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Dementia among migrants in Italy: a qualitative study of the ImmiDem project

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Abstract

Introduction. In recent years, the number of migrants referred to centres for cognitive disorders and dementias has increased. The aim of this study was to provide information on the provision of care for migrants with dementia through the perceptions and experiences of the professionals and caregivers involved.

Methods. The study is an exploratory qualitative research. Between 2020 and 2021, three focus group, involving caregiver and professionals were organized.

Results. The study explored several areas of care provision including needs, cultural representation of dementia, strengths and weaknesses and opportunities for improvement in care provision.

Discussion and conclusions. The perceptions of people directly involved in dementia care provide critical insights into the functioning of the care system, capturing nuances that standard care practices may overlook. Disorientation between services, language barriers and cultural representations of the disease are the main obstacles to continuity of care. A more holistic approach, which also addresses the emotional and social implications of dementia, is essential in ensuring equitable, timely and culturally sensitive care.

Key words
- dementia
- migrants
- provision of care
- culture-sensitivity

INTRODUCTION

Contemporary international migration has been a growing phenomenon over the past 30 years [1], due to socio-political, demographic, economic, and environmental influences [2]. The global ageing of the population leads to an increase in the number of older individuals also within migrant communities. At mid-year in 2020, globally, migrants aged 65 and older accounted for an estimated 34.3 million (12.2%) of all international migrants (i.e., people living in a country but born abroad) [1]. In Italy, a total of 316,796 elderly migrants are estimated to reside in 2023, with inter-regional heterogeneity ranging from 674 in Valle d'Aosta to 63,436 in Lombardy [3]. This demographic change is leading to substantial changes in health needs among migrants, including an increased prevalence of age-related chronic diseases and multimorbidity [4]. For instance, in recent years, there has been an increase in the number of migrants referred to Italian centres for cognitive disorders and dementias (CCDDs), especially in northern and central regions [5]. The application of age- and sex-specific prevalence rates [6-8] allowed estimating nearly 10,351 cases of dementia and 23,893 cases of mild cognitive impairment (MCI) in the age group of 65 years and over [9]. The female-to-male ratio is 2.5 in dementia and 1.86 in MCI [9]. Alongside the growth of this phenomenon, there is clear evidence of the need for action to improve help-seeking and promote timely diagnosis of dementia in migrant populations [10]. Migrants often access dementia care services later than the general population and experience difficulties in meeting their needs. This results in a higher dependency

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on support from caregivers and healthcare professionals [11]. Even though the symptoms of dementia are similar across races and ethnicities, the diagnosis of dementia in a cross-cultural context can be challenging [12]. The complexity of the clinical approach arises from language barriers and the lack of validated cross-cultural cognitive tools and dementia assessment scales [12]. Furthermore, in some cultures and populations, the stigma surrounding mental health problems can constitute an additional barrier [13].

To enhance accessibility, equity, and effectiveness in local healthcare systems, it is recommended to analyse the target population's needs to foster an effective reorganization of services that includes cultural mediation, peer-to-peer education and support, and the training of health professionals [14]. In addition, current public health initiatives should prioritize promoting cross-cultural dementia care that considers the values and preferences of different migrant populations [15]. However, there is limited knowledge of the experiences of migrant populations accessing dementia care services. This is the framework for the ImmiDem project, which aims to identify and promote good practices and care pathways for migrants with dementia and cognitive disorders.

The aim of this qualitative study was to provide information on the provision of care for migrants with dementia living in Italy, its strengths and weaknesses, and the perceptions and experiences of health and social care professionals and caregivers from their own perspectives.

MATERIALS AND METHODS

An exploratory qualitative study was carried out [16]. Three focus groups (FGs) were organized to collect the opinions of relevant stakeholders. Two FGs involved health and social care professionals including physicians (neurologists, geriatricians, internists, general practitioners, infectious disease specialists, dentists, and psychiatrists), speech therapists, cultural mediators, psychologists, sociologists, and social care workers with consolidated experience in the provision of care for migrants. These group interviews with professionals also served as a pilot study to test and refine a questionnaire for a national survey of CCDDs on the issue of dementia and migration [5]. One FG involved family caregivers of migrants with dementia. Participants were recruited through a purposeful sampling.

