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ARTICLE

Bridging the gaps: narratives of informal carers of older migrants with dementia using professional care

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Abstract
With society's growing diversity, it is increasingly crucial to comprehend the care needs of older migrants with dementia and their informal carers. This study explores the experiences of informal carers of older migrants with dementia using professional care, focusing on the participants' perceptions of whether the delivered professional care meets the needs of the informal carer and their family member with dementia. Purposive sampling identified 17 informal carers living in Belgium and caring for older first-generation labour migrants from Italian and Turkish backgrounds. In-depth interviews were conducted and inductive data were analysed using the Qualitative Analysis Guide of Leuven, a method inspired by the constant comparative method. The findings are presented through composite narrative vignettes. The data analysis revealed six predominant themes: (1) Informal carers are hoping for engagement from professional care providers, to create together a care alliance for the older person with dementia; (2) Informal carers experience cold substandard care provision from professional care providers towards their loved ones; (3) Informal carers need to feel a sense of home to be able to trust the professional care providers; (4) Informal carers experience culturally insensitive care practices by professional care providers; (5) Informal carers struggle with the responsibility of informal care-giving in the context of today's world; (6) Informal carers experience the cumulative mental load of care-giving. Informal carers of older migrants with dementia face a cumulative mental burden through limited adapted-care options, cultural insensitivity in services, care-giving duties and additional tasks to bridge the professional care gaps.

Keywords: composite vignettes; culturally sensitive care; dementia care; health care; informal carers; older migrants; professional health-care provider; qualitative analysis

Introduction

With the global population ageing, dementia is becoming more prevalent, increasing demands on health-care systems worldwide (WHO 2023). Older persons with dementia require careful, dedicated long-term care, which is often initially provided by informal carers (Ahmad et al. 2020). As the condition progresses, formal care becomes increasingly integrated in the total care provision, challenging ageing societies where care systems often depend on ageing family members to bridge the gap between needs and formal services (Duran-Kiraç et al. 2022; Nielsen et al. 2021; Vangen and Herlofson 2023).

As Western society is becoming increasingly diverse in terms of ethnicity and cultural background (Brussels Studies Institute 2022), this diversity is also present among older adults and persons with dementia and it impacts the way that care is, or should be, structured and provided (Nielsen et al. 2020, 2011). In the Belgian context as well, which mirrors these demographic trends, the provision of dementia care for the country's diverse population, including older labour migrants, presents unique challenges and opportunities in dementia care delivery (Berdai Chaouni 2021). In 1946, Belgium and Italy agreed that Italy would send guest workers to Belgian mines in exchange for coal (Morelli 1988). Labour migrants arriving in Western Europe from the 1950s to the 1970s worked in low-wage, manual labour jobs with limited upward mobility, facing language barriers, socio-economic challenges and exclusion related to their status as labour migrants. After a 1956 mining disaster ended the agreement with Italy, Belgium established new bilateral agreements, including one with Turkey in 1964. Today, Italian and Turkish communities remain present in Belgium, with many of the first-generation migrant workers now older persons. The migration history impacts their current disadvantaged socio-economic position (Berdai Chaouni 2021; Morelli 1988).

Culturally sensitive care is frequently promoted as a way to provide appropriate care for persons of diverse ethnic and cultural backgrounds (Sagar 2012; Shen 2015). A culturally sensitive care approach is used when patient and health-care professional – from different ethnic-cultural backgrounds – are in interaction with each other to search for a connection in order to build a (better-quality) care relationship (Uzun and Sevinç 2015). This care relationship is affected by the cultural characteristics of both the patient and the health-care professional. By accepting and overcoming these cultural differences, a customised concept of care begins. The health-care professional responds to the questions and needs of the patient, regardless of their culture, religion or origin (Claeys et al. 2021). However, in the context of care, it remains unclear how informal carers of older migrants experience the cultural sensitivity of the professional care they receive. Recent studies underline a discrepancy between professional care providers' interpretations of culturally sensitive care and the actual experiences of older adults – several studies highlight the unmet needs of persons with a migration background and their informal carers (Ospina-Caicedo et al. 2022; Tee et al. 2022; White et al. 2019) and other studies emphasise the difficult perception and implementation of culturally sensitive care by health-care professionals (Claeys et al. 2021, 2023). The literature indicates a misalignment between the professional care provided and the actual needs and preferences of older adults and their informal carers (Berdai Chaouni et al. 2020). This can result in culturally insensitive care – neglecting the patients' cultural backgrounds, preferences and needs – resulting in inadequate and sometimes harmful experiences (Almutairi et al. 2017; Markey et al. 2019; Qureshi 2020). Although more and more research is available, there is still little empirical literature that makes a clear connection between culturally insensitive care and implicit and explicit racial micro-aggressions in health care (Miller and Peck 2020; Moorley et al. 2020; Moorley and West 2022; Snyder et al. 2018). Micro-aggressions can be defined as deniable acts of racism that reinforce harmful stereotypes and hierarchies. The concept marks an evolution in understanding bias, as these actions are subtle, often covert in casual conversation, rather than overt. Micro-aggressions are often unconscious and noticed only by persons who are aware of gender or racial stereotypes in that context. They are cumulative, daily occurrences that result in psychological and physical trauma (Salmon 2024). Further research is needed to clarify this. However, this article will focus on the aim to better understand the experiences of informal carers relating to the professional care for older migrants with dementia by investigating whether the care provided aligns with the needs of both the informal carer and their family member.

Literature review

Older adults and informal carers with a migration background often invest a lot of effort and work to gain access to formal health-care services. Scientific research highlights the various challenges faced by informal carers with a migration background in their interactions with professional care (Stenberg and Hjelm 2023), including barriers in (1) accessing and (2) using formal services and (3) the informal carer's inter- and intra-personal barriers.

