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Caring for migrant older Moroccans with dementia in Belgium as a complex and dynamic transnational network of informal and professional care: a qualitative study.

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Abstract

Background: 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. **Objectives:** This study explores how dementia care is provided to these Moroccan older people with dementia, and what challenges do caregivers face in providing care. **Methods:** 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. **Results:** 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. **Conclusion:** 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.

Key words: Caregivers' perspectives, dementia care, informal care, older migrants, transnational care, othering

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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

2.1 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

1 qualitative research is better suited and even required when seeking a greater understanding of the experiences of
 2 people with dementia and of their informal and formal carers, especially when the aim is to include specific
 3 groups such as ethnic minorities (Carmody et al. 2015). Qualitative approaches intrinsically strive for nuances
 4 and seek to adhere closely to the narratives of the participants; they are therefore preferred in research that
 5 engages marginalized voices such as ethnic minorities (Braun et al. 2014).

2.2 Participants

8 Inclusion criteria for the informal caregivers were: being a child (or child-in-law) or partner of a senior with
 9 dementia; having previous experience in tending to someone with dementia; and being of Moroccan origin.
 10 Experience was seen as any form of engagement, current or previous, in caring for a senior with dementia.
 11 Dementia could be any subtype of the condition. Table 1 provides an overview of characteristics of the 12
 12 informal caregivers included in this study.

Table 1: 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 2 provides a detailed overview of the 13 included professional caregivers.

Table 2: 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

2.3 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 3.

Table 3: 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	Meaning of Dementia
Meaning experienced by IC and relatives, communication about dementia	Specificities in dealing with dementia by Moroccan families
Informal care challenges	Professional care challenges
Encountered challenges, how managed, help-seeking	Match demand/supply, needed form of professional care
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 of the condition (Evolution of) Moroccan population with dementia

2.4 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.

2.5 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.

2.6 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

1 destroyed after completion of the study. The study followed the guidelines of Human Sciences Ethical
 2 Committee of the VUB, respecting the European Framework for Research Ethics (European Commission, 2013).
 3 As the study included only competent human subjects and did not compromise any participant's integrity, no
 4 additional approval was needed by the committee (VUB, 2017).
 5
 6

