bhatta N.K., & Gharagozli, K. (2018). Incidence and risk profile of dementia in the regions of Middle East and North Africa. *Neuroepidemiology*, 50:144–152. <https://doi.org/10.1159/000487761>
- Bleijlevens MH, Stolt M, Stephan A, Zabalegui A, Saks K, et al. (2015) Changes in caregiver burden and health-related quality of life of informal caregivers of older people with Dementia: evidence from the European RightTimePlaceCare prospective cohort study. *J Adv Nurs*. <https://doi.org/10.1111/jan.12561>
- Bilsen, K. (2020) Mother. The documentary. Limerick productions. <https://www.motherdocumentary.com/> Retrieved on 05 June 2021
- Boughtwood, D., Shanley, C., Adams, J., Santalucia, Y., Kyriazopoulos, H., Pond, D., & Rowland, J. (2012). Dementia information for culturally and linguistically diverse communities: sources, access and considerations for effective practice. *Aust J Prim Health*,18(3):190-196. <https://doi.org/10.1071/PY11014>
- Bourabain, D., & Verhaeghe, P. P. (2020). The conceptualization of everyday racism in research on the mental and physical health of ethnic and racial groups: a systematic review. *Journal of Racial and Ethnic Health Disparities*. <https://doi.org/10.1007/s40615-020-00824-5>
- Bourabain, D., & Verhaeghe, P. (2021). Everyday racism in social science research: a systematic review and future directions. *Du Bois Review: Social Science Research on Race*, 1-30. doi:10.1017/S1742058X21000102

- Bradby, H., Humphris, R., & Padilla, B. (2018). Universalism, diversity and norms: gratitude, healthcare and welfare chauvinism. *Critical Public Health*, 30(2), 166–178. <https://doi.org/10.1080/09581596.2018.1522420>
- Bremer, P., Challis, D., Hallberg, I. R., Leino-Kilpi, H., Saks, K., Vellas, B., Zwakhalen, S. M. G., & Sauerland, D. (2017). Informal and formal care: Substitutes or complements in care for people with dementia? Empirical evidence for 8 European countries. *Health Policy*, 121(6), 613–622. <https://doi.org/10.1016/j.healthpol.2017.03.013>
- Broese van Groenou, M. I., & De Boer, A. (2016). Providing informal care in a changing society. *European Journal of Ageing*, 13(3), 271–279. <https://doi.org/10.1007/s10433-016-0370-7>
- Bronfenbrenner, U. (1979). *The ecology of human development: experiments by nature and design*. Massachusetts: Harvard College
- Brooke, J., Cronin, C., Stiell, M., & Ojo, O. (2017). The intersection of culture in the provision of dementia care: A systematic review. *Journal of Clinical Nursing*. <https://doi.org/10.1111/jocn.13999>
- Brotman, S., Ferrer, I., & Koehn, S. (2019). Situating the life story narratives of aging immigrants within a structural context: the intersectional life course perspective as research praxis. *Qualitative Research*. <https://doi.org/10.1177/1468794119880746>
- Cao, Y., & Yang, F. (2020). Objective and subjective dementia caregiving burden: The moderating role of immanent justice reasoning and social support. *International Journal of Environmental Research and Public Health*, 17(2). <https://doi.org/10.3390/ijerph17020455>
- Carbado, D. W., Crenshaw, K. W., Mays, V. M., & Tomlinson, B. (2013). Intersectionality. *Du Bois Review: Social Science Research on Race*. <https://doi.org/10.1017/S1742058X13000349>
- Carlsson, H., Pijpers, R., & Van Melik, R. (2020): Day-care centres for older migrants: spaces to translate practices in the care landscape. *Social & Cultural Geography*. DOI: 10.1080/14649365.2020.1723135
- Carlsson, H., & Pijpers, R. (2020). Diversity-mainstreaming in times of ageing and migration: implementation paradoxes in municipal aged care provision. *Journal of Ethnic and Migration Studies*, 0(0), 1–21. <https://doi.org/10.1080/1369183X.2020.1857231>
- Cès, S., Schmitz, O., Lambert, A., Pauwen N. & Macq, J. (2016). Mantelzorgers van thuiswonende ouderen in België: een cruciale en complexe rol. Data-onderzoek. Brussels: KBS-FRB
- Chawla, D. (2017). Othering and otherness. critical intercultural communication theories, issues, and concepts. <https://doi.org/10.1002/9781118783665.ieicc0230>
- Chimakonam, J.O. (2019). *Othering, re-othering and de-othering*. In: Imafidon E. (ed.) *Handbook of African Philosophy of Difference*. Handbooks in Philosophy. Springer. https://doi.org/10.1007/978-3-030-04941-6_20-1
- Chilunga, F. P., Boateng, D., Henneman, P., Beune, E., Requena-Méndez, A., Meeks, K., Smeeth, L., Addo, J., Bahendeka, S., Danquah, I., Schulze, M. B., Klipstein-Grobusch, K., Mannens, M. M. A. M., & Agyemang, C. (2019). Perceived discrimination and stressful life events are associated with cardiovascular risk score in migrant and non-migrant populations: The RODAM study. *International Journal of Cardiology*, 286, 169–174. <https://doi.org/10.1016/j.ijcard.2018.12.056>
- Ciobanu, R.O., Fokkema, T., Nedelcu, M. (2017). Ageing as a migrant: vulnerabilities, agency and policy implications. *Journal of Ethnic and Migration Studies*. <https://doi.org/10.1080/1369183X.2016.1238903>
- Claeys, A., Berdai-Chaouni, S., Tricas-Sauras, S., & De Donder, L. (2020). Culturally sensitive care : definitions , perceptions , and practices of health care professionals. *Journal of Transcultural Nursing*. <https://doi.org/10.1177/1043659620970625>

