

# Obstacles in accessing dementia care for people with a migration background in Basel. A qualitative interview study with professionals

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## Abstract

**Introduction:** As our population is aging, age-related medical issues including mild and major cognitive impairments are becoming more and more common. Literature shows concerns related to access to health care for people with a migration background in western countries. The connection between dementia and migration and the access to dementia care for people with a migration background has not yet been widely explored. Especially, in Switzerland, there are only a few studies on the subject. The canton (federal state) of Basel-Stadt has a high percentage of people with a migration background compared to the rest of Switzerland. This study aimed to explore the care situation for people with a migration background and dementia living in Basel-Stadt and to elaborate on the obstacles they might face to access dementia care services compared to their local counterparts, causing inequalities in access to dementia care, by interviewing professionals working in the thematic field.

**Methods:** Participants were acquired via online research and supplemented with personal contacts and recommendations of other participants. Therefore, the sampling strategy was both purposive and snowball. Interviews were performed via Zoom following a semi-structured interview guide. The interviews concentrated on differences in access to dementia care during different stages of the disease from a professional view. Data analysis was performed using MAXQDA 2020.

**Results:** Sixteen professionals were interviewed belonging to different professions such as general practitioner, hospital doctor, politicians, and those working in dementia support services, ambulant care, home care, and nursing homes. We found that the migrant population was underrepresented in the participating services, which lead to in-depth exchange about obstacles that could potentially burden their access to the available services. These challenges were grouped into four themes: (1) Delayed diagnosis and lack of diagnostic tools and scores; (2) Obstacles to seeking help; (3) Lack of migration sensitivity in dementia care services; and (4) Administrative and financial obstacles.

**Discussion and Conclusion:** Our findings are in line with literature from other countries. The interviewed services reported an underrepresentation of people with a migration background compared to the demographic numbers, especially in post-diagnostic services. During our interviews and in context with the actual literature from other countries it became clear that despite our broad and specialized health care system we have not yet reached a point of equal access for people with a migration background. To even out inequalities we suggest different measures including adapting the diagnostic process and existing dementia care services with a focus on migrant sensitivity in regard to language, culture, religion, and socio-economic aspects. We also touch upon legal and political changes necessary to advance migration sensitivity in dementia care. And finally, we want to encourage further research on a national basis and explore the needs of the migrant community directly with the affected population itself.

## Introduction

The population in Switzerland is aging and life expectancy is increasing steadily (Federal Statistical Office, 2020). Over one-third (38%) of the Swiss population has a migration background<sup>1</sup>. And four-fifths of them belong to the first generation. In the canton (federal state) of Basel-Stadt, 52.2% of the population is composed of people with a migration background (Federal Statistical Office 2021). The migrant population on average is younger than the Swiss population (Federal Statistical Office, 2021). However, the number of elderly people with a migration background (65 years and older) is increasing every year counting 367'000 people in Switzerland in 2020, which is about 13% of the migrant population in the age group over 65 years in Switzerland compared to 26% in the Swiss population (Federal Statistical Office, 2021). The top three countries of origin for Basel-Stadt are Germany, Italy, and Turkey (Cantonal Statistical Office 2021).

The growing number of people over 65 years is bringing to the center age-related health issues including major and mild neurocognitive disorders. In 2021, 146'500 people were living with dementia in Switzerland and this number is expected to double by 2050. Also, half of the people suffering from dementia do not have a diagnosis by a specialist (Alzheimer- Schweiz 2021). Dementia is not a concept known in all cultures, which is why Sagbakken et. al. used the term of cognitive impairment alongside dementia (Sagbakken, Spilker et al. 2018)<sup>2</sup>.

In the Swiss medical system, general practitioners (GP) are the ones contacted first in case of a medical problem. They can establish a long-time relationship with their patients and often also with other family members, and become familiar with their values. Newer studies have shown that the majority of GPs in Switzerland feel positive about establishing a dementia diagnosis (Giezendanner, Monsch et al. 2019) and 2/3 also are confident about taking further care of their patient after the diagnosis. However, half of the GPs stated that they did not feel confident about caring for dementia patients with a migration background (Giezendanner, Monsch et al. 2018). The importance of GPs in the integration of migrants in the health system is underlined by the fact that nine out of ten migrants have a GP (Federal Office of Public Health 2007) and consult them more often than natives (Federal Office of Public Health 2012).