The study was approved by the Italian National Institute of Health Ethics Committee (Istituto Superiore di Sanità, ISS, Comitato Etico). All participants were contacted by an ImmiDem project [17] manager through the project stakeholders' network. Health and social care professionals were recruited from CCDDs that were identified based on their logistical feasibility and the number of migrants they reported to have assisted in the ImmiDem survey [5]. All professionals were invited to participate in the study by telephone calls followed by email invitations. All participants were actively involved in the care of migrants in different settings (hospital and community services) at the moment of the study. FGs with professionals were conducted during 2020, while the one with family caregivers was held in 2021 due to the project setback following the outbreak of the COVID-19 pandemic. They were facilitated by experienced researchers of the Italian National Institute of Health in Rome, following a semi-structured set of questions (*Table 1*). These questions guide was built with the contribution of all researchers and shared with ImmiDem project managers. The following definition of migrants was adopted and shared with participants: any individual living in Italy but born abroad (regardless of reason for migration, length of stay, and legal status) [18]. Each discussion lasted around 90 minutes. All the FGs were audio-recorded and transcribed, with the informed consent of the par-

Table 1
List of aims and questions for the Focus Group

Aim 1. Analysis of the needs of migrants with dementia and their caregivers
1a) In your opinion, what are the bio-psycho-social needs of migrants? • What are yours? 1b) In your experience, what are the cultural representations of dementia, its course, symptoms, and outcomes in the various cultures of origin? • What effect (positive or negative) do these different visions have on the provision of care for migrants?
Aim 2. Strengths, weaknesses and action proposals in provision of care
2a) In your opinion, what are the strengths and weaknesses in the provision of care for migrants with cognitive disorders? The discussion can be about the perspective of: • people with cognitive disorders, caregivers, and professionals; • the available diagnostic tools (e.g., cross-cultural cognitive assessment tools); • communication of diagnosis; • pharmacological treatment; • promotion of healthy lifestyles and other treatments (social, non-pharmacological, living environment, and culturally-sensitive • interventions); • provision of care for caregivers; • provision of care for professionals (e.g., management of burnout). 2b) In your opinion, what are the possible improvements in the provision of care, communities, and policies? • Would improving clinical pathways for migrants improve clinical pathways for the general population?
Aim 3. National survey (after viewing the questionnaire) – *Only for professionals*
3) Concerning the national survey of Italian CCDDs on dementia and migration, which variables do you think it is relevant to assess?

CCDDs: centres for cognitive disorders and dementias.

ticipants. Socio-demographic data of participants were also collected in an anonymous form. A categorical data analysis was performed: categories were developed both deductively, based on the research question, and inductively, based on emerging contents. The data were independently coded by two authors who then discussed the themes and categories for defining the tree-nodes. In case of disagreement, a third researcher was involved. The tree-nodes were applied to the whole transcripts, and the most meaningful verbatim were identified. The software used for the qualitative analysis was NVivo Pro. Data saturation was not required.

The main themes explored during the FGs, according to the main research questions, were:

- the bio-psycho-social needs of migrants with dementia and their caregivers;
- the cultural representation of dementia;
- the strengths and weaknesses of care provision for migrants with cognitive disorders;
- the rooms for improvement in care provision, communities, and policies.

RESULTS

Three FGs were conducted in January 2020 and in October 2021, involving 20 participants (17 health and social care professionals and 3 caregivers). The country of origin for the health and social care professionals was Italy, while the caregivers were from Egypt, Colombia and Romania. The health and social care professionals involved 7 women and 10 men, with a mean age of 50 years. The caregivers included 2 women and 1 man, with a mean age of 62.7 years. Among the professionals, there were 4 neurologists, 1 geriatrician, 2 internists, 1 general practitioner, 1 infectious disease specialist, 1 dentist, and 1 psychiatrist. Additionally, there were 2 psychologists, 1 cultural mediator, 1 sociologist, 1 social worker, and 1 speech therapist. Most of these professionals worked in hospitals.

Table 2 describes the participants' characteristics, while *Figure 1* summarizes the main results.

Bio-psycho-social needs of migrants with dementia and their caregivers

The needs of migrants with dementia include difficulties in accessing healthcare services, which are greater for those in irregular situations than for those in regular situations, and for women than for men.

Informal caregivers also recognized that this difficulty in accessing healthcare services was exacerbated by the pandemic: "*because of the Coronavirus, (…) it was impossible for him to access any Centre*".

The difficulty in accessing services is often caused by a lack of knowledge on the available services in the community, which are organised in many cases differently from those in the country of origin. This lack of information requires professionals to dedicate time to provide adequate information to efficiently orientate and access services: "*they are very poorly informed, and accessibility to information is truly an issue (…). I spend a lot of my time giving information, explaining what is done in the Municipality, what is done at the Local Health Authority, (…) just the bureaucratic aspects*".