- Crenshaw, K. (1989). Demarginalizing the intersection of race and sex: a black feminist critique of antidiscrimination doctrine, feminist theory and antiracist policies. *The university of Chicago legal forum*, (1), 139–167. <https://doi.org/10.1525/sp.2007.54.1.23>.
- De Meuse, K.P. (2017). Learning agility: Its evolution as a psychological construct and its empirical relationship to leader success. *Consulting Psychology Journal*, 69(4), 267–295. <https://doi.org/10.1037/cpb0000100>
- Dely H., Verschraegen J., Steyaert J. (2018) *You and me, together we are human: a reference framework for quality of life, housing and care for people with dementia*. Antwerpen: EPO
- De Wilde, C., Carrington, J., Abbate, A., Burton, C.W., Bearman, G., & Salyer, J. (2019). Structural stress and otherness: how do they influence psychological stress? *Journal of Transcultural Nursing*, 30(5), 478–491. <https://doi.org/10.1177/1043659618823915>
- Dewing, J. (2019). On being a person. *In Dementia reconsidered, revisited. The person still comes first*. Kitwood, T./Brooker, D. (Eds.) (pp 17-23) London: Open University Press
- Engel, G.L. (1978). The biopsychosocial model and the education of health professionals. *Ann. N. Y. Acad. Sci.*, 21(310):169-87. doi: 10.1111/j.1749-6632.1978.tb22070.x
- Erol, R., Brooker, D., & Peel, E. (2015). *Dementia and women: an international review*. London: Alzheimer's Disease International
- Essed, P. (1991). *Understanding everyday racism: an interdisciplinary theory*. California: Sage Publications
- Epner, D.E., & Baile, W.F. (2012). Patient-centered care: the key to cultural competence. *Annals of oncology*, 23(3), 33–42.
- Fadil, N. (2019). It's not possible for me to be objective: on decolonisation in social sciences. <http://www.dewereldmorgen.be/artikel/2019/04/10/over-de-dekolonisatie-van-de-sociale-wetenschappen-%c2%93it-is-not-possible-for-me-to-be-objective%c2%94/>
- Fanon, F. (1952/2008). *Black skin, white masks*. Philcox R translation. New York: Grove Press.
- Farina, N., Page, T. E., Daley, S., Brown, A., Bowling, A., Basset, T., Livingston, G., Knapp, M., Murray, J., & Banerjee, S. (2017). Factors associated with the quality of life of family carers of people with dementia : A systematic review. *Alzheimer's & Dementia*, 1–10. <https://doi.org/10.1016/j.jalz.2016.12.010>
- Fider, C.R.A., Lee, J.W., Gleason, P.C., & Jones, P. (2019). Influence of religion on later burden and health of new Black and White caregivers. *Journal of Applied Gerontology*, 38(9) 1282–1303. DOI: 10.1177/0733464817703017
- Flemish Government. (2016). *Samen verder bouwen aan een dementievriendelijk Vlaanderen. Geactualiseerd Dementieplan Vlaanderen 2016-2019*. <https://publicaties.vlaanderen.be/view-file/25565> Retrieved 03 May 2021
- Forssell, E., Torres, S., Olaison, A. (2015). Care managers' experiences of cross-cultural needs assessment meetings: the case of late-in-life immigrants. *Aging Soc.*, 35(3), 576–601. DOI: 10.1017/S0144686X130 0 0901
- Fret, B., De Donder, L., Lambotte, D., Dury, S., Van der Elst, M., De Witte, N., Switsers, L., Hoens, S., Van Regenmortel, S., & Verté, D. (2019). Access to care of frail community-dwelling older adults in Belgium: a qualitative study. *Primary Health Care Research & Development*, <https://doi.org/10.1017/s1463423619000100>
- Gans, H. J. (2017). Racialization and racialization research. <https://doi.org/10.1080/01419870.2017.1238497>
- Ghosh, S., Muduli, A., & Pingle, S. (2020). Role of e-learning technology and culture on learning agility: An empirical evidence. *Human Systems Management*, 40, 1–14. <https://doi.org/10.3233/hsm-201028>

Gilhooly, K.J., Gilhooly, M.L.M., Sullivan, M.P., McIntyre, A., Wilson, L., Harding, E., Woodbridge, R., & Crutsch, S (2016). A meta-review of stress, coping and interventions in dementia and dementia caregiving. *BMC Geriatr.* DOI:10.1186/s12877-016-0280-8

Gonzalez-Sobrin, B., & Goss, D. R. (2019). Exploring the mechanisms of racialization beyond the black – white binary. <https://doi.org/10.1080/01419870.2018.1444781>

Grenier, A., Lloyd, L., & Phillipson, C. (2017). Precarity in late life: rethinking dementia as a ‘fraild’ old age. *Sociology of Health and Illness*, 39(2), 318–330. <https://doi.org/10.1111/1467-9566.12476>

Grosfoguel, R., Oso, L., & Christou, A. (2014). ‘Racism’, intersectionality and migration studies: framing some theoretical reflections. <https://doi.org/10.1080/1070289X.2014.950974>

Grosfoguel, R. (2016). What Is Racism? *Journal of World-Systems Research*, 22(1): 9–15.

Goudsmit, M., Uysal-Bozkir, Ö., Parlevliet, J.L., van Campen, J.P.C.M., de Rooij, S.E., & Schmand, B. (2017). The Cross-Cultural Dementia Screening (CCD): A new neuropsychological screening instrument for dementia in elderly immigrants. *Journal of Clinical and Experimental Neuropsychology*, 39(2), 163–172.

Gove, D., Georges, J., Nielsen, T. R., Plejert, Ch., Rauf, M.A., Lahav, D., Jaakson, S., Kaur, R., Her, M., Parveen, S., Golan-Shemesh, D., & Smits, C. (2018) *The development of intercultural care and support for people with dementia from minority ethnic groups.* Ethics Report. Alzheimer Europe. <https://www.alzheimer-europe.org/Ethics/Ethical-issues-in-practice/2018-Intercultural-care-and-support>

Gove, D., Georges, J., Rauf, M. A., van den Broeke, J., Berdai Chaouni, S., Claeys, A., & Watchman, K. (2019). *Overcoming ethical challenges affecting the involvement of people with dementia in research: Recognising diversity and promoting inclusive research on dementia in Europe.* Ethics Report. Alzheimer Europe. [https://www.alzheimer-europe.org/Ethics/Ethical-issues-in-practice/2019-Overcoming-ethical-challenges-affecting-the-involvement-of-people-with-dementia-in-research/\(language\)/eng-GB](https://www.alzheimer-europe.org/Ethics/Ethical-issues-in-practice/2019-Overcoming-ethical-challenges-affecting-the-involvement-of-people-with-dementia-in-research/(language)/eng-GB)