In general, people with a migration background rate their state of health lower than the Swiss population (Federal Statistical Office 2020). The biggest differences are seen concerning the first generation from the south-west and eastern Europe. Those who have been living here for a while rate their state of health lower than those who immigrated recently. This is described as the so-called "healthy migrant effect", describing a kind of selection bias, that young and healthy people tend to migrate more. Those advantages fade however with the duration of stay in the new country (Federal Statistical Office 2020). Inequalities in access to medical care originate from socio-

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<sup>1</sup> We use the definition of the Swiss Federal Statistical Office, which includes the following people into the group with a migration background: all foreign nationals, naturalized Swiss citizens, Swiss citizens at birth whose parents were both born abroad. It excludes people born in Switzerland and whose parents were both born in Switzerland. This means all migrants of the first and second generation. (Federal Statistical Office, 2021).

<sup>2</sup> During the interviews we used the term of dementia and did not exclude examples without a diagnosis. Often interviewees specified when someone did not have an established diagnosis, if they felt it to be relevant for the context.

economic differences, can be migration-related, or due to lack of knowledge about services or a lack of transcultural sensitivity in those services (Federal Office of Public Health 2013, Mogar and von Kutzleben 2015). In ambulant (Care at home) and stationary (nursing homes) care services the migrant community is underrepresented (Hungerbühler and Bisegger 2012).

The national strategy for dementia mentions the topic of migration and also the importance of connecting it to those issues (Federal Office of Public Health 2016). To our knowledge, there are so far a few studies exploring the care of people with dementia and migration background for Switzerland (Hanetseder 2013, Kovacic and Sariaslan 2017). The biggest study done on this group is from Red Cross Switzerland called “Doppelt fremd” meaning *twice foreign* (Hanetseder 2013). This national study focused on migrants with an Italian background suffering from dementia. One-on-one interviews were conducted with family members, professionals and an online survey with professionals working in nursing homes. As a result of this study, a brochure for professionals in the ambulant and stationary context on how to better support the affected person and their families was published (Hanetseder 2013).

More research investigating the care of migrants with dementia can be found abroad. There are studies from the US (Daker-White, Beattie et al. 2002, Kong, Deatruck et al. 2010) the UK (Kenning, Daker-White et al. 2017, Dodd, Pracownik et al. 2020, Hossain and Khan 2020), northern Europe (Diaz, Kumar et al. 2015, Sagbakken, Spilker et al. 2018, Sagbakken, Spilker et al. 2018, Czapka and Sagbakken 2020, Nielsen, Nielsen et al. 2020, Nielsen, Nielsen et al. 2021) and Germany (Ulusoy and Grassel 2010, Mogar and von Kutzleben 2015, Tezcan-Güntekin 2018).

Concerning diagnosis, minorities less often receive cognitive assessment and when they do, they have lower scores. The lower scores are attributed to different reasons including diagnosis at a later stage of disease (Dodd, Pracownik et al. 2020). Sagbakken identified four main problems about this: delayed help-seeking, health professionals lacking experience, lack of knowledge and use of migration appropriate diagnostic tools, and challenging assessment situations (Sagbakken, Spilker et al. 2018). Delayed help-seeking might be due to minorities rating the symptoms of dementia as normal aging due to a lack of knowledge about dementia, feeling ashamed, or having other more pressing issues to deal with (Daker-White, Beattie et al. 2002, de Graaff and Francke 2003, Mogar and von Kutzleben 2015, Kenning, Daker-White et al. 2017, Sagbakken, Spilker et al. 2018, Tezcan-Güntekin 2018, Czapka and Sagbakken 2020, Nielsen, Nielsen et al. 2021). Despite the lack of concept, there might also be many different understandings of dementia and illness in general. While some rate the symptoms of dementia as normal due to age, others even see it as a kind of punishment or fear to lose their face (Hanetseder 2013, Czapka and Sagbakken 2020, Nielsen, Nielsen et al. 2021).

Similar to the challenge of diagnostic situations reported by the Swiss study (Giezendanner, Monsch et al.), scholars from the UK and Norway have noted the same, that is, elders from minority ethnic groups were less often get a precise dementia diagnosis than older persons from the majority group (Diaz, Kumar et al. 2015, Dodd, Pracownik et al. 2020). While Dodd et al. (2020) found that minority ethnic groups often get their diagnosis from GPs compared to British people, Sagbakken (2018) in contrast

found that GPs tend to redirect patients with a migration background to a specialist, before even trying to assess the cognitive state themselves.