Table 2
Characteristics of social-health professionals and family caregivers involved in the FGs (n=20)

Data of participants'	**N**
Country of origin	
Social-health professionals (n=17)	
Italy	17
Family caregivers (n=3)	
Egypt	1
Colombia	1
Romania	1
Mean age in years	
Social-health professionals (n=17)	50 (SD±12.4)
Family caregivers (n=3)	62.7 (SD±2.5)
Gender	
Social-health professionals (n=17)	
Women	7
Men	10
Family caregivers (n=3)	
Women	2
Men	1
Social-health professions (n=17)	
Physician (n=11)	
Neurologist	4
Geriatrician	1
Internist	2
General practitioner	1
Infectious disease specialist	1
Dentist	1
Psychiatrist	1
Psychologist	2
Cultural mediator	1
Sociologist	1
Social worker	1
Speech therapist	1
Social-health professionals' workplace (n=17)	
Hospital	13
Territorial	2
University	1
Association	1

FG: focus group; SD: standard deviation; n: number.

Barriers to accessibility include difficulties in orientation, including spatial orientation, between services, which undermine continuity of care and lead to loss of follow-up: "*those who enter the hospital environment may also lose the spatial orientation sometimes*".

Language barriers also play a key role in accessing services, due to difficulties in doctor-patient interaction, reporting health problems, and using diagnostic tools. Migrants supported by family or friends and an IT tool for translation may benefit more: "*the lucky ones have a friend who speaks Italian, or, more often, they use an automatic translation tool on their smartphone*" "*Where I worked before, I used to solve the problem by myself (…) I mean, I asked a relative or a friend [of the patient] to be my translator*".

Difficulties in orientation and communication can lead to an inappropriate use, or abuse, of the emergency services: "*very often the migrant goes to the Emergency Room [because] he/she doesn't know which outpatient services are available, due to lack of information; therefore, there is definitely a 'wrong' use of the Emergency Room*".

Although not appropriate, for migrants, the emergency service is probably the first contact with the health

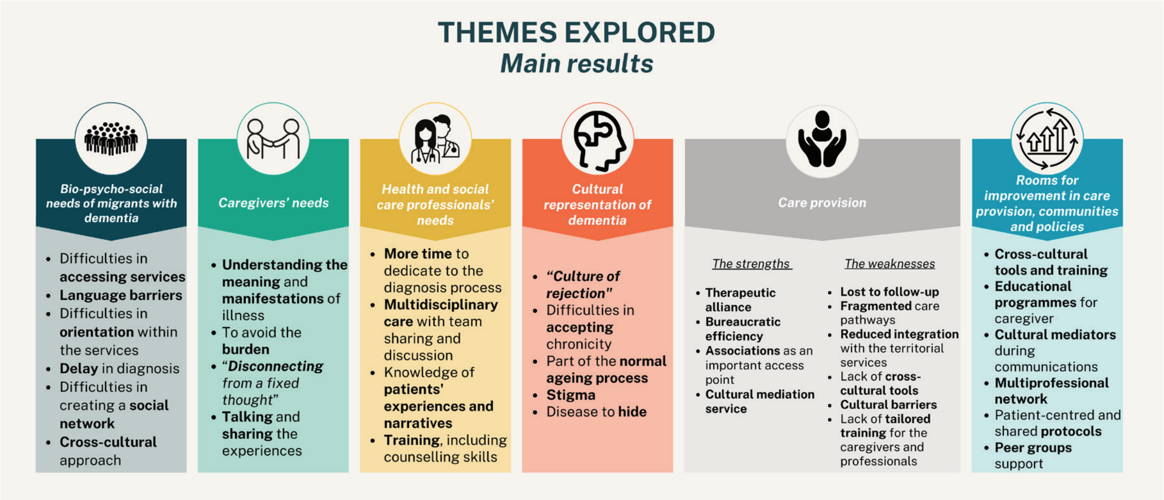

Figure 1
Summary of ImmiDem qualitative main results.

services. This may be challenging for them as "*the Emergency Room is not always able to respond to [their] needs*".

This leads to a delay in diagnosis, as migrants access emergency services when the symptoms of dementia are getting worse. Furthermore, cognitive disorders are not considered a priority compared to other essential needs: "*Often the disease is hidden, unrecognized, at least until it becomes so acute that they go to the Emergency Room*".