Hamed, S., Thapar-björkert, S., Bradby, H., & Ahlberg, B. M. (2020). Racism in European health care : structural violence and beyond. <https://doi.org/10.1177/1049732320931430>

Hardeman, R.R., Karbeah, J. (2020)? Examining racism in health services research: A disciplinary self-critique. *Health Serv Res.*, 55(2):777–780. <https://doi.org/10.1111/1475-6773.13558>

Hoens, S., Smetcoren, A-S., De Donder, L. (2019) Experiences of older people and informal caregivers with live-in migrant care workers in Belgium. *Innovation in Aging*, Volume 3, Issue Supplement_1, Page S578, <https://doi.org/10.1093/geroni/igz038.2142>

Horn, H., Schweppe, C., Böcker, H., Bruquetas-Callejo, M. (2019). Live-in migrant care worker arrangements in Germany and the Netherlands: motivations and justifications in family decision-making. 1–31. <https://doi.org/10.3384/ijal.1652-8670.18410>

Hulko, W. (2009). From “not a big deal” to “hellish”: Experiences of older people with dementia. *Journal of Aging Studies*, 23(3), 131–144. <https://doi.org/10.1016/j.jaging.2007.11.002>

[Jacobs, M., Van Tilburg, T., Groenewegen, P., & Van Groenou, M. B. \(2015\). Linkages between informal and formal caregivers in home-care networks of frail older adults. *Ageing and Society*, 36, 1604–1624.](https://doi.org/10.1016/j.jaging.2007.11.002)

Khanassov, V., & Vedel, I. (2016). Family physician–case manager collaboration and needs of patients with dementia and their caregivers: A systematic mixed studies review. *Annals of Family Medicine*, 14(2), 166–177. <https://doi.org/10.1370/afm.1898>

Keady, J., & Elvish, R. (2019) Requirements of a caregiver. In *Dementia reconsidered, revisited. The person still comes first.* Brooker, D. (Ed.) London: Open University Press

- Kilomba, G. (2020). *Plantation memories. Episodes of everyday racism*. Münster: Unrast-Verlag.
- Kilanowski, J. F. (2017). Breadth of the Socio-Ecological Model. *Journal of Agromedicine*, 22(4), 295–297. <https://doi.org/10.1080/1059924X.2017.1358971>
- Kirmayer, L. J., Jarvis, G. E. (2019). Culturally responsive services as a path to equity in mental health care. *Healthcare Papers* 18(2): 11–23.
- [Kitwood, T. \(1997\). *Dementia reconsidered. The person comes first*. Buckingham: Open University Press](#)
- [Kitwood, T. \(2019\). *Dementia reconsidered, revisited. The person still comes first*. Brooker, D. \(Ed.\) London: Open University Press](#)
- Krieger, N. (2020). Measures of racism, sexism, heterosexism, and gender binarism for health equity research: from structural injustice to embodied harm an ecosocial analysis. *Annual Review of Public Health*, 41, 37–62. <https://doi.org/10.1146/annurev-publhealth-040119-094017>
- Lambotte, D., Smetcoren, A.-S., Zijlstra, G. A. R., De Lepeleire, J., De Donder, L., Kardol, M. J. M., Smetcoren, A.-S., Dury, S., De Donder, L., Dierckx, E., Lambotte, D., Fret, B., Duppen, D., Kardol, M., Verté, D., Hoeyberghs, L. J., De Witte, N., De Roeck, E. E., Engelborghs, S., & Schols, J. M. G. A. (2019). Meanings of care convoys: the structure, function, and adequacy of care networks among frail, community-dwelling older adults. *Qualitative Health Research*, <https://doi.org/10.1177/1049732319861934>
- Lane, H., Sarkies, M., Martin, J., & Haines, T. (2017). Equity in healthcare resource allocation decision making: A systematic review. *Social Science and Medicine*, 175, 11–27. <https://doi.org/10.1016/j.socscimed.2016.12.012>
- Lee, J., & Song, J. H. (2020). Developing a conceptual integrated model for the employee's learning agility. *Performance Improvement Quarterly*, <https://doi.org/10.1002/piq.21352>
- Liew, T. M., Tai, B. C., Yap, P., & Koh, G. C. H. (2019). Contrasting the risk factors of grief and burden in caregivers of persons with dementia: Multivariate analysis. *International Journal of Geriatric Psychiatry*, 34(2), 258–264. <https://doi.org/10.1002/gps.5014>
- Life, L., & Author, T. (2019). Live-in migrant care worker arrangements in Germany and the Netherlands : motivations and justifications in family decision-making. <https://doi.org/10.3384/ijal.1652-8670.18410>
- Lopez Hartmann, M.(2020). *Social support for informal caregivers of community-dwelling frail elderly*. University of Antwerp: PhD dissertation
- Maldonado-Torres, N. n.d. Outline of ten theses on coloniality and decoloniality. http://frantzfanonfoundation-fondationfrantzfanon.com/IMG/pdf/maldonado-torres_outline_of_ten_theses-10.23.16_.pdf. Retrieved on 4 April 2021.
- Mahdavi, B., Fallahi-khoshknab, M., Mohammadi, F., Hosseini, M. A., & Haghi, M. (2017). Effects of spiritual group therapy on caregiver strain in home caregivers of the elderly with Alzheimer ' s disease archives of psychiatric nursing effects of spiritual group therapy on caregiver strain in home caregivers of the elderly with Alzheimer ' s disease. *Archives of Psychiatric Nursing*, <https://doi.org/10.1016/j.apnu.2016.12.003>
- Milberg, A., Torres, S., & Ågård, P. (2016). Health care professionals' understandings of cross-cultural interaction in end-of-life care: a focus group study. *PLoS One*, 11(11), <https://doi.org/10.1371/journal.pone.0165452>
- Milligan, C., & Morbey, H. (2016). Care, coping and identity: Older men's experiences of spousal care-giving. *Journal of Aging Studies*, 38, 105–114. <https://doi.org/10.1016/j.jaging.2016.05.002>
- Monteiro, A.M.F., Santos, R.L., Kimura, N., Baptista, M.A.T., Dourado, M.C.N. (2018). Coping strategies among caregivers of people with Alzheimer diseased: a systematic review. *Trends Psychiatry Psychothe*, 40(3),258-268.