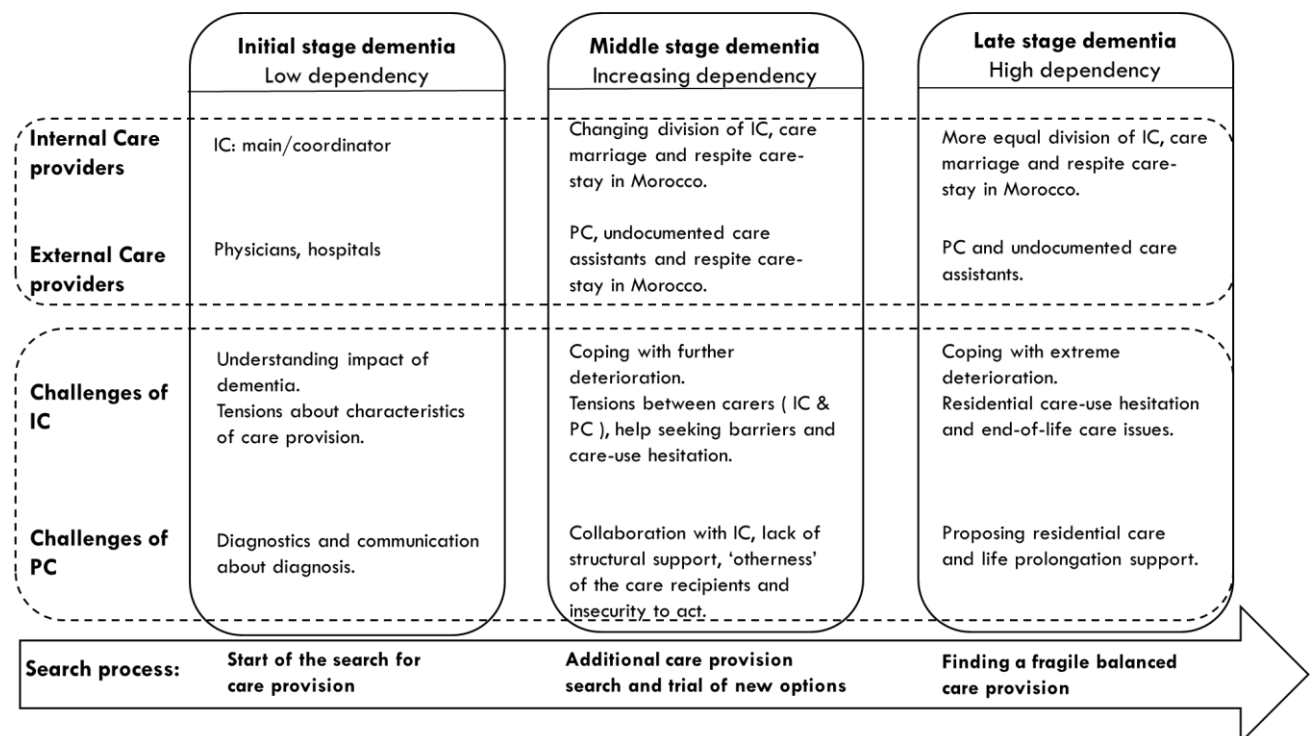
7 3. Results

8 3.1 How is care provided?

9 3.1.1 Dementia care: a dynamic search process

10 All the participants (n = 25) agreed that caring for older Moroccan migrants with dementia is a constantly
 11 evolving challenge. Informal caregivers called it 'a continuous search process,' thereby presenting a more
 12 dynamic image of dementia care than that offered by most of the professional respondents. Analysing the
 13 narratives of these informal carers revealed that dementia care was provided according to the increasing
 14 dependency of the person with dementia. Three general stages of dementia could be discerned within the
 15 respondents' narratives: initial, middle and final stage. The initial stage is characterized by emergence of the first
 16 symptoms of the condition, the diagnostic process and adjustment to the first cognitive, personality and
 17 functional changes. The middle stage is characterized by the increasing cognitive and functional losses reflected
 18 in the increased need for assistance and care. During the final stage the person with dementia is dependent upon
 19 his or her caregivers for all basic life necessities (e.g. eating). The respondents experienced different care needs
 20 and challenges during these stages. Table 4 offers a reconstruction of this dynamic dementia care process. This
 21 schema summarizes and structures the results, which are discussed in this section.
 22
 23
 24
 25

26 **Figure 1:** Dementia care as a dynamic search process



26 Note: IC = informal care; PC = professional care (physicians, nurses, etc.). This scheme summarizes and
 27 structures the results, which are discussed in this section.
 28
 29

30 **Figure 1 describes the** 'search' for dividing/balancing informal care responsibilities across the three stages, each
 31 stage reflecting different challenges. The initial stage of dementia was characterized by the respondents'
 32 describing a challenging start, as family members were now required not just to recognize but also, and more

1 importantly, to adapt to the reality of their relative's dementia. Respondents testified this often entailed many
2 family quarrels. Often during this stage one person (daughter/spouse) or a small group would take charge (e.g. to
3 communicate with doctors, to observe medication intake). The informal caregivers guided their relatives with
4 dementia through the diagnostic process and felt responsible for establishing the correct diagnosis. The
5 middle stage was typified by an increase in care-solution-searching by more relatives. Because of
6 increasing dependency (e.g. 24/24 alertness), more options were now taken into account. Approaching
7 the later, final stage, informal caregivers found more acceptable (e.g. equal contribution by all informal
8 caregivers, external help matched with specific desires) and applicable (e.g. sense of mastering the
9 situation, division of burden) ways to provide care. Respondents said this balance was fragile, however,
10 and in some cases the informal network faded. This often entailed restarting the entire search from the
11 beginning, with the remaining informal network leading the new search. In two cases, for example, other
12 siblings, both male and female, of the respondents withdrew from their care responsibilities.

13
14
15 “We are left only with two of us, me and my sister K – my other sisters and brother don't help anymore.”
16 (Daughter, IC 1)

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

18 **3.1.2 The role of informal carers**

19 Our results show that informal carers are considered the most crucial and central actors in dementia care. In
20 seeking solutions for increasing dependency, a combination of external professional care and non-professional
21 care was used (Table 4). In the initial stage of dementia, during the diagnosis process, medical services (general
22 practitioners and hospitals) were used. In the middle stage, the increasing care needs of the person with dementia
23 were addressed and more help was sought, including from outside the informal care possibilities. With the
24 augmentation of care tasks, finding solutions to these needs became more important than adhering to culturally
25 inspired images of care execution. Professional care was now considered and sometimes used to meet the care
26 needs.