Not only is the diagnosis established at a later stage for people with a migration background, but they also contact dementia services later in the course of the disease (Nielsen, Nielsen et al. 2020). After diagnosis, families often manage care inside the closer family system. On the one hand, this is based on a cultural or religious obligation to care for loved ones. On the other hand, available services are seen as inappropriate culturally and linguistically (Kong, Deatrick et al. 2010, Kohn, Tov et al. 2013, Czapka and Sagbakken 2020, Hossain and Khan 2020, Nielsen, Nielsen et al. 2021, Nielsen, Waldemar et al. 2021). Even getting information about the existing service opportunities can be a big obstacle for people with a migration background and hinder them from accessing those services (Czapka and Sagbakken 2020, Nielsen, Nielsen et al. 2021). Also, people with a migration background might have experienced negative encounters with services (Kenning, Daker-White et al. 2017, Nielsen, Nielsen et al. 2021). These reasons might lead to later contact with dementia care services and to an overstrain of familial capacities (Czapka and Sagbakken 2020, Nielsen, Nielsen et al. 2021, Nielsen, Waldemar et al. 2021).

Language plays a big role in the process of diagnosing dementia and service delivery (Daker-White, Beattie et al. 2002). It is not only a question of understanding, due to a lack of information in specific languages (Gross, Ammann et al. 2014) but also adjusted language levels (Pfluger, Biedermann et al. 2009). Access to adjusted or translated information is not easy to get by and is not routine for professional dementia care workers (Nielsen, Nielsen et al. 2020).

Based on the demographic and research data available on elder persons with a migration background, we assume that there might be issues concerning the provision of dementia care to people with a migration background in Switzerland. To evaluate barriers that might hinder people with a migration background from accessing dementia care services we focused on the area of Basel- Stadt.

## Methods

The data for this project was collected by CW, who is trained in medicine and has experience in qualitative methodology under the supervision of the co-authors. To assess the care situation of older people with a migration background and dementia, we focused on the region of Basel-Stadt because it has a high percentage of migrant population. Before data collection, the project was submitted for evaluation to the Ethics Commission (EKNZ) and found to not fall under the law for Human Research in Switzerland. Hence, no ethics approval was required, however, the commission judged the study protocol to be ethically sound. Participants were informed about the study and their voluntary participation was obtained in writing before data collection.

## Participants and Data collection

To assess the situation from professionals' views working in the thematic field, a broad selection of existing services and organizations was contacted. The aim was to interview professionals from different domains during the disease progress (primary care physicians, hospital doctors, and those working in support services, ambulant and

at-home care services, and nursing homes). Online research was used to get an overview of the available local organizations and supplemented with personal contacts and recommendations from the participants themselves. Thus, the sampling strategy was both purposive and snowball. After an initial e-mail contact, prospective professional participants were provided with a written informed consent form. Furthermore, some participants were reached again via phone to discuss details and have a first thematic exchange on the topic. During this initial recruitment phase, three of the contacted persons did not want to participate, because they felt that their field of work did not fit the thematic description. Most of the contacted organizations showed a strong interest in the thematic content of the study and were eager to share their experiences.

Participants were provided with the interview questions in advance, which gave them the opportunity for reflection and discussion inside their team, should they feel that they are representing not only their voice but the opinions of their organization as well. In total 16 professionals from various organizations agreed to participate. CW conducted all the interviews via Zoom due to safety measures in place during the COVID-pandemic in 2021. The interview guide first invited the participants to introduce themselves and their organization. Thereafter, questions concerning the diagnosis of disease were posed with the aim to find out if the time of diagnosis or the level of diagnostic interventions differed when people had a migration background. Also, the difficulties professionals faced, when diagnosing dementia in someone with a migration background were discussed. This was followed by contact points for support, here the focus lay on how support organizations worked with people with a migration background and on possible differences they registered during their consultations compared to Swiss clients, and on how they tried to meet those differences. From there the conversation went further into the process of disease and on to at-home care and in the end to nursing homes. Furthermore, participants were asked about the family's involvement in care, how they organized care and decision-making. In the end, the different players in the professional network for the care of people with dementia were reflected. Finally, three questions about the difficulties people with a migration background faced during the process of dementia, what had to be considered when working with this subgroup, and if there were specialized projects for people with dementia and a migration background topped of the interviews.