First, barriers in accessing formal services include a lack of information on formal services (Wangler and Jansky 2021) and a lack of understanding and awareness of the offer of formal services (Parveen et al. 2018), coupled with a general lack of adapted services for persons with a migration background (Herat-Gunaratne et al. 2020; Sagbakken, Spilker and Nielsen 2018). Professional care providers are less likely to provide information to informal carers with a migration background (Wangler and Jansky 2021) and are less likely to make referrals to professional services (Duran-Kiraç et al. 2023; Mukadam et al. 2011). Consequently, informal carers have less interaction with formal services as well as less knowledge of the existence of these services and what they offer (Nielsen et al. 2021; Parveen et al. 2018). Moreover, there is an absence of health-care organisations specifically tailored to the needs of older migrants (Berdai Chaouni et al. 2020; Herat-Gunaratne et al. 2020; Sagbakken, Spilker and Nielsen 2018). However, research has shown that minority-specific services could facilitate access to health care in general, not only for the specific minority they are targeted towards. Minority-specific services can be seen as a gateway to a broader range of formal care services (Carlsson 2023).

Second, when informal carers do access professional care services, they often face barriers related to the use of the care services and the care delivery. The quality of the care expected by informal carers does not always correspond with the actual care delivered (Blix and Munkejord 2022). Quality concerns and distrust arise from inexperienced professional care providers, who lack competencies to work with older persons with dementia with a migration background and their informal carers (Duran-Kiraç et al. 2022; Stenberg and Hjelm 2023). Language and communication barriers exacerbate the challenges faced by individuals with a migration background in using health-care services (*e.g.* lack of a shared language between the older adult and the health-care provider, the informal carer's concern that limited use of the mother tongue may impact dementia progression, and hindered communication with services owing to language differences starting from information about services to service provision itself) (Blix and Munkejord 2022; Greenwood et al. 2015). Other challenges in care utilisation include encounters with professional care providers lacking experience in person-centred care (Sagbakken, Spilken and Nielsen 2018), a lack of continuity of care (Duran-Kiraç et al. 2022) and insufficient consideration of the individual needs of the older migrant – resulting in culturally insensitive care (Herat-Gunaratne et al. 2020). Behaviours experienced as discrimination and othering lead to distrust in both the informal carer and the person in need of care (Alpers 2018; Zemouri et al. 2024).

In the specific context of Belgium, informal carers must navigate a complex and often non-transparent health-care and service-delivery landscape in which it is not always clear which services to approach for certain needs and what compensatory aids or support they can rely on (De Lepeleire 2022). Such barriers contribute to the complexities inherent in informal carers accessing and using formal care. As in other countries – such as those operating under quasi-market systems and where de-institutionalisation of care takes place – informal carers may encounter similar challenges in understanding, accessing and using available care services and support mechanisms (Egdell 2013).

Third, other challenges contribute to inter- and intra-personal barriers experienced by the informal carer when using formal services. Among other things, the experience of the informal care-giving depends on the nature of the relationship, the circumstances in which the care is provided and whose choice it is (Palacios et al. 2022). Research has identified that barriers often revolve around expectations placed upon the informal carer, which either originate from the older person or their surrounding network or are self-imposed expectations by the informal carer (Herat-Gunaratne et al. 2020; Mazaheri et al. 2011; Shrestha et al. 2023). These expectations are commonly characterised by the terms 'duty of care' and 'filial responsibility' (Ahmad et al. 2020; Herat-Gunaratne et al. 2020; Sagbakken, Spilker and Ingebretsen 2018). Further, informal carers encounter stigma, inhibiting them from seeking professional care (Guan et al. 2023; Nielsen et al. 2021). This stigma may be associated with the specific condition (such as a diagnosis of dementia) or with the utilisation of professional care in connection with the sense of filial responsibility (Sagbakken, Spilker and Nielsen 2018).

Recognising the imperative of person-centred care, it is essential to integrate the voices of older adults and informal carers in health-care evaluation and change-management processes (Brooks et al. 2022; Fjær 2022). Informal carers, being closest to the older person with dementia, play a crucial role in the overall care provision. By focusing on their experiences of the cultural sensitivity of professional care, the present study aims to better understand the experiences of informal carers relating to professional care for older migrants with dementia, particularly in terms of whether it meets the needs of both the informal carer and their family member.

Methods

This study is part of the larger Diverse Elderly Care research project (funded by the European Regional Development Fund [ERDF]), which investigated culturally sensitive dementia care for older first-generation labour migrants in Brussels, Belgium. The Consolidated Criteria for Reporting Qualitative Research (COREQ) checklist guided the methodological reporting (Tong et al. 2007). Ethics approval for this study was obtained from the Ethics Committee of the University Hospital of Brussels (CE 2016–105).

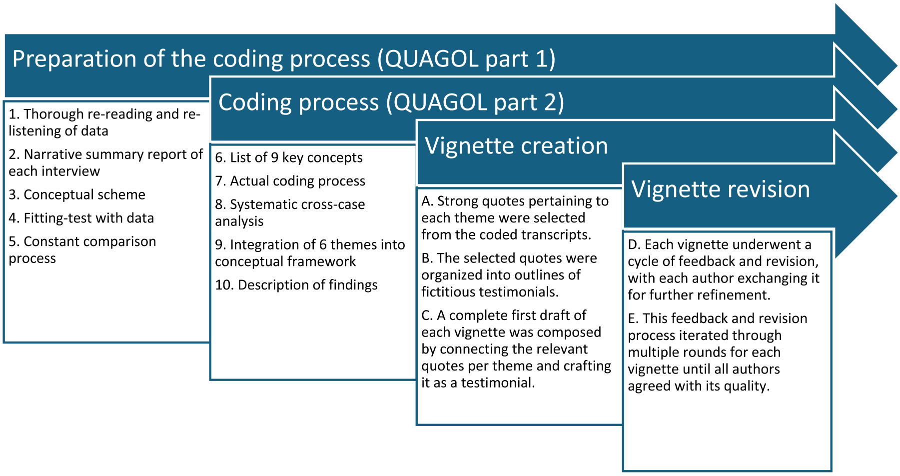
Design

This study employs a phenomenological approach to describe and understand the lived experiences of informal carers. Because the aim of the study is to describe experiences, a qualitative research method with individual in-depth interviews was chosen. The descriptive phenomenological research design aims to understand the nature of the phenomenon by exploring the perspectives of those who have lived through it (Marshall and Rossman 2014). By integrating the narrative approach, this study also sought to include the stories that individuals told about their experiences in the analysis (Riessman 2008). This study combines a phenomenological and narrative approach and thus works with the strengths of both approaches, providing a more comprehensive understanding of experiences by integrating the essence of the experiences with the richness of personal stories.