Caregivers living with a relative with dementia reported their relative's difficulties in finding or keeping a job, due to the onset and progression of the disease. The inability to attend a job interview or to work reduces the person's self-esteem: "*We looked for [a job for his father] and the sons found it (…) but after a day or two, the restaurant owner tells them: 'Are you sure he was a chef? And that he worked for more than 35 years in a restaurant kitchen?'* "; "*Considering the person's self-esteem, (…) when she had moments of mental clarity, she realised that she had zero income, that she couldn't find a job because (…) she couldn't even pass the first interview*".

In some cases, this situation generated forms of exploitation where adequate remuneration and suitable contractual forms were not always guaranteed. In other cases, the disease was not recognized by institutions (e.g., social security) as the person with dementia successfully answered the simple questions asked during the interview. This led to the loss of welfare benefits: "*Since he was 50 years old, he has been exploited a lot by many companies that hired him, made him work hard, paid him very little, did not offer him a contract*".

In some cases, there is the presence of Non-Governmental Organizations (NGOs) that offer persons with dementia the opportunity to work, however, the latter fear the loss of government welfare benefits if they take advantage of this opportunity. In addition, the fear that the diagnosis of dementia could jeopardise employment status or residence permits, and consequently the access to healthcare services, is another relevant issue. Hence "*the need to be welcomed and to be reassured that access to these services has no [negative] consequences [for them]*". This sense of precariousness, together with an unhealthy lifestyle, is destabilising, with repercussions on a person's health and well-being: "*when residence permits expire and there is that empty time moment, when the health card expires, at that point there is a high risk of strong destabilisation*"; "*The inactivity, the frustration of not working, not having a home, not being able to have a family, not being able to have children, all these things reduce that glimmer of humanity*".

The sense of emptiness is also due to the lack or difficulty in creating a social network, giving rise to loneliness in dealing with cognitive impairment. When a family network exists, the caregivers often work full time with limited time left to care for their relatives. Therefore, it is necessary to promote the creation of a relational network, to "*maximize the emotional and cognitive abilities of that person, that is, provide a relational context*".

The presence of a "strong" caregiver ensures continuity of care and treatment compliance. Conversely, when the caregiver is lacking, this affects the diagnostic process, as the patient alone is unable to find the appropriate information needed for the medical history: "*if there is a strong, precise, punctual caregiver, then the patient comes back, takes the drugs, and does everything he/she is told; if there is no caregiver, the patient may not take care of himself/herself, may not come back to the outpatient clinic*".

Furthermore, to promote the building of a social support network, people with dementia express a strong need to be listened to, understood and to receive positive feedback from professionals. For their part, professionals should devote adequate time to counselling, despite often having limited time: "*It is not enough to give and say things, you have to try to understand if the other person has understood*". "*This is my burning inside. When you have these high-demanding patients and time is what it is*".

For this reason, in order to optimize care, it has been reported that it is essential to go beyond cultural aspects and get to know the narratives and personal experiences of these people: "*you have to go beyond culture.*

It is very important to understand the person, because that person [behind him] has a different story (...) we have to understand who we are dealing with".

For their part, migrants with cognitive impairment need to fully understand the pathology, which is more cognitive/mental than physical, to understand how to manage it: "*[there is] the difficulty of understanding the disease (…) it is not easy for these people to identify where their illness lies*".

In this context, it is important to use a cross-cultural approach, as the care provision they experience in the host country is often different from that in their country of origin. The multi-professional approach, typically implemented to manage dementia, can be difficult to understand and can generate disorientation. Moreover, the same culturally sensitive approach is also important when it comes to interpreting the clinical manifestations of the disease, which may differ from one culture to another: "*sometimes it is difficult to explain why there are two professionals, for example why there is a doctor who deals with the body and a psychologist who deals with the mind*".

Caregivers' needs by professionals' perspective

Who is the *caregiver*? - Participants' definition
The caregiver has been identified not only in the classic form of the person who cares for an elderly family member with a disease, but also as a person whose job it is to care for patients with dementia, as in the case of formal caregivers. As for the migrant population, caregivers may be family members, including adolescent children and, if necessary, all of them also cover the role of cultural mediators.