27 **3.1.3 The role of professional carers**

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

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

39
40
41 The professional participants were aware of the families' non-use of these services. However, this sometimes
42 resulted in stereotypical thinking and behaviour, such as assuming that these families would not consider
43 professional care options and consequently not even proposing such measure to them. As a head nurse explained
44 (PC 12):

45
46 “We often presume that these families go back home (after a hospital stay). We don't talk to them about the
47 other options... Maybe this is a prejudice from us.”

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

1
2 **3.1.4 Alternative care provision sources**

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

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

16
17 Second, most of the older care receivers still owned a residence in Morocco where informal carers could take
18 their older relative. Relatives or strangers in Morocco (e.g. couples or adult women without children) were asked
19 and paid to care for the person with dementia while the informal caregivers returned to Belgium. This financially
20 affordable option was often chosen as a form of respite care and as a compromise between two forms of
21 pressure: the heavy care burden that informal carers experienced in Belgium and the expected condemnation
22 they would receive from within the community if they stopped caring for their relative.

23
24
25
26
27 “Every time I feel I cannot cope anymore, I send her (mother) to my cousin in Morocco for a month or three...
28 this is the only way to regain my strength to sustain this situation, without bad talk from the community.”
29 (Daughter, IC 10)

30
31 The third alternative source of help was also based in Morocco. ‘Care marriages’ were used as a solution when a
32 father with dementia was also widowed. The new marital arrangement would allow him to stay in his home and
33 relieved the caregivers of their own care burden. The search for a suitable adult woman in Morocco, usually
34 childless and living in humble conditions, was a task for one of the siblings. The woman was aware of the
35 conditions and goal of this proposed ‘marriage.’

36
37
38 Only a few professional caregivers were aware of this care practice. Some agreed with this solution and had seen
39 that the arrangement could be beneficial to both parties. Professionals testified that such marriage arrangements
40 can also provide the caregiver a better and more stable future, while the man with dementia benefits from care at
41 home. As a general practitioner of Moroccan origin noted (PC 8):

42
43
44 “I often see such cases resulting in a good situation for both of them. The woman finds a stable home and the
45 man improves because of better adherence of treatment.”

46
47
48 According to the same GP, the marriage will sometimes even result in a positive, loving relationship between the
49 marital partners.

50
51
52 Conversely, this care solution sometimes resulted in vulnerable situations, especially when the female caregiver
53 was dependant on the guidance and the goodwill of the children. As formulated by a psychologist (PC 1):

54
55
56 “I’ve seen it often with these women: the day the person with dementia dies is the day that her bags are packed
57 and she is asked to leave.”

58 **3.2 Encountered challenges in provision of dementia care process**

59
60 **3.2.1 Challenges for informal carers**

1
2 3.2.1.1 Dementia related challenges

3 Informal caregivers were challenged by universal dementia-related sources of distress combined with challenges
4 specific to their search process. The informal caregivers identified the following dementia-related distress
5 factors: 1) adjustment to behavioural changes and deterioration of the loved one; 2) role reversal between
6 caregiver and the person with dementia; and 3) the combination of being a caregiver and having responsibilities
7 towards one's own work, partner and children.
8

9 3.2.1.2 Professional help-seeking obstacles

10 Informal caregivers also encountered obstacles when they decided to seek professional help. Their lack of
11 knowledge about professional care options made it difficult for them to find appropriate and effective help. The
12 available information about dementia care options did not reach the participants. It was only by being assertive
13 or happening to come across a professional that they received the needed information. Another obstacle related
14 to how professional caregivers performed their care. Informal carers felt a person-centred approach was often
15 lacking, due to a lack of (cultural) sensitivity in combination with quick technical execution of the necessary care
16 tasks with minor attention for more humane aspects. Despite the informal carers' appreciation for the
17 professionalism of these caregivers, these humane aspects were decisive in their opting not to use professional
18 care. Some informal caregivers also experienced discrimination and racism during their encounters with
19 professional caregivers, as formulated by an informal caregiver (IC 11):
20

21 "You should have seen the way how he (a doctor) talked to me and to my father. Without any respect, like we
22 were animals...it hurts me that my father has to endure such racism at this stage of his life."
23

24 Such experiences enhanced the informal caregivers' anxiety to entrust the person with dementia to professional
25 caregivers who evinced little sensitivity for cultural and religious aspects such as prayer, halal food and gender
26 matching.
27