Data collection

The (interview) participants were recruited by the first and second authors, who identified them through a network of contact persons within the local community (*e.g.* social worker in local community centre or local organisation, general practitioner). Participants were selected using purposive sampling, the inclusion criterion being that they were caring for a first-generation labour migrant family member with dementia. They were invited to participate, either directly by the first or second author via telephone, where the study's aim was explained, or through the contact person who facilitated the meeting. Data collection took place between November 2017 and January 2019, with interviews arranged at convenient times and locations for the participants. The average duration of the interviews with the informal carers was 82 minutes, with a range of 49–123 minutes. The conducted interviews included rich and thick data.

Interview guidelines, informed by a literature review, covered topics including experiences with illness trajectory and diagnosis, provision of informal care, cooperation with professional care and identified care-giving needs. During the data collection, a flexible approach was adopted that allowed the participants to discuss personally relevant issues beyond predetermined themes. The interviews were audio-recorded and then transcribed verbatim by an official transcription service. Following each interview, debriefing reports were compiled, incorporating observational notes and process-related comments. The data collection was conducted by the first and second authors, both of whom were working as researchers on the project at the time.



1. Thorough re-reading and re-listening of data
2. Narrative summary report of each interview
3. Conceptual scheme
4. Fitting-test with data
5. Constant comparison process
6. List of 9 key concepts
7. Actual coding process
8. Systematic cross-case analysis
9. Integration of 6 themes into conceptual framework
10. Description of findings

A. Strong quotes pertaining to each theme were selected from the coded transcripts.

B. The selected quotes were organized into outlines of fictitious testimonials.

C. A complete first draft of each vignette was composed by connecting the relevant quotes per theme and crafting it as a testimonial.

D. Each vignette underwent a cycle of feedback and revision, with each author exchanging it for further refinement.

E. This feedback and revision process iterated through multiple rounds for each vignette until all authors agreed with its quality.

Figure 1. An overview of the data analysis process and the design of the composite vignettes.

Throughout the research process, joint reflective exercises were undertaken by the researchers collecting the data to mitigate potential biases. Both researchers have expertise in qualitative research methods, health-care organisation, management and culturally sensitive care.

Throughout the process, confidentiality was strictly maintained, with special attention given to ensuring data protection and General Data Protection Regulation (GDPR) compliance. Informed consent forms were provided in multiple languages, namely Dutch, French, Turkish and Italian, and explained to each participant at the start of their interview to ensure that they understood the content before consenting. Interviews were conducted in Dutch, French or Turkish, with the assistance of an interpreter as needed. The participants were assured of anonymity and confidentiality, as identifiers were replaced by numerical codes in transcriptions. The researchers' contact details were provided along with the informed consent forms.

Data analysis

Figure 1 gives an overview of the data analysis process. Following the qualitative method of constant comparative analysis, the data were analysed through the ten steps of the Qualitative Analysis Guide of Leuven (QUAGOL), which consists of two parts: (1) thorough preparation of the coding process and (2) the actual coding process. Each part consists of five stages. While these stages follow a sequential path, it is impossible to rigidly isolate the parts or the stages. The ongoing interaction between data collection and analysis naturally leads to merging and interaction among the parts and the stages (Dierckx de Casterlé et al. 2021, 2012).

In the first part, all of the interviews underwent meticulous review, including thorough re-reading and re-listening. Subsequently, a narrative summary report was generated for each interview, incorporating contextual characteristics to contextualise the interviews. This process facilitated a deeper understanding of each interview within its specific context. During this step it became clear that the interviews from the Italian and Turkish transcripts contained similar themes and thus could be analysed together. Using a conceptual interview schedule, nine key concepts were distilled from these narrative summary reports. This inductive list of concepts underwent validation through discussion with the co-researchers, and they were again cross-checked with the interviews. In the second part, data were coded with this list, using the qualitative data analysis software MAXQDA©. The interpretation of these concepts was guided by narrative theory, with particular attention paid to the narratives of the informal carers. The analysis of the nine concepts took place in several iterative rounds and the essential structure of six concepts was extracted as reflective of the informal carers' experiences with professional care (see Table 1 in the Appendix).

Thereafter, the authors created composite vignettes to present the findings. This approach allowed the authors to combine common themes identified from the participants using a creative writing process, merging the participants' experiences rather than presenting only a selection of individual participant quotes, and thereby crafting a more comprehensive and cohesive shared story (Bradbury-Jones et al. 2014; Spalding and Phillips 2007). Drawing upon the different steps for designing and using vignettes, and following Schinke and colleagues' approach, the authors used the six finalised themes from the data analysis to serve as a framework for the composite vignettes (Schinke et al. 2016, 2017). The vignettes incorporate both direct participant quotations and paraphrased expressions in order to provide a holistic representation of the experiences of informal carers of older persons with dementia. It is important to note that these first-person vignettes do not singularly represent any individual participant's experience; rather, they offer a synthesised representation of various perspectives, fictionalising the experiences of the informal carers (Ekengren et al. 2020; Spalding and Phillips 2007). The vignettes are conceived as 'collective stories' that recognise the interconnectedness among informal carers (Blodgett et al. 2011; Paquette et al. 2019). The silencing of informal carers has been documented in other studies (Hengelaar et al. 2024). By using vignettes, we amplify their voices, allowing them to share their experiences in a more powerful way. This approach enables the authors to better illustrate the interactions and contexts that shape the informal carers' experiences.

As explained, the experiences of carers with Italian and Turkish roots were analysed together, which led to the identification of the six themes. In constructing the vignettes, decisions were made to share experiences from the perspectives of carers with Italian or Turkish backgrounds when contextually appropriate, thus underlining the shared nature of the experiences across both groups.