Morelli, A. (1988). L'appel à la main d'oeuvre italienne pour les charbonnages et sa prise en charge à son arrivée en Belgique dans l'immédiat après-guerre. *Revue Belge d'Histoire Contemporaine*, XIX(1–2), 83–130.

Moreno, A., Darío, C., Nahui, C., Gabriel, C., Vasquez, E., Vanwing, T., & Ponce, N. T. (2021). Breaking monologues in collaborative research : bridging knowledge systems through a listening - based dialogue of wisdom approach. *Sustainability Science*, <https://doi.org/10.1007/s11625-021-00937-8>

Mujica, C., & Cruz-Gonzalez, M. (2020). Association between patient-provider racial and ethnic concordance and patient-centered communication in outpatient mental health clinics. *APA PsycNet*, 30(3), 423–439.

Mukadam, N., Cooper, C., & Livingston, G. (2013). Improving access to dementia services for people from minority ethnic groups. *Current Opinion in Psychiatry*, 26(4), 409–414. <https://doi.org/10.1097/YCO.0b013e32835ee668>

NAPAR coalition. (2021). Memorandum. <https://nl.naparbelgium.org/revendications> Retrieved on 05 May 2021

Nazroo, J. (2006). *Health and social research in multiethnic societies*. Abingdon: Routledge

Nielsen, T.R., Vogel, A., Phung, T.K.T., Gade, A. & Waldemar, G. (2011a). Over- and under-diagnosis of dementia in ethnic minorities: a nationwide register-based study. *Int Journal of Geriatric Psychiatry*, 26(11), 1128–1135.

Nielsen, TR., Vogel, A., Riepe, AM., de Mendonça, A., Rodriguez, G., Nobili F, Gade, A. & Waldemar, G. (2011 b) Assessment of dementia in ethnic minority patients in Europe: a European Alzheimer's disease consortium survey. *International Psychogeriatrics*, 23,1, 86-95

Nielsen, T.R., Segers, K., Vanderaspolden, V., Bekkhus-Wetterberg, P., Minthon, L., Pissioti, A., Hanevold Bjørkløf, G., Beinhoff, U., Tsolaki, M., Gkioka, M., & Waldemar, G. (2018). Performance of middle-aged and elderly European minority and majority populations on a Cross-Cultural Neuropsychological Test Battery (CNTB). *Clin Neuropsychol*. DOI: 10.1080/13854046.2018.1430256

Nielsen T.R. & Waldemar, G. (2020). Rotational care practices in minority ethnic families managing dementia : A qualitative study. <https://doi.org/10.1177/1471301220914751>

Norris, M. (2015). The complexities of “otherness”: reflections on embodiment of a young White British woman engaged in cross-generation research involving older people in Indonesia. *Ageing & Society* 35, 986–1010. DOI:10.1017/S0144686X14001366

Orfila, F., Coma-Sole, M., Cabanas, M., Cegri-Lombardo, F., Moleras-Serra, A., Pujol-Ribera, E. (2018). Family caregiver mistreatment of the elderly: prevalence of risk and associated factors. *BMC Public Health*, DOI 10.1186/s12889-018-5067-8

Parland, P. M., Kelly, F., & Innes, A. (2017). Dichotomising dementia : is there another way ? *Sociology of Health & Illness* 39(2), 258–269. <https://doi.org/10.1111/1467-9566.12438>

[Pascoe, E.A., & Smart Richman, L. \(2009\). Perceived discrimination and health: a meta-analytic review. *Psychol Bull.* 135\(4\):531–54. https:// doi.org/10.1037/a0016059.](https://doi.org/10.1037/a0016059)

Phillipson, C. (2015). Placing ethnicity at the centre of studies of later life: Theoretical perspectives and empirical challenges. *Ageing and Society*, 35, 917–934. <https://doi.org/10.1017/SO144686X14001032>

Powell, J. A., & Menéndian, S. (2016). The problem of othering: Towards inclusiveness and belonging. In *Othering and belonging: Expanding the circle of human concern*, Issue 1, Andrew Grant-Thomas (Ed.). Berkeley: Haas Institute.

Prince, M., Bryce, R., Albanese, E., Wimo, A., Ribeiro, W., & Ferri, C. P. (2013). The global prevalence of dementia: A systematic review and meta-analysis. *Alzheimer's and Dementia*, <https://doi.org/10.1016/j.jalz.2012.11.007>