According to the professionals, the caregivers, as well as the person with dementia, need to understand the meaning and the manifestations of the disease to avoid a sense of frustration due to the inability to understand the evolution of symptoms. Therefore, an accurate and properly communicated diagnosis should be provided: "*relatives feel distressed about this disease that overwhelms them. This applies to Italians but also to migrants, who have great difficulty in understanding the complaints of the person with dementia (…) it is anguish, frustration; we must therefore give them an explanation of any symptoms or [on the contrary] reassure them that, despite the relative's behaviour, there is no pathology*".

The need for explanation and clarification refers to the whole care pathway, from the cognitive evaluation to the communication of the diagnosis. For instance, this need may relate to the explanation of the administered test, which consists of "*questions that are used to understand if there are objective cognitive impairments or if there is something else*".

Caregivers sometimes experience a daily burden of caregiving, both physical and emotional. When this happens, the demand on health professionals to dedicate time to the sick person increase: "*Definitely caregivers are overloaded (…) family members sometimes expect from those who provide care to be extremely available*".

Some emphasised the importance of providing free care benefits to migrant caregivers in socio-economically disadvantaged conditions to enable them to continue caring for their family members in the host country.

It was reported that the second and third generation of migrants may face more problems when they are involved in caring for elderly people with dementia, as they tend to adapt to the culture of the host country, by creating "*fractures in cultural and family habits*"; "*the problem is [greater for] the second and third generation (…). Even the mother says: 'You have to take care of grandpa. Grandpa is like this now and you have to stay home (…)'. For the mother there isn't a problem. The child, however, since he was born here, or arrived as a child, says: 'No, I want to go and play football like my friends' (…) so you break cultural, family habits*".

Caregivers' needs by caregivers' perspective

Family members also express their own needs about their role as caregivers, as described below.

The need for clarity and understanding of the disease was confirmed by the caregivers themselves, which is essential to help their relatives in the right way. Moreover, caregivers declared that they needed to understand how to care for themselves as well and avoid burdens: "*First of all, I need to understand how not to feel bad, because when I feel bad I can't help him much (…) I want to give 100%*".

The need to "*break away from fixed thinking*" and the daily routine was expressed: "*people who have a relative (…) with a history of dementia, memory loss, schizophrenia, need to disconnect. I know I have to feed [my mother], so I have to run home from work (…) I come home stressed. In fact, I can no longer sleep continuously for 10 hours like I used to. In my opinion, the most important thing for family members of people with this type of illness is that they have to unplug, because people also burn out their brains too*".

It was reported how caring for a relative with cognitive impairment can be more difficult for younger caregivers, as they find it harder to accept the worsening of the disease and the increase in care: "*For young people it is very, very hard. (…) because they don't accept [the disease and its symptoms], and they don't have the patience*".

These experiences completely change the caregivers' lives and negatively affect their ability to interact with the sick person. When caring for a family member, there is a strong emotional component that influences the provision of care (e.g., the ability to give rules or restrict freedom of movement outside the home). At some point, the emotional component prevails over rationality and generates denial of the disease progression and hope for a possible improvement: "*having a family member with this type of disease implies the emotional component that blocks you. (…) she is my mother, (…) hope takes over, and I think: 'Maybe tomorrow she will be better; maybe tomorrow she will understand better'. (…) it is difficult, really, to detach the emotional component (…) you struggle because she is always the mother or the wife or the sister*".

These experiences are so pervasive that caregivers run the risk of not living their own lives, because they have to devote themselves to the relative with dementia. Therefore, talking and sharing their experience helps them feel "*lighter*" and relieves them of an inner burden. It has been confirmed how a strong social and family network can help them to cope and deal with the difficulties.

Health and social care professionals' needs

Health and social care professionals expressed the need for more time to dedicate to the diagnosis process, tests, and to communication, and so that multidisciplinary care provision involves also occasions for team sharing and discussions to avoid burnout: "*Share even when you disagree [with a decision], because sometimes disagreement challenges you and maybe makes you change your mind or make other decisions. I would say the mindset is to always work in a project way, because that's how we can move forward*".

Due to the potential emotional implication on professionals' mental health, psychological support was reported as being needed: "*[a] psychological support also for us, not only for the patient and the caregiver, because sometimes we have to communicate something very, very strong*".

Moreover, in some cases, a sense of frustration was also reported due to the fact that organizations do not enable professionals to *"do what is possible*": "*I don't expect to ensure excellence [in all circumstances] (…) but even if you see that it is possible, you are not [always] in a condition to do it*".

Professionals also reported the need to learn about patients' experiences and narratives in order to gather information that could be useful for tailored care, in order to avoid "*thinking as Westerners, proposing some things that (…) might not be good or might be far-fetched*".