The data analysis was conducted by the first author, in close interaction and exchange with the other authors. All of the authors are experienced in conducting qualitative research and using data analysis, and they hold positions as lecturers in health-care or research programmes.

Findings

The findings are based on a total of 17 individual interviews conducted with informal carers from migrant backgrounds. The 17 participants comprised 12 women and five men, including nine individuals with Italian backgrounds and eight with Turkish backgrounds, as described in Table 2 in the Appendix. All cared for first-generation labour migrants, providing help and support on a regular basis. Nine participants lived in the same household as the older adult.

The experiences of these informal carers with professional care, in caring for a person with dementia, are reflected in six major themes. Although the findings are listed here as separate themes, it is important to emphasise that these are not isolated experiences and that the different experiences can influence each other in a positive or a negative cumulative way. Each theme is first described and then presented in a collective vignette.

1 Engagement to create a care alliance

Warm, empathetic relationships among professional care providers, older adults and informal carers fostered trust, security and support. Participants noted that these interactions, characterised by an open attitude and initiative from the professional care providers, built a trusting bond. For the informal carer, trust in this context means the assurance that the professional care provider will deliver care with the same dedication as the informal carer, fostering confidence that the older person is in safe hands. Warmth is experienced as a positive connection, feeling acknowledged and receiving empathic attention from the health-care provider. Professional care providers' genuine concern, expressed through listening attentively and giving emotional support, made informal carers feel like allies in the care process.

> *It's so important for me and my mother that the people taking care of my father are truly involved. It's not just about meeting his physical needs, but also about understanding who he is as a person.*
> *Luckily, we've found a few care providers who have really built a warm relationship with him. They're really great guys. They listen to him and make him feel valued. It is so funny. They call him uncle in Turkish – even though they are not related – and that makes him feel respected. It warms my heart to see how they interact with him, how he goes to day care during the week and asks about them on weekends.*
> *My father couldn't go to day care for a while because he was in the hospital. They called us from day care to ask about him. It gives me so much peace and confidence to know they're there and that they really care about him.*
> *Of course, there are also times when things don't go so well. Like in the hospital, none of the team spoke Turkish, we dealt with nurses who didn't understand what my father needed and weren't willing to make an effort or show some dedication.*
> *But, overall, I'm grateful for the involvement we've experienced. It gives me hope and confidence that, together, we can provide the best care for my father.*
> *(Vignette composed with extracts from interviews T1, T4, T5, T3)*

The open attitude from the professional care providers showed engagement – for example, through creative thinking to tailor the care to the individual needs of the older person. The participants also experienced an initiative-taking attitude in the care providers, through actions like arranging home care or anticipating future needs. However, the narratives of the participants showed that this level of engagement was not inherent in all professional care providers and was often hindered by systemic limitations such as inaccessible health-care structures (*e.g.* lack of adapted services), time constraints and limited staffing.

2 The experience of cold substandard care from professional care providers

The participants shared how they were confronted with professional care that was experienced as cold and inhuman, where the rules, procedures and cost-cutting measures outweighed the needs of the individual person. The participants experienced a cold attitude (as being distant, indifferent, unresponsive) from both individual health-care providers and the policies of care organisations. The participants expected a certain standard of quality and humanity in the professional care practice. If they did not experience this – and if, on the contrary, they were confronted with substandard care – it was difficult to have confidence in the professional care practice and to 'transfer' the older person from informal care to formal care with a feeling of confidence and trust. For the informal carer, care is experienced as human if it is respectful and acknowledges each individual as a unique person with a unique life history and unique needs. They experienced cold substandard care in different health-care settings – for example, home care, hospitals and long-term-care facilities. The participants experienced substandard care as a rigid, supply-side-oriented structure that was rushed and impatient and lacked attention to the specific needs of the older person with dementia. Though their needs and questions were heard, the participants felt that these were then ignored or not addressed. They reported insufficient supervision for older persons with dementia who were confused and had the tendency to run away, alongside experiences of disrespectful treatment, poor personal hygiene, inadequate staffing with inexperienced health-care providers and frequent provision of sedatives.

> *My mother used to scream a lot and shouted and cursed. But that's just how my mother is, I've always known her like that, I guess it's the temperament of Southern Italy from back in the days, you see? But in the hospital and later in rehabilitation, they found it abnormal, so they gave her sedatives. At the rehabilitation centre, they said my mother couldn't go home anymore. I wanted to give it a try, but my brother and the rehabilitation centre were against that. The nursing home we had chosen had a waiting list, but she had to leave the rehabilitation centre, so she was taken to another nursing home farther away.*
>
> *During the years she stayed in the nursing home, she received a lot of sedatives for her supposedly unmanageable behaviour. Yet whenever I was there, giving her attention and speaking or singing with her in Italian, she was always calm. Because of the sedatives, I didn't recognise my mother anymore; she was drowsy, often fell, and was covered in bruises. My mother was there, with 24-hour supervision, but I was never at ease. Is that what we want for our parents? To put them in a nursing home and sedate them until we no longer have to deal with them? I protested against the sedatives, but they gave me no choice. It was 'take it or leave it'.*
>
> *I had a good contact with some of the carers; they were just doing what they could. In the evenings, there were only two of them for all the work. That was the case every day: far too many residents for far too few staff. Often young girls without*

> *experience, and certainly no experience with dementia. Some of them, I believe, didn't like their job. My mother sat in a wheelchair for three days, with the cushion and the wheelchair soiled with urine, until I couldn't bear it anymore and protested vehemently.*
> *I visited her at the nursing home every day and often brought food. She even said to me: 'I don't like the food here.' It didn't look good either, often unrecognisably mashed with no taste. There were other things too, like eating bread for dinner; my mother was never used to that.*
> *Look, I went along with a lot of things, but I still feel guilty about how she spent her last years.*
> *(Vignette composed with extracts from interviews I4, I7, T4, I1, T3, I9, T7)*

The participants described their experience of cold substandard care as lacking quality, compassion and respect. This led to experiences of unsafe situations and poor communication, resulting in feelings of insecurity and distrust.