- Rathier, L.A., Davis, J.D., Papandonatos, G.D., Grovorn C., & Tremont, G. (2015). Religious coping in caregivers of family members with dementia. *J Appl Gerontol.* 34(8), 977-1000.
- Rajan-Rankin, S. (2018). Race, embodiment and later life: Re-animating aging bodies of color. *Journal of Aging Studies*, 45,32–38. <https://doi.org/10.1016/j.jaging.2018.01.005>
- Rast, M. C., & Ghorashi, H. (2018). Dancing with ‘the other’’: Challenges and opportunities of deepening democracy through participatory spaces for refugees.’ *Social Inclusion*, 6(1), 188–198. <https://doi.org/10.17645/si.v6i1.1300>
- Reisberg, B., Ferris, S.H., de Leon, M.J., & Crook, T. (1982) The global deterioration scale for assessment of primary degenerative dementia. *American Journal of Psychiatry*, 139: 1136-1139.
- [Resnicow, K., Baranowski, T., Ahluwalia, J.S., & Braithwaite, R.L. \(1999\). Cultural sensitivity in public health: defined and demystified. *Ethn. Dis.* 9\(1\), 10–21 .](#)
- [Saeyen, A., Neyens, I., Hermans, K., & Van Audenhove Ch. \(2020\). Onderzoek om zorgverleners te zoeken bij ethnische minderheden.Welzijn Volksgezondheid en gezin. <https://steunpuntwvg.be/images/swvg-3-rapporten/ef45-diversiteit-zorgberoepen>](#)
- Sagbakken, M., Spilker, R. S., & Nielsen, T. R. (2018). Dementia and immigrant groups: A qualitative study of challenges related to identifying, assessing, and diagnosing dementia. *BMC Health Services Research*, 18(1), 1–14. <https://doi.org/10.1186/s12913-018-3720-7>
- Sagbakken, M., Spilker, R.S., & Ingebretsen, R. (2017). Dementia and migration: family care patterns merging with public care services. *Qual. Health Res.*, 28(1), 16– 29. DOI: 10.1177/1049732317730818
- Said, E. (1978) *Orientalism*. UK: Penguin Random House, (Reissued version 2019) ISBN: 978-0-141-18742-2
- Sayegh, P., & Knight, B. G. (2013). Cross-cultural differences in dementia: the sociocultural health belief model. *International Psychogeriatrics*. <https://doi.org/10.1017/S104161021200213X>
- Schaffler, J. L., Tremblay, S., Laizner, A. M., & Lambert, S. (2019). Developing education materials for caregivers of culturally and linguistically diverse patients: Insights from a qualitative analysis of caregivers’ needs, access and understanding of information. *Health Expectations*, 22(3), 444–456. <https://doi.org/10.1111/hex.12867>
- Schwiter, K, Berndt, C. & Truong, J. (2018). Neoliberal austerity and the marketisation of elderly care, *Social & Cultural Geography*, 19(3), 379-399. DOI: 10.1080/14649365.2015.1059473
- Segers, K., Benoit, F., Colson, C., Kovacn V., Nury, D. & Vanderaspolden, V. (2013). Pioneers in migration, pioneering in dementia: first generation immigrants in a European metropolitan memory clinic. *Acta Neurol Belg.* 113(4), 435-40. doi: 10.1007/s13760-013-0245-z.
- Sellevoid, G. S., Egede-Nissen, V., Jakobsen, R., & Sorlie, V. (2013). Quality care for persons experiencing dementia: the significance of relational ethics. *Nursing Ethics*, 20(3), 263–272. <https://doi.org/10.1177/0969733012462050>.
- Sherkat, D. E., Kilbourne, B.S., Cain, V.A., Hull, P.C., Levine, R.S., & Husaini, B.A. (2007). The impact of health service use on racial differences in mortality among the elderly. *Research on Aging* 29(3): 207–224.
- Snyder, C. M., Fauth, E., Wanzek, J., Piercy, K. W., Norton, M. C., Corcoran, C., Rabins, P. V., Lyketsos, C. G., & Tschanz, J. T. (2014). Dementia caregivers’ coping strategies and their relationship to health and well-being: the Cache County Study. *Aging & Mental Health*, 19(5), 390–399. <https://doi.org/10.1080/13607863.2014.939610>
- Söderman, M., Rosendahl, S., & Sällström, C. (2018). Caring and uncaring encounters between assistant nurses and immigrants with dementia symptoms in two group homes in sweden-an observational study. *Journal of Cross-Cultural Gerontology*, 33(3), 299–317. <https://doi.org/10.1007/s10823-018-9351-y>

- Stephan, A., Möhler, R., Renom-Guiteras, A., & Meyer, G. (2015). Successful collaboration in dementia care from the perspectives of healthcare professionals and informal carers in Germany: Results from a focus group study. *BMC Health Services Research*, 15(1), 208. <https://doi.org/10.1186/s12913-015-0875-3>
- Sue, D.W. (2010). *Microaggressions in everyday life. Race, gender, and sexual orientation*. New Jersey: John Wiley & Sons.
- Swaffer, K. (2014). Disability dementia: stigma, language, and dementia-friendly. *Dementia*, 13(6). <https://doi.org/10.1177/1471301214548143>
- Thomas, C., & Milligan, C. (2017). Dementia, rights and disablism: understanding the social position of people living with dementia. *Dissability & Society*, 33, 115-131. <https://doi.org/10.1080/09687599.2017.1379952>
- Tronto, J.C. (2014 a) Moral boundaries after twenty years: from limits to possibilities. In *Moral boundaries redrawn. The significance of Joan Tronto's argument for political theory, professional ethics and care as practice*. Olthuis, G., Kohlen, H. & Heir, J. (Eds). (pp 9-28) Ethics of Care. ISBN 978-90-429-3023-0
- Tronto, J.C. (2014 b). Ethics of care: present and new directions. In *Moral boundaries redrawn. The significance of Joan Tronto's argument for political theory, professional ethics and care as practice*. (pp 215- 228) Olthuis, G., Kohlen, H. & Heir, J. (Eds). Ethics of Care. ISBN 978-90-429-3023-0
- Torres, S., Ågård, P., & Milberg, A. (2016). The 'other' in end-of-life care: providers' understandings of patients with migrant backgrounds. *Journal of Intercultural Studies*, 37(2), 103–117. <https://doi.org/10.1080/07256868.2016.1141756>
- Torres, S. (2019, a). *Ethnicity and old age. Expanding our imagination*. Policy Press. ISBN-10: 1447328116
- Torres, S. (2019, b). Ethnicity, race and care in older age: What can a social justice framework offer? In *Ageing, Diversity and Equality: Social Justice Perspectives*. Westwood, S. (Ed.). New York: Routledge ISBN: 978-0-415-78669-0
- Torres, S. (2020). Racialization without racism in scholarship on old age. *Swiss Journal of Sociology*. 46(2), 331–349. <https://doi.org/10.2478/sjs-2020-0017>
- Van der Lee, J., Bakker, T.J., Duivenvoorden, H.J., Dröes, R.-M. (2014). Multivariate models of subjective caregiver burden in dementia: A systematic review. *Ageing Res. Rev.* 15, 76–93.
- van Dyk, S. (2016). The othering of old age: Insights from postcolonial studies. *Journal of Aging Studies*, 39, 109–120. <https://doi.org/10.1016/j.jaging.2016.06.005>
- van Mierlo, L. D., MacNeil-Vroomen, J., Meiland, F. J. M., Joling, K. J., Bosmans, J. E., Dröes, R. M., Moll van Charante, E. P., de Rooij, S. E. J. A., & van Hout, H. P. J. (2016). Implementatie en (kosten-)effectiviteit van casemanagement voor mensen met dementie en hun mantelzorgers: resultaten van de COMPAS-studie. *Tijdschrift Voor Gerontologie En Geriatrie*, 47(6), 223–233. <https://doi.org/10.1007/s12439-016-0197-x>
- Van Wezel, N, Francke, A., Kayan-Acun, E., Lim Devillé, W., van Grondelle N.J., & Blom M.M. (2016). Family care for immigrants with dementia: The perspectives of female family carers living in The Netherlands. *Dementia*, 15(1), 69–84.
- Van Wijngaarden, E., Wedden, H., Van Der Henning, Z., & Komen, R. (2018). Entangled in uncertainty : The experience of living with dementia from the perspective of family caregivers. *PLOS*. <https://doi.org/10.1371/journal.pone.0198034>
- Van Wijngaarden, E., Alma, M., & The, A. M. (2019). 'The eyes of others' are what really matters: The experience of living with dementia from an insider perspective. *PLoS ONE*, 14(4), 1–23. <https://doi.org/10.1371/journal.pone.0214724>