28 **3.2.2 Challenges for professional cares**

29
30 3.2.2.1 Collaboration with family members

31 The professional caregivers who participated in this study also experienced challenges (Table 4) in providing
32 care for older migrants with dementia. In these experiences there was a distinction between caregivers of
33 Moroccan origin and those of non-Moroccan origin. Two challenges were named by all respondents:
34 collaboration with the family members and structural support measures to deal with the diversity of care
35 recipients. Most of the respondents found it challenging to collaborate with families of older migrants. They
36 found it difficult to deal with the various family members involved in caring for the older Moroccan relative with
37 dementia and preferred instead to deal with one contact person from the family. The various family members
38 involved all wanted information, wished to participate in caring for the older person and had different opinions
39 and expectations. All of this rendered it difficult to work in a context where there is already limited time and
40 staff to meet multiple expectations. However, some professional carers anticipated this reality and tried to
41 collaborate with the family by organizing family meetings.
42

43 Some participants even noticed that having multiple family members involved could be a positive source of help,
44 as stated by a head nurse in Antwerp (PC 5):
45

46 "If the family wants to come earlier to feed the patient, that's fine by me. Less work for my colleagues."
47

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

49 3.2.2.2 Lack of structural support system

50 Professional caregivers also complained about the lack of investment in structural support measures such as
51 affordable translation services and education and training that would prepare them to deal with this reality in
52 general. Those who worked in care services did not feel supported by their management when making decisions.
53 They needed room for flexibility, time and support measures. These same factors were also missing in a highly
54 regulated context with increasing time pressures and budget cuts, as formulated by neurologist (PC4):
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1
2 “You see, we could call intercultural care mediators or translation services when we had a patient with a
3 different background – that was helpful, but due to hospital decisions we cannot use these services anymore.”
4

5 3.2.2.3 Challenges for native Belgian professionals

6 The following challenges were experienced only by participants of Belgian origin. The first challenge was the
7 language barrier. This barrier resulted in poor communication, making it difficult to develop a good relationship
8 with the patient’s family and to connect with older people with high risk of poor care provision.
9

10 Professional caregivers of Belgian origin also struggled with their own hesitancy to act. This hesitation stemmed
11 from a perceived distance between their own culture and that of the care recipient. The caregivers perceived
12 these older people with dementia as being different from themselves and referred to the patients in terms of ‘us’
13 and ‘them.’ Not sharing the same cultural background resulted in a sense of doubt and wariness as to how to
14 provide effective care, as formulated by a head nurse (PC12):
15

16 “For us, you see, it is normal to wash someone in a dry way, just using a toilet glove, but he (patient with
17 dementia) started to get agitated. We didn’t know what to do. We finally called the intercultural mediator, who
18 explained to us that he needed to be wet washed...”
19

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

22 A last challenge experienced by caregivers of Belgian origin was fear of being accused of discrimination and
23 racism. They did not understand why families sometimes accused them of such behaviour in discussions about
24 provision of care, as stated by a head nurse in Antwerp (PC 5):
25

26 “I’m very careful about what I say (to the family members), to avoid being blamed for discrimination.”
27

28 4. Discussion

29
30 The elderly population of Europe is becoming increasingly more ethnically diverse, yet little is known about
31 how dementia care is provided within migrant families (Gove et al., 2018). This study meets that gap by
32 examining the dementia care provision within Moroccan families, specifically in Belgium. In response to the
33 first research question, the results of this study indicate that provision of dementia care within these families is a
34 dynamic, continuous and transnational search process across the three care stages of dementia. In each stage,
35 various constellations of informal and external help are engaged. This complex reality of dementia care within
36 migrant populations aligns with recent findings of Sagbakken et al. (2017), who highlight fluctuating care needs
37 and decisions among migrant families in Sweden.
38