3 A sense of home to build trust in care

The participants experienced that recognising and acknowledging the life story and the specific needs of older migrants was important in creating trust and familiarity among the older migrants and their network. The participants shared that, when using professional care, familiarity and feeling a sense of home was an important aspect that built trust for both the older person with dementia and the informal carer. The participants illustrated the importance of food (*i.e.* offering traditional, familiar, well-prepared meals and a recognisable meal pattern), language (*i.e.* the ability to communicate in the native language, especially in situations where dementia has progressed and language skills have declined) and general habits and environment (*i.e.* recognisable furniture, habits and religious customs). These were an essential component of quality of life and comfort for older migrants and their informal carers. It gave them a sign that the care provided respected the cultural background of the older person. When it was provided, it helped the older person with dementia feel comfortable and safe and accepting of the professional care provided.

> *You know, for me as a carer, it's all about familiarity when it comes to getting help for my mother. Take food, for instance: it's more than just nourishment. In our family, food is the solution for every problem. It's a sense of home, of our traditions. But sometimes, the care providers don't get it. They see food as just food; but for us, it's much more.*
> *And then there's the language. It's comforting to know there's someone around who understands her when she's anxious or starts panicking in Italian. When she can express herself in her own language, she feels more at ease. And so do I.*
> *In addition, there are the little things, like her familiar furniture and belongings. They may seem trivial, but they're part of her identity, who she is. They bring her peace in the middle of the dementia chaos.*
> *But it's not only about the physical stuff; it's also about the people around her. Like the head nurse, who happens to be my niece's mother-in-law. Knowing that created an instant connection.*

> *You know, it's frustrating sometimes. For all those years, my parents worked hard in difficult conditions in a country that wasn't their home. I believe they deserve to be treated with respect.*
> *So, yeah, familiarity matters to us. It's about creating a sense of home, of comfort, especially during the toughest times.*
> *(Vignette composed with extracts from I1, I5, T4, I4, T5, T8)*

When the professional carer fostered familiarity and a sense of home, it helped establish a bond of trust among the older person, the informal carer and the professional care provider.

4 The experience of culturally insensitive professional care

Culturally insensitive care neglected the older persons' cultural backgrounds, preferences and needs – leading to inadequate, and sometimes harmful, experiences (*e.g.* refusing to provide halal meals or refusing an older Italian woman's request to avoid male nurses). This was sometimes influenced by the care providers' lack of cultural competence (*e.g.* care providers washing an older Turkish man in the toilet area, not being aware that this is considered inappropriate in his Islamic religion). Additionally, the rigid, supply-side-oriented nature of the health-care system inhibited tailored care. Care managers or providers often refused to deviate from uniform policies or were unable to provide tailored care owing to limited availability of care options that consider the older person's background. The participants also experienced racial micro-aggressions, both implicit and explicit (*e.g.* limited explanations of dementia diagnoses, not being referred to further care solutions owing to assumptions about self-care, and negative comments when food is brought to the hospital).

> *So, being a carer for my mother, who was dealing with dementia, let me tell you, making use of the health-care system… It felt like we were met with some kind of challenge or obstacle every step we took.*
> *After the decision to start with home-care help, we were passed around like a hot potato between about ten different care-givers in one week, none of whom could even communicate with my mother.*
> *My mother isn't religious, but she just didn't want male care-givers. We passed this on to the home-care nurses, but then they said: 'We won't start with that.' We then searched for a private service that would actually listen to us.*
> *When my mother was in the hospital, I would drop by after work and bring food, you know, to make her feel a bit at home. The nurse in the hallway said to me: 'Why do you always bring food; she gets food from us, you know?' When I visited her together with my brothers, we again received comments that there were too many of us in the room.*
> *Honestly, I always hated standing out and asking for something particular, so we usually made it work with what was available. But at my mother's insistence, or for her wellbeing, I sometimes did it anyway. And then it often seemed like I was asking for something impossible. Like in the residential care facility, I asked if they could bring her dinner last and put her in bed last, because she simply isn't used to eating dinner at 4pm and going to bed at 6pm. When I asked, it felt like they would have*

> *to change their entire system and put in a lot of effort to meet my request. Which wasn't actually the case at all, of course, but that's how their reaction made me feel.*
> *(Vignette composed with extracts from interviews T4, I5, T2, I2, I4)*

As the participants' narratives showed, these issues occurred in home care, hospitals and residential care facilities.

5 Struggling with the responsibility of informal care-giving in today's world

The informal carer felt a deep duty to care for their older relative, based on the consideration that 'they cared for us, [so] now it is our turn to care for them'. The participants perceived informal care-giving as a duty motivated by tradition, religion and migration history, carried by love and devotion.

First, the participants' search for professional care was hindered by lack of support and information. They felt a strong responsibility for their family member's care, even when delegating tasks to other family members or professional care providers. This responsibility was paired with distrust towards professional health care owing to a lack of suitable quality care. For informal carers, quality of care also encompasses expertise, experience, capability and empathy, providing them with a sense of reliability and safety. The participants often filled gaps where professional care fell short (*e.g.* creating pictograms to overcome language barriers or organising supervision in a residential care facility).

Second, the participants were expected to mediate, negotiate and educate between the professional care provider, the older person and other family members – making the bridge between everyone involved to ensure that everything was, and remained, coordinated. They experienced it as challenging to find the right tone in this mediation and communication, in combination with the overall struggles and challenges they experienced.

Third, not all of the participants could fully take on informal care-giving owing to other tasks like a paid job and family obligations. They experienced care-giving as a struggle, fulfilled with love, loyalty, creativity and sacrifices. Cultural background and traditions also played a role, with informal carers often facing social pressure and judgement from both the community and the professional care providers. Decisions about residential care or end-of-life care placed a heavy burden on the informal carers, making them feel that they must fight for their family member's interests.