Training for professionals is one of the most important needs, not only to improve care but also to give formal recognition to the care pathway of migrants with dementia. The training contents should include counselling skills: "*in my opinion, one of the big gaps in the training of physicians and health professionals is that they do not have adequate training in the field of communication and relations and that they have no support in this area. We are completely abandoned with regard to this aspect, the relational aspect*".

Cultural representation of dementia

The cultural representation of dementia changes across cultures and nationalities. In some cultures, there is the habit of returning to the country of origin when the disease becomes more severe to receive care, and have a family network to rely on, considering that some populations mainly migrate for work: "*when the diseases become a little more severe, they go to be treated in (…) they return home both to be treated and to be cared for (…) because people come here to work, so it would become a burden for those who have the disease*".

Some professionals underlined the "*culture of rejection*" affecting mental disease in some cultures. Some professionals described how mental disease is stigmatized, with the risk of being marginalized by the family and the community: "*I have a patient that I have been taking care of for 25 years (…), who in 25 years has never told her family that she is being treated and has a major depression. She never said it, terrified that her family could marginalize her*".

In some cases, this refusal results in blaming the person with cognitive impairment or dementia. On the other hand, there is the perception that some cultures develop a sense of loving kindness towards the older person with cognitive impairment. In these cultures, even at a young age, there is a sense of having the duty to take care of the patient.

While in some cases, cognitive impairment is believed to be a natural evolution of aging, in other cases, the long-term chronic evolution is more difficult to accept: "*Some people have to ferry themselves into the idea that you are in a limbo, that you have a disease, but this disease will follow you, it characterizes you throughout your existence in the next twenty years, and you have to manage this thing*".

Due to this perception of the chronicity of the disease, it is also difficult to manage chronic treatment regularly and with continuity: "*there is an emergency drug-taking culture because 'when I'm fine, why should I take the drug?' (…). There is a tendency to take the drug [only when] you need it [and then discontinue it]*".

Strengths and weaknesses of care provision for migrants with cognitive disorders

One of the main strengths shared by the professionals was the therapeutic alliance with the patient. On the other hand, caregivers mentioned the bureaucratic efficiency of the practices related to citizenship and recognition of disability. The municipalities were an important support for caregivers by providing information and clarifications to deal with administrative procedures to request allowances: "*For some years, we could talk to a social worker from the municipality who has helped us a lot, especially with information and clarifications because we knew some pieces, we had heard something, like the assistant, support administrator, tutor and various, and therefore we did not understand very well how the request could be made*".

It was stated that the main strength regarding hospital services was the cultural mediation service, available in several languages and several times a week, as well as the support of associations, such as NGOs, in offering an important access point for irregular migrants.

Among the weaknesses, a considerable number of losses to follow up were described. These losses were mostly related to homeless or irregular people, who do not declare their real health conditions, and it is difficult to keep them within the system: "*irregular immigrants are clearly those most exposed to traumatic experiences (...) the more you are integrated and the more it is possible to get a great collaboration*"; "*many patients are lost even at follow-up (...) Very often, they are homeless people who live with friends, who often lie even for all sort of reasons, and it is very, very difficult to gain their trust and keep them hooked up to the outpatients clinics (...) when an acute episode occurs, (…) this is when we discover situations not known to the social services, of people who live in absolutely unhealthy ways*".

These situations adversely affect the treatment plans, as these take a long time and require continuous contact with migrants: "*Maybe they give it [the therapeutic plan] at three months and, clearly, if it is already difficult to cage an Italian patient for about three months, I don't dare imagine a patient like that, (…). There is a practical problem which is the follow-up (…) if you don't have a patient who follows [the therapeutic plan]*".

For some participants, the problem is the fragmented care pathways that reduce accessibility and compliance, especially for vulnerable people. This generates blame for the patient who does not fit into the care pathway: *"we, as institutions, are generally quite repulsive; we are unattractive, not so much as people but especially in the context, how we are close to frailties. (…). So, we slip into measurement, instinctively, and we are rewarded for this. Actually, the question is: what can I do to keep these people on a care pathway?"*.

A health professional reported that when care is provided by a private organization, dementia becomes an "*elite*" disease because these types of organizations have more tools and resources, but they are not within everyone's reach.

In some cases, voluntary associations meet the needs but sometimes are occasional services that do not always guarantee continuity of care.