- Wade, D. T., & Halligan, P. W. (2017). The biopsychosocial model of illness: A model whose time has come. *Clinical Rehabilitation*, 31(8), 995–1004. <https://doi.org/10.1177/0269215517709890>
- Wekker, G. (2016). *White innocence, paradoxes of colonialism and race*. Duke University Press
- Wilding, R., Baldassar, L. (2018). Ageing, migration and new media: the significance of transnational care. *J. Sociol.* 54(2), 226–235. DOI: 10.1177/1440783318766168 .
- Wilks, S.E., Spurlock, W.R., Brown, S.C., Teegen, B.C., & Geiger, J.R. (2018). Examining spiritual support among African American and Caucasian Alzheimer’s caregivers: a risk and resilience study. *Geriatr Nurs.* 39 (6), 663-668.
- Wittenberg, Y., Kwekkeboom, R., Staaks, J., Verhoeff, A., & de Boer, A. (2017). Informal caregivers’ views on the division of responsibilities between themselves and professionals: A scoping review. *Health and Social Care in the Community*. <https://doi.org/10.1111/hsc.12529>
- World Alzheimer Report. (2019). *Attitudes to dementia*. London: Alzheimer’s Disease International
- WHO. (2007). Global age-friendly cities: A guide. *Community Health*, http://www.who.int/ageing/publications/Global_age_friendly_cities_Guide_English.pdf
- WHO. (2020). *Decade of Healthy Ageing*. <https://www.who.int/initiatives/decade-of-healthy-ageing%0Ahttps://www.who.int/initiatives/decade-of-healthy-ageing/connection-series%0Ahttps://www.who.int/ageing/decade-of-healthy-ageing>
- WHO. (2021a). *Global report on ageism*. <https://www.who.int/publications/i/item/9789240016866> . Retrieved on 21 March 2021
- WHO. (2021b). *Initiating conversation about ageism*. <https://www.who.int/publications/m/item/initiating-a-conversation-about-ageism> Retrieved on 21 March 2021
- Zubair, M., & Norris, M. (2015). Perspectives on ageing, later life and ethnicity: Ageing research in ethnic minority contexts. *Ageing and Society*, 35(5), 897–916. <https://doi.org/10.1017/S0144686X14001536>
- Zwaanswijk, M., Peeters, J. M., van Beek, A. P., Meerveld, J. H., & Francke, A. L. (2013). Informal caregivers of people with dementia: problems, needs and support in the initial stage and in subsequent stages of dementia: a questionnaire survey. *The Open Nursing Journal*, 7, 6–13. <https://doi.org/10.2174/1874434601307010006>

Summary

Belgium has a growing ethnic diversity among its older population, with Moroccan migrants as the largest non-European migrants. Although exact numbers on dementia prevalence among ethnic minority populations in Belgium are missing, there is a hypothesis that dementia is higher among this subpopulation. Older migrants with dementia seem to follow a specific dementia care trajectory with diagnostic challenges, preference for family care and under-use of professional care. Knowledge about dementia and older migrants in Belgium is rare and the situation of older migrants with dementia is often addressed by 'culture' as a dominant one-sided perspective. Moreover, gerontological research on this topic seems to be biased, resulting in the reproduction of narrow assumptions about this population and of societal inequality within and throughout research itself. Yet, limited knowledge is available on how to conduct ethical research on dementia among older migrants. The dissertation aimed to address these research gaps and explores: 1) a multilayered image of the dementia experience and dementia care provision among labor migrant families, and 2) methodological pathways to contribute to more ethical research involving this population.

For the empirical part of this dissertation 65 caregivers (informal and formal) were engaged in 3 qualitative cross-sectional studies. 49 family caregivers with a labor migration background (28 Moroccan, 11 Turkish and 10 Italian) and 16 professional caregivers (with and without migration background) shared their experience about dementia and dementia care provision among migrant families. To answer the question of how we can improve gerontological research on older migrants and their family caregivers 2 studies were conducted. The first one engaged 10 experts besides a narrative literature review to zoom in on the inclusion of older migrants with dementia and their caregivers in research. The second, was a theoretical paper about the opportunities of decolonial frameworks for an ethical gerontological research on the intersection of ageing and ethnicity.

This dissertation shows that dementia and the dementia care trajectory as experienced by older migrants and their families is both a recognizable and an unknown story. It is 'recognizable' when it entails issues related to the fluidity and course of dementia, the dementia care burden and the general inaccessibility to care. And yet the story is unknown when it considers the added layers resulting from the unique intersectional social position of older migrants and their families shaping their experiences, encountered challenges and found answers. This dissertation invites us to move beyond the binary division between migrants and non-migrants with "having a different culture" as the division line, and recognize the impact of having a migration background, a non-normative culture and religion on care provision. Current dementia care is provided by a complex and dynamic network that includes alternative care forms and caregivers within a transnational context. This picture of care provision is sought by family caregivers as an answer to unmet needs to provide "complexity-sensitive person-centered responsive care", which considers the multilayered identity of the older migrant with dementia. This reflects individual and structural professional care gaps to provide suitable, affordable and inclusive dementia care. Understanding this complexity can advance the provision of better dementia care for older migrants with dementia.

Finally, this dissertation contributes to the debate about dementia care for older migrants by moving away from the culturalist frame where it is currently embedded both at the care provision and the research level. At the care provision level, we question person-centred care and cultural-sensitive care

and suggest a new conceptual lens to examine dementia care for a diverse population. This lens highlights that dementia care provision should be seen in its global, colonial and neoliberal context with structural mechanisms (e.g. ageism, ableism, racism) shaping this care provision. This while taking into consideration the specific intersectional position all parties involved in the care relationship: older migrants with dementia, their family and professional caregivers. On a research level this dissertation suggests further exploration of decolonial frameworks as compass for an ethical gerontological research praxis: a praxis that acknowledges the pluriversality of knowledge and knowledge production and which engages us into a process of awareness of and resistance to the historically rooted coloniality of mind in our own knowledge production. A praxis that truly enriches and broadens our gerontological knowledge while integrating various unheard voices and achieving this aim without reproducing inequality.