> *As a carer for my father, I felt the weight of the responsibility resting on my shoulders. It's a duty deeply tradition-rooted in our culture, the belief that it's our duty to look after our parents, just as they cared for us when we were young. I remember how my sister, my brother and I came together and unanimously decided that it was our turn to care for our father. But while we were determined to take on this task, we quickly realised that the challenges were overwhelming. Balancing care-giving with a job, our own family and other responsibilities required an enormous effort from all three of us. We searched for creative solutions: I developed a whole system with calendars and pictograms, and I would call him every few hours from my workplace. My sister made meals for several days and stored them in jars in his refrigerator and freezer.*

> *But then he would eat all his meals for that day in the morning, or he would fall, and the door would be locked from the inside so my brother couldn't get in. There was a time when our father called us several times during the night – we just didn't sleep. At a certain point, it wasn't safe for him to continue living alone. And then, as a carer, you also have the responsibility to make that decision.*
>
> *We decided together to have him admitted to a nursing home; we tried every other option, but there was no other choice left. It was truly a heartbreaking moment. The lack of understanding from our Turkish community only made the decision harder. We visited him every day, taking turns. Sometimes it felt like we were reaching our limits, like we didn't know how to keep it all together. But still, we did. It wasn't until after his death that I realised how much this demanded of me.*
>
> *(Vignette composed with extracts from interviews I2, T8, I4, T4, T5)*

The experiences of informal carers highlight the multifaceted dynamic of love, duty, responsibility and burden in care-giving for older migrants with dementia.

6 The cumulative mental load of care-giving

Caring for an older family member with a chronic cognitive condition was demanding for the participants. This was compounded by the responsibility of providing 24/7 care for an older person with dementia, leading to physical and emotional exhaustion. Dedicated care-giving involved a continual mental burden, alternating between hope and disappointment, and managing frustrations when the carefully organised care solution did not turn out as hoped or when the care needs increased over the course of the dementia and the entire process started again.

In addition, they faced the cumulative stress of the added burden of professional care that either failed to meet the older person's personal needs or was experienced as cold, substandard and culturally insensitive. The additional tasks of mediating, negotiating and educating added more stress.

Finally, the mental burden was compounded by the guilt of care-giving responsibilities, the weight of making difficult decisions – and facing the consequences of these decisions – leaving the participants torn between rationality and emotion, often accompanied by feelings of regret and remorse.

> *Powerless, as a carer, I've often felt so powerless. I want to find solutions that don't exist; I want to change things over which I have no control. It feels like a constant battle between hope and disappointment, between seeking solutions and the feeling of powerlessness when those solutions aren't found. I've tried everything, from seeking help from professionals to negotiating appropriate care, but again and again, it feels like I hit walls.*
>
> *Caring for my parents is a 24/7 task that takes all my energy; I feel emotionally drained. I'm alone; I constantly have to make choices, organise, negotiate. Sometimes it feels like I'm running on empty, both physically and emotionally. The guilt of responsibility weighs heavily on me, even when I know I'm doing everything I can. This is the double-edged sword of my Catholic faith, I guess. I feel guilty, but my faith also gives me the strength to keep going. So, despite all the challenges and*

> *setbacks, I continue to dedicate myself to caring for both of my parents, for as long as I can.*
>
> *(Vignette composed with extracts from interviews I2, T4, I4, T8)*

This mental burden was further influenced by whether or not the professional care met their expectations. When the reality of professional care-giving fell short of the expectations, this caused frustration, guilt and regret among the participants. When expectations were met, informal carers found support and satisfaction.

Discussion

The aim of this study was to explore the experiences of informal carers relating to the professional care provided to older migrants with dementia, focusing on the participants' perceptions of whether the delivered professional care met the needs of both the informal carer and their family member with dementia.

The findings reveal a number of insights into the experiences of those providing informal care for an older migrant with dementia. Although the six themes were discussed separately, it is important to stress that they are not separate but rather cumulative experiences.

The first and second themes demonstrate the importance of genuine engagement on the part of the professional carer in the care provision, to create together with the informal carer a care alliance for the older person with dementia, and the importance of caring encounters. While research often highlights barriers and negative experiences among older adults and carers from migrant backgrounds when accessing and using formal care – similar to the experiences of cold and substandard care in this study (Blix and Munkejord 2022; Sagbakken, Spilker and Ingebretsen 2018; Stenberg and Hjelm 2023) – our research also yielded positive interactions with professional care and testimonies of warm, quality care by professionals. Research shows that cultural factors (*e.g.* a shared language) can influence whether caring interaction occurs between professional care providers and older adults (Söderman et al. 2018). A caring encounter can be reaching out to initiate connection or acknowledging the unique person, whereas an uncaring encounter can be lack of interest and insensitivity towards the other (Halldorsdottir 1997; Söderman et al. 2018). Uncaring encounters, often attributed to workload and time constraints, may reflect a disengagement strategy rooted in indifference towards the older migrant, who is perceived as 'the other' (Markey et al. 2019). It is important to situate the experiences of the informal carers within the context of contemporary working conditions in the health-care sector, given its economic constraints and staff shortages (Bridgeman et al. 2018; Cheloni and Tinker 2019). These conditions impact how health-care providers work, leading to mental strain, low morale and burnout – issues that have worsened since the Covid-19 pandemic (Hines et al. 2021) but had already been observed before (Hall et al. 2016; Lyndon 2018). Research shows that poor wellbeing and burnout among health-care providers are linked to poor patient safety, including more medical errors (Bridgeman et al. 2018; Hall et al. 2016). These working conditions can also impact the provision of culturally sensitive care. While the role of the individual health-care provider is often considered, the role of management and policy in supporting the health-care provider should not be overlooked (Claeys et al. 2023).