Interviews were audio-recorded, and some notes were taken by the interviewer after the discussion. No repeat interviews took place, and there was no prior relationship between the study participant and the interviewer. During the zoom interview, no other person other than the participant was present. The duration varied between 30 and 90 minutes which allowed space for other topics deemed important to the participants. Transcription was performed by a master's student using f4Transkript.

### Data analysis

Data analysis was done following the thematic analysis (Braun and Clarke 2006). We used MAXQDA2020 and fitted the codes to the interview guide's questions, adding subthemes during the process where necessary.

## Results

We interviewed 16 professionals from different organizations working in the contexts of elder care and/or migration (see Table 1). The study participants represented a wide spectrum of professionals from those providing care during the process of disease to primary care physicians to politicians responsible for policies that affect seniors and immigrants.

<b>Alzheimer Beider Basel</b>	dementia support center and ambulant care
<b>Foundation Wirrgarten</b>	dementia support center and ambulant care
<b>Counseling center for Migrants and Refugees</b>	support center, language courses
<b>Neues Marthastift</b>	Nursing home for people with dementia
<b>Red Cross Switzerland</b>	dementia support center and care services, research
<b>Home instead</b>	Care at home service
<b>Politician, SP Migration</b>	Social and political engagement in different projects
<b>Falkenstein, BSB</b>	Nursing home with a floor for immigrants from Mediterranean countries
<b>Spitex Basel</b>	Care at home service
<b>Dandelion</b>	Nursing home for people with dementia
<b>GP, National Forum Age and Migration</b>	Primary care physician, engagement in different projects
<b>Competence Center for diversity and integration, Presidential departement BS</b>	Cantonal concept planning for better integration
<b>Memory Clinic</b> University Department of Geriatric Medicine	Diagnosis and medical therapy of dementia
<b>Fundus Basel</b>	Outreach quartier work
<b>Department for long-time care, BS</b>	Planning and assessment for nursing home admission
<b>Red Cross Basel</b>	Local projects, consulting, and care services

Table 1: Interview partners and their respective fields of work

First, we present the dementia care network in Basel, followed by the discussion surrounding the representation of people with a migration background in the respected

services. We found that the migrant population was underrepresented in the participating services, which lead to in-depth exchange about obstacles that could potentially burden their access to the available services. These challenges are noted below within the following four main themes:

- 1) Delayed diagnosis and lack of diagnostic tools and scores
- 2) Obstacles for seeking help
- 3) Lack of migration-sensitivity in dementia care services
- 4) Administrative and financial obstacles

### Dementia Care Network in Basel

Based on the data obtained from our study participants, we grouped the availability of dementia care for older persons in Basel into three groups: medical care, supporting services from various organizations, and family care.

**Medical:** During the interviews, participants stated that family doctors had a central role in the whole process of dementia care. Often, families and their primary care physicians were thought to have a long-lasting and trustful relationship and participants said that in moments of uncertainty, the families turned to their GPs. The key role of GP was deemed to be the same for people with migration backgrounds. Focusing on the diagnosis itself, besides the family doctor, hospital doctors were thought to play an important role as well. The Memory Clinic functions as a central and highly specialized player when it comes to diagnosing dementia.

**Advisory/ supporting services:** Since study participants represented different organizations caring for persons with dementia, they mentioned several opportunities available for persons and families of persons with dementia. These included support centers (Alzheimer Beider Basel, Foundation Wirrgarten) that offer counseling services for people with dementia and their families. They have support- groups and organize different activities from visits to concerts over day-care services to group holidays. In Basel, there is a wide range of services for migrants (GGG, Cantonal Office for Integration) and elders (Pro Senectute, Fundus, Red Cross), and their support is geared towards helping to navigate through the system or more concrete help in everyday life like shopping for groceries or driving services. Finally, legal and financial support services are available through multiple players (KESB, Social services, department of long-term care).

**Support and relief services for family members:** Participants reported that families play the main role when it comes to caring over the whole process of dementia. During the interviews, participants often mentioned that the presence of family members in families with a migration background was more intense compared to the native population. To support and complement private care there are various options of different extents in ambulant care (Foundation Wirrgarten, Alzheimer Basel, Spitex, Home instead, Red cross) or even stationary care such as nursing homes (Dandelion, neues Marthastift, Falkenstein).