Samenvatting

België kent een groeiende etnische diversiteit onder de oudere bevolking. Ouderen met Marokkaanse achtergrond vormen hierbij de grootste niet-Europese groep. Hoewel exacte cijfers over de prevalentie van dementie onder etnische minderheden in België ontbreken, is er een hypothese dat dementie hoger is bij deze subpopulatie. Oudere migranten met dementie lijken een specifiek dementiezorgtraject te volgen met diagnostische uitdagingen, voorkeur voor mantelzorg en ondergebruik van professionele zorg. Kennis over dementie en oudere migranten in België is zeldzaam en de situatie van oudere migranten met dementie wordt vaak vanuit 'cultuur', als een dominant eenzijdig perspectief, bekeken. Bovendien blijkt gerontologisch onderzoek over dit onderwerp gevoelig voor reproductie van enge aannames over deze populatie en bij te dragen aan maatschappelijke ongelijkheid van deze groep binnen en doorheen het onderzoek zelf. Daarnaast is er beperkte kennis beschikbaar over het uitvoeren van ethisch onderzoek naar dementie bij oudere migranten. Het proefschrift onderzocht daarom deze lacunes en verkent: 1) een meerlagig beeld van de dementie-ervaring en dementiezorg bij arbeidsmigrantengezinnen, en 2) methodologische vormen die aan meer ethisch onderzoek over dit thema bijdragen.

Voor het empirische deel van dit proefschrift voerden we 3 kwalitatieve cross-sectionele onderzoeken uit, met inclusie van 65 zorgverleners (informeel en formeel). 49 mantelzorgers met een arbeidsmigratieachtergrond (28 Marokkaanse, 11 Turkse en 10 Italiaanse) en 16 professionele mantelzorgers (met en zonder migratieachtergrond) deelden hun ervaringen over dementie en dementiezorg onder gezinnen met migratieachtergrond. Twee bijkomende studies zijn uitgevoerd om de vraag over hoe we gerontologisch onderzoek bij oudere migranten en hun mantelzorgers kunnen verbeteren te beantwoorden. De eerste studie bevroeg 10 experts over de inclusie van oudere migranten met dementie en hun mantelzorgers in onderzoek. De tweede (literatuur)studie resulteerde in een theoretisch artikel over de mogelijkheden van dekoloniale kaders voor een ethisch gerontologisch onderzoek op het snijvlak van veroudering en etniciteit.

Dit proefschrift toont aan dat de ervaring van dementie en het bijhorende zorgtraject door ouderen met migratieachtergrond en hun families zowel een herkenbaar als een onbekend verhaal is. Het is 'herkenbaar' als het gaat om vraagstukken die te maken hebben met de eigenschappen en het beloop van dementie, de zorglast en de algemene toegankelijkheid van zorg. Het verhaal is onbekend wanneer het gaat over hoe de unieke intersectionele sociale positie van deze oudere en hun families lagen aan deze ervaringen, de tegengekomen uitdagingen en gefundeerde antwoorden toevoegt. Dit proefschrift nodigt ons daarom uit om voorbij te gaan aan de binaire scheiding tussen migranten en niet-migrant, met "een andere cultuur hebben" als scheidingslijn en de impact van het hebben van een migratieachtergrond en een niet-normatieve cultuur en religie op dementiezorg te erkennen. De huidige dementiezorg wordt geleverd door een complex en dynamisch zorgnetwerk, met alternatieve zorgvormen en zorgverleners in een transnationale context. Dit beeld van zorgverlening wordt gezocht door mantelzorgers als een antwoord op onvervulde behoeften om "complexiteitsgevoelige persoonsgerichte responsieve zorg" te bieden: een zorg die rekening houdt met de meerlagige identiteit van oudere migranten met dementie. Dit weerspiegelt ook individuele en structurele uitdagingen binnen de professionele zorg om passende, betaalbare en inclusieve dementiezorg te bieden. Inzicht in deze complexiteit kan het verstrekken van een betere dementiezorg voor oudere migranten met dementie bevorderen.

Daarom draagt dit proefschrift tenslotte bij aan het debat over dementiezorg voor ouderen met migratieachtergrond door het perspectief te verbreden om deze vraag te analyseren. Dit zowel binnen

de zorgverlening als op niveau van onderzoek en loskomend van het culturaliserende kader waarin het debat momenteel is ingebed. Op het niveau van de zorg worden persoonsgerichte en cultuursensitieve zorg in vraag gesteld en wordt er een nieuwe conceptuele lens voorgesteld om naar dementiezorg voor een diverse populatie te kijken. Deze lens benadrukt dat de zorgverlening voor dementie gezien moet worden in zijn globale, koloniale en neoliberale context met structurele mechanismen (bijv. ageism, ableism, racisme) die deze zorgverlening vormgeven. Tegelijkertijd houdt deze lens ook rekening met de gevolgen van de specifieke sociale positie van alle betrokken partijen in de zorgrelatie: oudere migranten met dementie, mantelzorgers en professionele zorgverleners. Op onderzoeksniveau suggereert dit proefschrift een verdere verkenning van de inzichten uit dekoloniale kaders als kompas voor een ethische gerontologische onderzoekspraktijk die de pluriversaliteit van kennis en kennisproductie erkent. Eentje die ons, na een bewustwordingsproces, uitnodigt om weerstand te bieden tegen de historisch gewortelde kolonialiteit van het denken en zijn gevolgen in onze eigen kennisproductie. Een onderzoekspraktijk die onze gerontologische kennis verrijkt en verbreedt, met plaats voor ongehoorde stemmen en zonder ongelijkheid te reproduceren.