The third and fourth themes point towards the experienced lack of culturally diverse care options and the need of the informal carers for recognising the specific needs of the older person with a migration background. Informal carers desire person-centred and high-quality care that expresses familiarity and a sense of home. Therefore, this study aligns with previous calls for more and better care approaches that acknowledge individual needs and preferences (Torres 2015). The experienced lack of culturally diverse care options is also confirmed in other studies. Especially in the area of communication and language, more attention should be paid to the interaction of older migrants with dementia (Chejor et al. 2023; Herat-Gunaratne et al. 2020; Sagbakken, Spilker and Ingebretsen 2018). Informal carers expect professional care providers to acknowledge the life story (*e.g.* migration history) and religious customs of older migrants. If these aspects are perceived as being disregarded by the care provider, a lack of trust in the professional care provider can result (Jutlla 2015). In addition, the experiences of the informal carers show that it is important to consider cultural explanations for behaviours in older persons with dementia (*e.g.* loud screaming among Italian women or cursing in Turkish men). Not taking into account that this behaviour could also be a behavioural or psychological symptom of dementia could lead to misinterpretations in care-giving, especially in care for older persons with the possible occurrence of dementia or delirium (Chejor et al. 2023; Sagbakken, Spilker and Nielsen 2018). The cultural attribution may indicate a lack of knowledge among informal carers about dementia and its symptoms, but it can also suggest internalisation of cultural stereotypes, leading to a failure to recognise the actual symptoms of the condition. It is important to point out that, for many participants in this study, the interview was the first time they were able to share their care-giving experiences. It must be understood that some had not fully processed their encounters with care-giving and professional care, which requires time for reflection to gain deeper insights. Issues related to migration and cultural background sometimes involved experiencing othering and micro-aggressions of racism, which are not always easy to put into words (Carter et al. 2017). When addressing racial trauma, the informal carers sometimes had no words, or they were not able to pinpoint what was going on or what actually happened in certain situations. And if the informal carer was indeed able to put this into words, he or she often needed a safe environment to do so (Carter et al. 2017).

Finally, the fifth and sixth themes underscore the informal carers' sense of moral duty in care-giving in the context of the migration history of first-generation labour migrants in Belgium, who left their native country with the hope of providing a better life for future generations. This context influences the difficult balance in the experienced duty and responsibility towards the informal carer (Jutlla 2015). Moreover, the long-standing tradition of informal care-giving faces challenges in today's modern, more individualistic and capitalist society. With increasing pressure from individualism and smaller family units, there is a growing gap between the perceived sense of duty and the practical fulfilment of care-giving responsibilities (Sagbakken, Spilker and Ingebretsen 2018; Shrestha et al. 2023; ten Kate et al. 2021). In addition, the findings show how the participants mediate among the professional carer, the older person and their network by negotiating, translating (in both language and terms relevant to each person) and educating. This is perceived as an additional task for which the informal carers receive little recognition and are often held accountable (Duran-Kiraç et al. 2022; Duran-Kiraç et al. 2023; Stenberg and Hjelm 2023).

The findings have highlighted cumulative stress among the informal carers with a migration background who participated in this study. They have undertaken three tasks to fill gaps in professional care – namely, providing quality care, creating a sense of home, and mediating and educating. These tasks add to their already burdensome responsibilities. Despite their efforts, the informal carers receive little recognition for these roles and are often held accountable for them. Moreover, the informal carers who participated in this study encounter challenges such as limited access to appropriate professional care and interactions with culturally insensitive or insufficient services. Balancing between hope and disappointment – along with the continuous task of negotiating and mediating between care providers and their older family member – places a heavy mental burden on them, which is also confirmed by findings in other studies (Berdai Chaouni et al. 2020; Herat-Gunaratne et al. 2020; Stenberg and Hjelm 2023). In addition, the informal carers often encounter unmet expectations, resulting in frustration and disappointment. This burden contributes to physical and emotional stress, which often manifests in chronic health issues, both during and long after providing care. This physical and emotional stress can further intensify the mental strain on informal carers (Parveen et al. 2018; Stenberg and Hjelm 2023; Wangler and Jansky 2021). Finally, the burden is further compounded by the difficult decisions they must make and the accompanying feelings of guilt. International research indicates that informal carers often find themselves isolated and facing seemingly insurmountable challenges (Guan et al. 2023). All of these conditions create cumulative stress, which causes a high burden.

In summary, this study shows that there is an urgent need for adapted and high-quality care for older persons with a migration background who live with dementia. Additionally, there is a strong need to support and recognise informal carers. The concept of a care alliance, discussed in the first theme, shows that cooperation and understanding are possible and can lead to positive experiences.

Context, strengths and limitations of this study

This study concerns informal carers as family members of older migrants with dementia. This inclusion criterion implies that the informal carers all have a migration-related family history. With regard to the professional care providers mentioned in the informal carers' experiences, this study primarily focuses on the informal carers' perspectives. It does not specifically detail whether the professional care providers themselves have a migration background. Moreover, the participants usually did not discuss or enquire about the ethnicity or migration background of the professional care-givers. When mentioned, it was typically in situations where there was a shared characteristic, such as a similar migration background.

That said, Koehn (2009) demonstrated that, even when health-care providers and older persons share the same ethno-cultural background, the importance of middle-class values and the process of professional socialisation may hinder the health-care providers from critically examining the ways in which race, gender and class intersect in the delivery of health care.

In addition, the researchers' profiles – particularly their ethnic-cultural backgrounds – may have influenced the data collection process: one researcher had a migration background, while the other did not. During the interviews, the shared migration background between the respondent and the researcher was occasionally referenced (*e.g.* 'you know what I mean'). It is important to recognise that certain aspects may have been left unspoken, influenced either by the shared migration history with one researcher or by the absence of such a shared history with the other. The profile of the researcher can also influence the decision whether or not to work with an interpreter to conduct the interviews. In this study, three interviews were conducted with a translator, which may have had an influence on the data collection (Wallin and Ahlström 2006).

The use of composite vignettes seemed most suitable for this study for several reasons. First, the intention of this study was to present the findings in a way that let the data 'speak for themselves', in order to foster awareness among readers concerning the experiences of informal carers. Second, this method offers a clear and compelling format for data representation, ensuring accessibility by a diverse readership. Lastly, it facilitates understanding of the experiences of informal carers, whereby the results can be used to address policies that provide support and intervention strategies for informal carers (Crocker et al. 2021; Knight et al. 2023). In contrast to the Paquette study, in which composite vignettes were used to shape composite characters, this study explicitly chose not to display the vignettes in the form of created characters or fictive persons in order to avoid stereotyping the informal carers (Paquette et al. 2019).