Overall, Basel-Stadt was recognized to have a wide range selection of services for people with dementia and their relatives. The different actors know and value each other's work. However, many of them mentioned feelings of insufficient interprofessional collaborations. Some voiced a need for targeting services for those

falling through the network. Especially people living alone having few social contacts were mentioned to be particularly vulnerable. To reach those groups, participants agreed that outreach services and collaborations were needed with representatives of the migrant community. Also, transcultural competencies were said to be capable of development, as most services did not yet educate their staff in that field.

*“There is actually, to be honest, not much duplication. I always use the metaphor of a football field. We don't even have half of the field used and everyone has their own little corner where they act. The other half of the football field is not used at all. Thus, you don't get in each other's way too much, but everyone works, works a lot (some organizations offering services of different intensity of care under the same roof). With a little better cooperation, we could make it a little better, so that there are no dead corners in the half-played field so that we can coordinate with each other. But the big problem is that no one is in the other half of the football field, no one is there.”*

(Foundation Wirrgarten)

### Underrepresentation of people with a migration background using dementia care services

When asking specifically about people with a migration background it became clear that this subgroup of dementia patients is underrepresented in all the participating institutions (except of course for the counseling center for migrants and refugees). The nationality reported the most was Italian descent. Other origins mentioned were Spanish, Portuguese, Turkish, and some Eastern European countries. Also, individual cases with a Japanese or Eritrean background were mentioned.

*“We have contact with people with a migration background at the level of the day-care center. Of course, we have contact with people with a migration background from time to time, and we also have contact with people with a migration background in the counseling center. And I must say that they compose maybe 5-10% (max) of our contacts. So not so much ... of course, that doesn't correspond to the proportion of the migrant population that we have in Basel-Stadt.”*

(Foundation Wirrgarten)

*“So, we don't have a very large number of residents with a migration background. We have 101 residents, mainly residents with severe dementia... At the moment, I would say, we have a maximum of four to five residents with a migration background (from the 101 total).”*

(Neues Marthastift)

The representation of people with migration backgrounds became more specific in the case of medical care services provided by the Memory Clinic, University Department of Geriatric Medicine. In their case, it was reported that ten to twenty percent of patients have a migration background.

*“We have a huge database if we want to really find out. But I can guess. I would already guess that it's between ten and twenty percent, non-German speakers. So, it's a big percentage.”*

(Memory Clinic)

Participants said that they could only talk about those people already using their services and that they could only make assumptions on how the other part was cared for. Many suspected that a big part of the migrant community was cared for at home by family members.

### Delayed diagnosis and lack of diagnostic tools and scores

Study participants stated that to gain access to support services, the actual diagnosis of dementia plays an important role. Specifically, it determines the right to use different services or at least, to get financial support for services used such as the Spitex or courses from Alzheimer Basel. Moreover, a diagnosis delivers valid information to caregivers on how to handle the situation.

It was mentioned that in most cases it was the GP who did the initial dementia screening. However, fewer people with migration backgrounds were mentioned to have diagnosis and were less often seen by a specialist in the Memory Clinic. Also, some participants had the impression that patients with migration backgrounds received the diagnosis later than those without. A reason for difficulties during the diagnostic process mentioned was that the consultations with doctors are very short and therefore there is not enough time to discuss shortcomings in every-day life that dementia might create. Also, cognitive anomalies on the part of the person with dementia might not be seen as problematic or thus not recognized as their illness character by the person him or herself and their families. It was mentioned that cognitive impairment is often seen as normal due to age, which was thought of originating in a lack of knowledge about dementia. Hence, these may not be brought up in consultations or only if they have already progressed or if other behavioral anomalies occur. Participants revealed that often the information about those impairments is relayed by family members or professional care workers. Another participant mentioned that depending on the cognitive resources that someone had before the onset of dementia, the cognitive decline might be less relevant in everyday life and therefore might not have reached a threshold of being an actual limitation.

*“So, if you and I could no longer read a book, then we would suffer because we define ourselves through cognitive achievements and are so used to it. But the cognitively strong are not only cognitively strong, but they are also dependent on it functioning well, and if there is a problem, the pain associated starts quickly.”*

*But if it's, say, an older Turkish woman who never went to school and mainly cooked for the family, looked after the children. And if she can no longer read the newspaper properly and never did before, then it goes on much longer until something no longer works."*

(Memory Clinic)

If the affected or their families did not speak the same language as the doctors or medical professionals, it was seen as a big obstacle for enabling the diagnosis. It was mentioned as very difficult for families and patients to report their observations and therefore also more difficult for professionals to detect them.