List of publications

International peer reviewed papers

Berdai Chaouni, S., Claeys, A., van den Broeke, J., & De Donder, L. (2021). Doing research on the intersection of ethnicity and old age : Key insights from decolonial frameworks. *Journal of Aging Studies*, 56(November 2019), 100909. <https://doi.org/10.1016/j.jaging.2020.100909>

Berdai Chaouni, S., Smetcoren, A.-S., & De Donder, L. (2020). Caring for migrant older Moroccans with dementia in Belgium as a complex and dynamic transnational network of informal and professional care: A qualitative study. *International Journal of Nursing Studies*. <https://doi.org/10.1016/j.ijnurstu.2019.103413>

Claeys, A., **Berdai Chaouni, S.,** Tricas-Sauras, S., & De Donder, L. (2020). Culturally sensitive care : definitions , perceptions , and practices of health care professionals. *International Journal of Nursing Studies*. <https://doi.org/10.1177/1043659620970625>

Berdai Chaouni, S., & De Donder, L. (2018). Invisible realities: Caring for older Moroccan migrants with dementia in Belgium. *Dementia*, 18 (7-8), 3113-3129. <https://doi.org/10.1177/1471301218768923>

Berdai Chaouni, S., Claeys, A. & De Donder, L. (2018). How to (qualitatively) involve older people with dementia and their informal carers with a migration background in research? Insights from a longitudinal project in Brussels. *Proceedings European Congress of qualitative inquiry*

Research Reports

Gove, D., Georges J., Rauf, M.A., van den Broeke, J., Jongsmā, K., Claeys, A., **Berdai Chaouni, S.,** Hellstöm, I., Tromp, K., Porteri, C., & Watchman, K. (2019). *Overcoming ethical challenges affecting the involvement of people with dementia in research : recognising diversity and promoting inclusive research*. Alzheimer Europe.

Books & Book chapters

Berdai Chaouni, S. & Claeys, A. (2021). *Dementie bij ouderen met migratieachtergrond*. Antwerpen: Garant

Berdai Chaouni, S., Claeys, A., Hoens, S., Pan, H., & Smetcoren, A. . S. (2021). The fallacy of migrants-culture preventing access to care in later life. I. In *Migration, Equality, Racism: 44 opinions* (pp. 141-148). VUB.

Berdai Chaouni, S., Claeys, A., & De Donder, L. (2019). Dementie bij ouderen met migratie-achtergrond. In *Kleine gids voor dementie* (VIEWZ ed., pp. 191-202). Brugge: Vanden Broele.

Berdai Chaouni, S., Gronthoud, W., de Kam, I. & Witter, Y. (2017). (Eds.) *From home to home. Guided by older migrants in Europe*. The Netherlands, ENIEC.

Valorization papers

Berdai Chaoui, S. (2021). Elderly care must pay more attention to exclusion mechanisms. *Ageing Equal, AGE Platform*. <https://ageing-equal.org/elderly-care-must-pay-more-attention-to-exclusion-mechanisms/>

Berdai Chaoui, S. (2021). Ouderenzorg moet meer aandacht hebben voor uitsluitingsmechanismen. *Sociaal.net*. <https://sociaal.net/opinie/ouderenzorg-moet-meer-aandacht-hebben-voor-uitsluitingsmechanismen/>

Berdai Chaoui, S., Claeys, A., & De Donder, L. (2019). Geloof beïnvloedt hoe iemand dementie beleeft. *Sociaal.net*. <https://sociaal.net/achtergrond/geloof-beinvloedt-hoe-iemand-dementie-beleeft/>

Berdai Chaoui, S. (2018). Dementie speelt verstoppertje bij Ali en Antonio. *Sociaal.net*. <https://sociaal.net/opinie/onderdiagnose-dementie-ouderen-migratie-achtergrond/>

Berdai Chaoui, S., & Claeys, A. (2018). Older migrants have the right to be treated with respect: respect of their age, and respect of their culture. *Ageing Equal, AGE Platform*. <https://ageing-equal.org/the-othering-of-older-migrants-in-care/>

Berdai Chaoui, S., & De Donder, L. (2016). Dementie bij Marokkaanse ouderen: Culturele kortsluiting tussen zorgverleners? *Sociaal.net*. <https://sociaal.net/achtergrond/dementie-bij-marokkaanse-ouderen/>

Contributions in Expert magazines and General Media

Berdai Chaoui, S. (2021). De onzichtbare ouderen "Mensen uit die cultuur willen niet een woonzorgcentrum? Dat is een mythe". In *Visie* (by Nils De Neubourg pp. 10-11). <https://www.cm.be/diensten-en-voordelen/advies-en-informatie/publicaties/visie/1-april>

Berdai Chaoui, S. (2021). Goed omgaan met verschil, de uitdaging in België. *Zorgzaamwonen, Netherlands*. <https://www.zorgzaamwonen.nl/node/1361>

Berdai Chaoui, S. (2020). Voorbij het applaus durven we na corona kiezen voor een echte zorgende samenleving. *Knack*. <https://www.knack.be/nieuws/belgie/voorbij-het-applaus-durven-we-na-corona-kiezen-voor-een-echte-zorgende-samenleving/article-opinion-1605869.html>

Berdai Chaoui, S. (2020). Er bestaat niet één recept voor cultuursensitieve zorg: heb oog voor de meerlagigheid van het individu. In *Weliswaar, interview by Liesbeth Van Braekel*. <https://www.weliswaar.be/cultuursensitievezorg>

Berdai Chaoui, S. & Claeys, A. (2019). Nood aan betere dementiezorg voor allochtone ouderen. In *Knack interview by Carine Stevens*. <https://www.knack.be/nieuws/gezondheid/wereld-alzheimer-dag-nood-aan-betere-dementiezorg-voor-allochtone-ouderen/article-longread-1635627.html>

Berdai Chaoui, S. & Claeys, A. (2019). De onzichtbaarheid van 'Malcom X' ouderen. *Dewereldmorgen.be* <https://www.dewereldmorgen.be/artikel/2019/03/22/de-onzichtbaarheid-van-malcolm-x-ouderen/>

Berdai Chaoui, S. (2018). Respect. Daarmee begint alles. *Zorwijzer magazine, Zorget Icuro* <https://zorqwijzermagazine.be/diversiteit/respect-daarmee-begint-alles/>

Berdai Chaoui, S. & Claeys, S. (2018). Ouderenzorg in volle omwenteling. *Tertio* nr. 898 van 26/4 (Regional). <https://www.tertio.be/magazines/898/artikels/dossier%3A%20ouderenzorg%20in%20volle%20omwenteling>

Berdai Chaoui, S. (2016). De zorgsector moet worden afgesteld op verschillende soorten mensen *Radio 1, VRT*. <https://radio1.be/de-zorgsector-moet-worden-afgesteld-op-verschillende-groepen-mensen>