The choice to jointly analyse the experiences of informal carers with Turkish and Italian backgrounds ensured that a shared, lived story emerged in the findings. However, this choice limited the ability to explore potential differences in experiences between the two groups of informal carers. Moreover, by not distinguishing between the types of professional care the older persons received (*e.g.* home care, residential care) in the inclusion criteria, the findings cannot be differentiated according to the type of professional care experienced. Nonetheless, it should be noted that the focus of this study is on the experiences of the informal carer, and that the care trajectory for a person with dementia often involves different types of care throughout the chronic course of the condition.

Conclusion

The informal carers for older migrants with dementia who participated in this study experience a high and cumulative burden owing to a range of factors unique to their situation. In addition to the universal challenges experienced by all informal carers, informal carers with a migration background encounter an extra layer of burden.

This extra layer stems from the specific needs of the older person related to the migration story or the cultural background as well as barriers to accessible care, a lack of support and information, a lack of culturally tailored care options, the experiences of culturally insensitive care and racial micro-aggressions. Moreover, the informal carers take on extra tasks and responsibilities to bridge both more general and more culture-specific gaps in professional care, such as mediating, negotiating, overcoming language barriers and educating health-care providers. Further, the informal carers experience the duty motivated by tradition, religion and migration history.

It is important to recognise this extra layer as a cumulative burden on top of the universal challenges faced by all informal carers. This makes caring for older migrants with dementia especially challenging for informal carers from a migration background.

Although substandard professional care is often encountered, it is important to note that not all interactions with professional health-care services are negative; some informal carers report positive experiences.

Finally, informal carers need more support and resources to relieve their mental burden and ensure both their own wellbeing and that of the older migrants they care for.

Implications for policy and practice

Addressing the high and cumulative burden experienced by informal carers demands policy interventions aimed at improving access to person-centred and high-quality care services. Policies could focus on expanding and enhancing professional care options tailored to the needs of older migrants with dementia. Moreover, the working conditions for health-care providers need to be enhanced to ensure that they have the capacity to deliver high-quality care.

In addition, training programmes for health-care professionals could be enhanced. While it is generally the case that health-care students receive training in communication skills and patient interactions, research shows that training in cultural competencies and culturally sensitive care remains limited and fragmented (Diaz et al. 2024). The focus and integration of these courses could be improved by incorporating development of critical self-awareness and knowledge of social exclusion mechanisms, such as racism (Diaz et al. 2024; Hamed et al. 2022). Moreover, policies should prioritise providing support services for informal carers, such as respite care and counselling, to relieve the care-giving burden and prevent further implications for their physical and mental health. It is evident that support programmes for informal carers can be successful only if there is sufficient high-quality and appropriate professional care for the older person at the same time.

Furthermore, there is a need for policies that promote better communication, coordination and care alliances among informal carers, professional care providers and older migrants with dementia – such as, for example, case managers who support informal carers in navigating the health-care system.

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Appendices

Table 1. The essential structure of six themes as informal carers' experiences with professional care are extracted from the nine original concepts in the analysis process

Original concepts divided into nine categories	Intermediate stage	Essential structure of the six final themes
Engagement (engagement gives trust)	(Stayed the same category)	Informal carers are hoping for engagement from the professional care providers in order to create together a care alliance for the older person with dementia.
Cold-hearted and efficient care (cold-hearted care), with the emphasis on efficiency and economic savings, leads to distrust • with subcategory 'culturally insensitive care'	(Stayed the same category)	Informal carers experience cold-hearted substandard care provision from professional care providers towards their loved ones.
Familiarity (familiarity leads to trust)	(Two categories merged)	Informal carers need to feel a sense of home in order to be able to trust the professional care providers.
Not being seen/heard/supported (feeling of not being heard/seen as an older migrant worker or as an older migrant)		

(*Continued*)

Table 1. (*Continued.*)

Original concepts divided into nine categories	Intermediate stage	Essential structure of the six final themes
Culturalising	Subcategory 'culturally insensitive care' becomes a new category, together with the category 'culturalising'	Informal carers experience culturally insensitive care practices by professional care providers.
Filial responsibility and its implementation	(Two categories merged)	Informal carers struggle with the responsibility of informal care-giving in the context of today's world.
(Final) responsibility about the care provision (informal carer feels/caries the final responsibility)		
Mental load (the mental load of informal care-giving)	(Two categories merged)	Informal carers experience the cumulative mental load of care-giving.
Expectations of the informal carer (met, unmet and changed expectations of the informal carer)		

Table 2. Description of the participants

Interviews with informal carers of Italian (I) or Turkish (T) background	Sex of the informal carer	Relationship to the older person they cared for	Care setting used by the older person	Language of the interview
I1	F	Niece	Home care and nursing home	French
I2	M	Son	Home care and residential hospital care	Dutch
I3	F	Daughter	Home care and residential hospital care	French
I4	F	Daughter	Home care, residential hospital care, rehabilitation centre and nursing home	French
I5	M	Son	Home care and residential hospital care	Dutch
I6	F	Daughter	Home care	French
I7	F	Daughter in law	Home care	French
I8	F	Daughter	Home care, residential hospital care and rehabilitation centre	French

(*Continued*)

Table 2. (*Continued.*)

Interviews with informal carers of Italian (I) or Turkish (T) background	Sex of the informal carer	Relationship to the older person they cared for	Care setting used by the older person	Language of the interview
I9	M	Spouse	Home care and nursing home	French
T1	F	Niece	Home care, day care centre and residential hospital care	Dutch
T2	F	Daughter	Home care and residential hospital care	Dutch
T3	M	Son	Home care and residential hospital care	Dutch/Turkish (+ interpreter)
T4	F	Daughter	Home care, residential hospital care, nursing home	Dutch
T5	F	Daughter	Home care and residential hospital care	Dutch
T6	M	Son	Home care	Turkish (+ interpreter)
T7	F	Spouse	Home care and residential hospital care	Turkish (+ interpreter)
T8	F	Daughter	Home care and residential hospital care	Dutch

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