*"As said, once again the lack of German is an obstacle to early diagnosis. We have to be aware of that. Even though we try everything to compensate for this well."*

(Memory Clinic)

Furthermore, diagnostic tools and their numerical values are designed specifically for language, education levels, gender, age, etc. So, many factors have to be taken into account when making the diagnosis of dementia. This complexity becomes clear when looking at the following quote, which again illuminates the difficult situation in everyday GP consultations.

*"And if you have to do it (diagnose dementia) for a patient with a migration background, where there are also language difficulties, it is a question of time. Everyday life is hectic, we don't have so much time and then you just do without it. You simply don't do it or you put it off and at some point, you have to do it because certain symptoms manifest themselves more and more, and then you do it or you delegate it to a memory clinic."*

(General practitioner)

Even if the suspicion of cognitive decline comes up, the most common diagnostic tools are not standardized for people with a migration background, and by not adjusting variables such as age, gender, and level of education the actual level of dementia might be misjudged. This lack of adapted diagnostic tools and scores for their interpretation was said to be another reason for inequality during the diagnostic process. It was said that it was not completely clear how it affected the diagnostic evaluation, but that it might lead to a delay of diagnosis.

*"One would actually need to build standards for exactly these people and we don't have that and we can't do that ... ultimately what happens is that we probably diagnose these people a little too late. We estimate clinically what these norms are (for this group), we already make norms and simply take our*

*German-language norms. Then often we see that they are partly already clearly advanced if you take the German norms.”*

(Memory Clinic)

### Obstacles for seeking help

After diagnosis, participants said, that patients and their families were offered information material about available support services and invited to contact and use those services. Still, the lack of knowledge about support and advisory services was mentioned as a possible obstacle for families with a migration background to seek help. When asked, participants said, that such information material was mostly available in the national languages (German, French and Italian) and some cases English as well. Only a few of them had other languages available. This language gap was seen as an important barrier when aiming for equal access to dementia care.

It was also stated that the content of that information might be difficult to understand for people with lower educational levels. However, participants also noted that there are migrants with higher educational levels, who were connected with easier access to information and the use of the available services.

*“It still depends a little on the class. The expats are also migrants, I think they are much better informed and organized. I think it also has to do with the level of education.”*

(Verein Fundus)

*“It is probably specific that they are highly educated and that is why they come to us.”*

(Alzheimer Basel)

Translating and adjusting the available information material in content was seen as the first step to better reaching the migrant community. However, some participants raised concerns that this would not be enough and that besides distributing written information, establishing a personal connection with a key person was important. Different possibilities of who this key person could be were mentioned (GP, quartier worker, representatives of the migrant communities, etc.).

*“It's about people, about trusted people, and not about a brochure that I put in their hands.”*

(Verein Fundus)

Other obstacles for seeking help and using the available services were mentioned to be more due to differences in culture and as a result of migration. For one it was mentioned that in some cultures the handling of disease tended to differ from that of the host population. Participants observed that in some cultures illness was seen as something shameful.

*“As with other illnesses that affect brain functions or mental health, dementia is still very much a taboo in certain migrant circles. I observe a strong reluctance among some patients and their relatives to speak openly about the disease. This is because the illness could damage the family's reputation. After all, it signals vulnerability and weakness. This would contradict the strongly internalized attitude of always showing no weakness and saving face in every life situation. Fare bella figura!”*

(GP)

Others even described it as a kind of punishment from God. Often, it was mentioned to be important to save the face in front of outsiders and handle such problems within the closer family.

*“I: Are there certain obstacles or certain hurdles and fears why you don't let someone else take care of you first?”*

*B: Yes, it's because of the culture, so one is in good hands with the family, friends or he feels good in the family, circle of friends or so. If a stranger suddenly takes care of him, that's a problem.”*

(Counseling center for Migrants and Refugees)

Further, participants sensed a feeling of obligation to manage the elderly care inside the family. This expectation was sometimes recognized to come from the elderly person themselves and sometimes be more of a feeling of duty experienced by the caring family members (spouses/ children).