39 This complexity challenges the current, one-dimensional image of dementia care within migrant families,
40 according to which such care is performed only by female informal caregivers (van Wezel et al., 2016). On one
41 hand, informal carers are still crucial actors within dementia care, as is already evident during the diagnostic
42 process (Botsford et al., 2011; Berdai-Chaoui and De Donder, 2018). On the other hand, our results reveal that
43 the reality of the course of dementia, with care needs that increase over time, challenges the informal caregivers
44 to adjust their culturally and religiously inspired conceptions of care. Their continuous search for internal and
45 external care solutions confirms the need for additional professional support during all stages of dementia
46 (Zwaanswijk et al., 2013), especially when the care burden increases. Because of its limited culture-sensitive and
47 person-centred approach, Moroccan informal caregivers generally do not seek professional care, although doing
48 so could relieve their burden (de Graaff et al., 2012). These older people of Moroccan origins fall into a gap
49 between the inaccessible provision of elderly care and the fragmentation of traditional family caregiving
50 (Moriarty et al., 2014; Ahanddour et al., 2015; Suurmond et al., 2016). This situation appears to force the
51 respondents in this study to use their transnational resources of care (Näre et al., 2017) and to generate new
52 forms of culturally and religiously acceptable external care, i.e. engaging in a care marriage, bringing in
53 undocumented domestic helpers and sending the person with dementia to Morocco for a short stay.
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2 Regarding the second research question, about encountered challenges, both informal and professional carers
3 experience different sources of challenges. Informal caregivers of Moroccan origin face many challenges,
4 resulting in a care burden. Conceptual models, such as the stress model of Campbell (2009), regard the care
5 burden as a result of different stress factors. Our results confirm primary (e.g. behavioural and psychological
6 changes due to dementia) and secondary stress factors (e.g. family quarrels) as sources of caregivers' distress. In
7 line with findings of Zwaanwijk et al. (2013), informal caregivers' problems and needs differ during the distinct
8 stages of dementia. While informal caregivers would, in the first stage, benefit from information concerning
9 dementia (e.g. how to recognize the different stages, how to deal with associated behavioural changes) and
10 where to find help, in the last two stages more emphasis needs to be focused on care supply and respite care to
11 cope with diminishing social networks.

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

19
20 Professional caregivers are also confronted with challenges in providing care to older people of Moroccan origin
21 with dementia. Collaboration with the numerous family members involved in a patient's treatment is
22 experienced as being difficult, especially in a context of acute time and performance pressures. However, some
23 professional caregivers were able to see the 'win-win' scenario in such collaboration. Sagbakken et al. (2017)
24 emphasize that increased collaboration and care sharing with relatives can facilitate better and more coherent
25 care. Inclusion of family carers in professional care is a near universal wish among family members and one that
26 transcends ethnicity (Wittenberg et al., 2017)

27
28 Professional caregivers of Belgian background struggle with what Torres et al. (2006) have termed the
29 'otherness' of elderly immigrants. In addition to navigating language and communication barriers (Drewniak et
30 al., 2017), these caregivers also feel uncertain in how to respond when a care recipient's demand seems to be
31 deviate from what they categorize as 'normal' (Sagbakken et al., 2017). In line with these studies, the
32 participants respond individually to care questions they perceive as non-confirming. Their response results from
33 internal negotiation between the patient's request and what is perceived as a standard care and the organizations'
34 guidelines. Such an equation, where a reasonable question is one that does not differ significantly from what is
35 perceived as a standard (i.e. the Belgian) practice and which is expressed in terms of 'us' and 'them,' leads to an
36 ethnocentric care approach that is discriminatory toward ethnic minority care recipients (Forssell et al., 2015).

37 Fear of being accused of discrimination and racism is also a challenge for caregivers of Belgian origin. This
38 genuine fear of being perceived as racist does not mean that the professional caregivers will challenge the
39 existing stereotypes, as shown by Markey et al. (2017). The professional caregivers in our study were not aware
40 of the discrimination and racism experienced by the informal caregivers, and regarded possible accusations
41 against themselves as unreasonable. This aligns with a general unawareness of harmful activation of implicit
42 biases and stereotypes towards ethnic minorities by health professionals, as discussed by Drewniak et al. (2017).
43 Our respondents experience a lack of knowledge about the culture of the 'others.' They wish for organizational
44 support actions that could help bridge culture and language gaps, such as investment in education and
45 collaboration with intercultural mediators and interpreters (Regan, 2013). Such actions have limited results,
46 however, and therefore actions on a 'deep structure' level are needed (Resnicow et al., 1999). This means that
47 care professionals and organizations should be aware of their ethno-centric, essentialist approach and move
48 towards an intersectional approach which can address the complexity and the heterogeneity of ethnic minority
49 care recipients (Zubair and Norris, 2015; Torres, 2015).