Another weakness of the care system that impacts on patient's everyday life is the difficulty in obtaining welfare benefits and allowances, which is possible only when a diagnosis is established. This also has an impact on the possibility to keep the patient in the care pathway, also due to the limited time and resources of working caregivers: "*because you have to convince the caregiver and the caregiver [who] has his time, his resources, because the caregivers work*".

The reduced integration with the community services was another stated weakness, especially in the relationship with general practitioners, "*who don't send patients*", and this may result in long waiting lists. Caregivers also reported that the long waiting lists lead families to turn to private services, despite economic difficulties, thus further hampering the continuity of care: "*So, the two appointments were so distant, so sporadic; we are trying to have a third appointment with the doctor, but they always tell us that the agenda is full, to call later; every day on the phone to see if we can get an appointment and it wasn't possible. Paying a fee is difficult for us because not having a salary, it is not easy to have paid appointments which are a bit expensive, at least for those who don't have the money*"; "*So far, for two times, we have had the same doctor, very kind and professional. But I asked her: 'What should I do, to meet you next time?' [She said] 'No. You ask for an appointment. If you want have a visit with me, you should book a private visit'* ".

The lack of cross-cultural tools is another critical aspect that emerged during the discussion. Health professionals described this difficulty using these words: "*Concerning diagnoses, the situation is a little more complicated because I use a series of observational, informal tools that are not linguistically adapted. (…) We ask if the patient can go to their country of origin to make a more thorough assessment. This was possible in a few cases. However, it allowed us to reach a diagnosis*"; "*I try with the tools I know because, in this way, I can actually find something, but a specific tool is definitely missing*".

Cultural and linguistic barriers make it difficult to communicate the diagnosis and to understand the difference between disease and illness, between disease and the perception of disease. Moreover, the concept of prevention is accepted with some difficulties "*the separation between disease and illness, between the actual disease and the perception of disease, is perhaps more accentuated in countries with cultures further away from ours*".

These cultural barriers also negatively impact the treatment. In addition, according to the different cultural representations, it is often difficult to accept long-term treatment and cognitive or group interventions "*cognitive treatment (...) we propose something different (...) a group intervention (...) there is also taking care of the emotional aspect, of self-esteem, of socialization*"; "*they do not have the ability to give importance to something that seems intellectual compared to the pill*".

The lack of specific training for the caregivers and patients with a migratory background was another weakness.

Rooms for improvements in care provision, communities, and policies

Rooms for improvement include the strengthening of care services, closely linked to the need for intercultural training to develop a culturally sensitive approach. Regarding the assessment and diagnosis process, the need for more support from intercultural tools and a multidisciplinary network during the assessment phase emerges. Furthermore, the importance of cultural mediators during the communication of the diagnosis is emphasised. In order to develop patient-centred and shared protocols, the use of narrative medicine is proposed, which enables an understanding of the person's life course through their personal stories. It is essential to spend more time on information and building a caring relationship. Finally, the need for educational programmes aimed at migrants is highlighted, with the possibility of creating peer support groups for caregivers to share experiences and emotions.

DISCUSSION

In our study, the perceptions of the professionals and caregivers directly involved in dementia care offer a critical insight into the functioning of the care system. Caregivers' limited awareness of available dementia services [19], due to inadequate communication about both the services themselves and the access procedures, was confirmed in the FGs. This aspect affects the health literacy level of this population [20], leading to significant implications for continuity of care, disease worsening, and delayed or inappropriate use of services, especially emergency-urgency ones. Moreover, as indicated by both interviewed caregivers and the health professionals, the lack of a designated reference health professional throughout the care pathway increases disorientation and the fragmentation of care. In order to overcome the lack of an effective and structured information system, the initiative of individual professionals proves to be crucial in supporting the carer during the care pathway. In addition, this results in the caregivers' spending time in managing bureaucratic aspects that reduce time for care and social relationships, which were reported as a strength to be preserved. Personnel needs to have adequate time to establish meaningful relationships with patients, considering this time as an integral part of the care process. As previously reported [21], the implementation of narrative medicine is a promising approach, allowing a greater understanding of the patient's experience, and improving the care provision. Our study is in line with the Consensus Conference Guidelines for the use of narrative medicine in clinical care for rare and chronic degenerative diseases, which defines narrative medicine as "a subset of the broader field of medical humanities, which includes the use of narrative methods in health care". These methods are able to capture complex personal and cultural nuances that standard clinical practices may overlook, thereby increasing understanding of migrants' experiences and improving clinical outcomes [22]. This requires a change in the way personnel interact with patients, emphasising the personal histories and emotional experiences of both caregivers and patients related to dementia. Another frequently reported topic, also confirmed in this study, was the presence of language barriers, perceived as a major barrier to effective communication [23-25]. The communication gaps impact not only the ability of the person with dementia and their caregiver to accurately describe symptoms but also the effectiveness of the administered tests, partly due to the limited use or lack of cross-cultural tools. The lack of systematic use of cultural mediation services further exacerbates the situation, complicating the communication of diagnosis and the understanding of information on the characteristics and evolution of the disease. Findings from this study show that the inclusion of a cultural mediation service within facilities, where available, is perceived as a strength, aligning with the results of previous studies [26]. It is clear from the results that dementia represents a source of *burden* for caregivers of the person with the dementia. The risk factors contributing to this burden include female gender, low level of education, living with the patient, spending a high number of hours in caregiving, experiencing depression, facing social isolation, financial stress, and lack of choice in being a caregiver [27]. The emotional and physical burden of caring for persons with dementia can be overwhelming, to the extent that the literature [25, 28] shows how caregivers, mainly female, dedicate considerable effort to care, often reaching impracticable levels. In this way, they are unable to provide the necessary care for their relatives on their own. In fact, the need for caregivers to understand how to take care of themselves to prevent the development of burden was also highlighted by the participants.