50
51 The findings raise a number of issues for policy and practice concerning this first generation of caregivers – both
52 informal and professional – now facing a rather new population of Moroccan older people with dementia in
53 Belgium. They need a different kind of knowledge and support in order to provide effective care to these

1 patients, thereby enhancing the wellbeing of all parties. The results of our study underscore the need for
2 investment in migration-, culture- and religion-sensitive care on several levels. Policy makers and professional
3 care providers should also be aware of and validate the creativity and transnational recourses (Wildler and
4 Baldassar, 2018) of these informal caregivers. Another recommendation is to eliminate barriers that impede
5 people in this minority community from seeking help (Mukadem, 2011; Regan, 2016) and to provide tailored
6 and effective support to family carers (Johl et al., 2015). Tailored care that enables professional caregivers to feel
7 competent in caring for these older people requires both a multi-faceted care policy that is aware of its own
8 ethno-centricity, and development of ‘deep structure’ support measures that take into account the complex
9 identities of minority care recipients (Resnicow et al., 1999; Torres, 2015, Drewniak et al., 2017). This requires
10 health policy planning (Denier and Gastmans, 2013) that involves the perspectives of all concerned parties
11 (Stephan et al., 2015; Jutlla, 2015).

14 5. Study limitations

16 Our findings should be considered in light of the following limitations. The informal carers were mostly second-
17 generation Moroccans and female. Half of these participants were highly educated, which is not representative of
18 the labour market position of migrants in Belgium (Laurijssen and Glorieux, 2015). Recent data suggest that
19 Belgium has the lowest employment rate for non-EU migrants: 54 per cent, as compared to the European
20 average of 65 per cent (Eurostat, 2019). More research is needed that would involve caregivers from various
21 socio-economic profiles (Nazroo, 2006) and caregivers who are male (Snyder et al. 2014). Adding the
22 perspective of Moroccan older people with dementia – through observations, tailored interviews or longitudinal
23 approach – could improve on the limited triangulation (e.g. both informal and formal carers, focus group and
24 interviews) of our approach (Cobb and Forbes, 2002). Such research is necessary, despite the fact that engaging
25 ethnic minorities in general (Carmody et al., 2015) and older migrants specifically (Berdai Chaouni et al. 2018)
26 is considered challenging as a methodological approach. Researchers face different challenges in their attempts
27 to gain access to ethnic minority communities, not least because they often have limited skills by which to
28 engage and to collaborate with these communities and so require more time and resources than that provided by
29 ‘classic’ research approaches (Carmody et al., 2015; Berdai Chaouni et al., 2018). Researchers must therefore
30 develop additional skills by which to gain access to and engage older migrants, such as flexibility, cultural
31 competences and communication skills (Shanley et al., 2013). They must also invest in strategies to overcome
32 the multiple barriers that ethnic minorities face when considering whether to participate in research: such
33 barriers include distrust in research and researchers, fear of being abused or exploited, and reluctance to become
34 involved in unfamiliar research projects, especially those with an essentialist Western framework or with no
35 clear added value to the minority participants or their community (Shanley et al., 2013; Berdai Chaouni et al.,
36 2018).

39 6. Conclusion

41 Our study looked at the current dementia care provision for older Moroccan migrants in Belgium. How is
42 dementia care provided and what challenges do the caregivers, both informal and professional, encounter? The
43 results show a dynamic and complex picture of how dementia care is provided. The dementia course, with its
44 increasing care needs, defines the continuous search process to provide good care to these people. At first glance,
45 this search process, led by the informal caregivers, is driven by universal dementia-related care needs and
46 challenges. Regardless of ethnic background, the condition’s impact includes similar aspects, such as adjusting
47 to the degenerative character of the condition, balancing the care burden, finding proper information and
48 obtaining suitable professional care. On closer examination, it is clear that migration, culture and religious
49 background affect this search process; these factors add a different layer to the care burden, resulting in
50 alternative transnational solutions and strategies to manage the burden. Moreover, professional caregivers also
51 search for suitable dementia care for these migrant older people. However, they appear to do so in an ethno-
52 centric and essentialist context, often unaware of the individual complex reality of both the migrant older people
53 and their informal caregivers. Structurally supportive policy and organizational measures with more space for

1 flexibility and collaboration with informal caregivers are needed; this is especially relevant for nurses and
2 physicians, as in our research they were the only health professionals involved during all stages of the care
3 process. A better understanding of this complex reality in which different aspects intersect could lead to
4 interventions that would not only relieve the informal care burden but also provide effective and tailored person-
5 centred care that is sensitive to the elderly patient's life experiences, culture and religious background.
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