Support from local institutions, such as municipalities, in dealing with disability recognition procedures is seen by the participants as a strength. However, there is a difficulty or slowness by institutions in recognising the diagnosis of dementia and providing financial support in a timely manner. The lack of formal recognition represents an additional emotional and financial burden on caregivers and persons with dementia [28] as it results in difficulties in accessing the needed financial support to maintain an optimal level of care. On the other hand, there is widespread concern that formal recognition of the disease may affect the residency permit.

This social perception of dementia can be an obstacle to help-seeking behaviours and building social and support networks, which are crucial to avoiding feelings of isolation. There is often a lack of acceptance of the disease, which is seen as something to be hidden, or an underestimation of cognitive disorders, wrongly perceived as part of the normal ageing process. Furthermore, there are fractures in cultural and family habits between different generations [29], due to the cultural contamination between their current country of residency and their country of origin. This phenomenon results in increased challenges in the caregiving process. A "*culture of rejection*", stigma, and underestimation of symptoms creates a "vicious circle" with delayed access to services, late diagnosis, and late and inappropriate treatment, resulting in a rapid worsening of the disease. The acceptance of the disease emerges as a significant obstacle, both for the person with dementia and the caregiver [30], also due to the difficulty in understanding the nature of the disease. The inability to clearly identify where the disease lies generates considerable distress and frustration, complicating the understanding of the concept of prevention and negatively influencing the evolution of the disease.

The interviewed professionals underline also that many patients are lost to follow-up also due to a lack of integration between hospital and community services (particularly in primary care settings). This is especially true for homeless people, who are often afraid to declare their real life and health conditions. They come to services in the acute stages of the illness, which makes it difficult to keep them within the care system and, consequently, to ensure a continuity of care that allows for gradual and continuous action [31].

In this context, it is evident that specific training on the topic is necessary, both for people with the condition and their caregivers. The organisation of training courses, discussions, and comparisons involving both personnel and caregivers would be helpful to conduct a critical analysis of success and failure strategies. This approach would facilitate the identification of shared solutions to improve care provision, as well as be useful for formal recognition of care pathways for migrant populations with dementia.

This study has some limitations: the smallness of the sample, especially with regard to caregiver, and the limitation to a single national context limit the consideration of all possible experiences in this field. Further research, both quantitative and qualitative, involving a larger sample and in different international contexts, would allow a more comprehensive understanding of the phenomenon from a public health perspective.

CONCLUSIONS

The use of qualitative tools, such as focus groups, proved to be a valuable support to explore health and social needs from caregivers' and health and social care professionals' perspective. Migrants with dementia represent a public health challenge and a more holistic approach is needed, addressing not only the clinical but also the emotional and social implications of dementia. This is useful in order to ensure equitable, timely, and culturally sensitive care. It is also essential to strengthen the training and information system, adopt psychological support strategies, and foster an organisational culture that recognises and addresses these challenges.

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Conflicts of interest statement

Authors have no conflicts of interest.

Authors' contributions

All Authors approved the final manuscript as submitted and agree to be accountable for all aspects of the work.

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