*“... people who have come here in old age really assume that their relatives will take care of them...And there is no alternative to home care. These are differences we notice to be there, but this is now a family situation....”*

(Department for long-time care, BS)

However, one participant said that the younger generations were more familiar with the local system. Thus, with more younger generations growing up here and adjusting to local lifestyle (organization of work and private life), he observes, some changes inside the migrant population concerning elderly care. For example, he said, that older people did expect their children to provide less care for them.

*“... And the first-generation migrants are well aware of that. They say that we don't want to burden our children and that we want to live independently within our four walls as long as possible.”*

(General Practitioner)

In light of these cultural differences in elderly care, it was expected, that different care options might not be well known in the migrant community. This unfamiliarity was seen as another barrier in accessing dementia care. Negative experiences during their migration and integration processes were also seen as a possible reason for their skeptical attitude towards the available services. However, one of the participants, who had a migration background himself, qualified this and attributed it more to the lack of knowledge about the available options.

*“There are assumptions in certain areas and that remains the case and that is also such an area, isn't it? I mean, if people notice that there is a solution here, why should they be skeptical? ... I think that it is simply a false assumption. It's often the case that people don't really know what concrete support instruments they have.”*

(Politician, SP Basel- Stadt)

However, it was argued that cultural differences should not be weighted too heavily as an obstacle and that other socio-economic differences might play a bigger role, such as poverty, and that migration could represent cognitive resources and resilience.

*“I wouldn't overemphasize the cultural differences. I think historical differences play a bigger role, in the sense that often affected people, if they are also socio-economically disadvantaged, it makes the whole situation even more difficult.”*

(Red Cross Switzerland)

*“These are people who have fled from their homeland to a new country or whatever and have to adapt to a new culture here, and that is of course an incredible achievement to be able to do this. And that is certainly very beneficial for cognition and cognitive abilities.”*

(Memory Clinic)

### Lack of migration-sensitivity in dementia care services

Except for the nursing home Falkenstein with its Mediterranean floor for people with dementia and migration background from Italy or sometimes Spain, none of the other participating institutions offered a service that was specially tailored for older migrants. When asked participants could not name other services that were specially fitted for people with a migration background and dementia. Even though few of the participants reported having migrant-specific programs, most of them had some approaches to meet the needs of the migrant community.

Participants recognized culture as important when offering dementia care to people with a migration background and said that being sensitive to different needs and habits was key for someone to feel understood and well cared for, especially when experiencing cognitive impairments.

*“I think there are, or yes, many such cultural-ritual things where I think they would be important. Or that are becoming more and more important when you have dementia because you grew up in there, it gives you security, it gives you support and if certain things can be taken over and are familiar to you, then you find better access.”*

(Red Cross Basel)

Participants felt that offering information and care in one's native language was an important factor to establish a trusting connection between professional services and the affected migrant population. Two of our interview partners mentioned the regular use of interpreters in their daily work. This intensive involvement of translators was due to the importance of a carefully assessed cognitive state before implementing the diagnosis.

*"We examine all patients in their mother tongue, especially in neuropsychology, this is, of course, important, because even someone who has learned a foreign language is not as comfortable as in their language. And we always have an interpreter with us...."*

(Memory Clinic)

It was also mentioned that during cognitive decline with dementia, people might lose the ability to speak another language, even if they did learn for example German in the past and therefore were particularly dependent on care services offering dementia care in their mother tongue. Also, language was said to get less important in late state dementia when the ability to communicate via language is lost completely.

*"They lose the German they once had, maybe they never had it, but then they lose it altogether and they are practically out of reach in German."*

(Falkenstein)

*"So, if the dementia is more advanced, you can certainly yes, you can sometimes no longer reach people on the cognitive level anyway and then you become more creative in care, or a lot goes over body language...."*

(Spitex Basel)

Other services available were mostly suited for German-speaking people. For instance, courses (memory training, support groups) were only offered in German. Sometimes if there were enough interested people, they also offered one in French or Italian. Often it was family members who helped with the communication. Different problems were mentioned when engaging family members as translators such as their lack of ability to understand medical terminology leading to loss of quality of information. Also, emotional and personal involvement were seen as pitfalls for conscious and unconscious alterations of content and to pose emotional pressure on those family members.

*"So, that is a big additional risk, the language, the misunderstanding not only linguistically, but also what is said, what is not said, because of this dialogue situation (with the relative as a translator) who is not a professional one. So, a professional interpreter who knows that one translates one-to-one and can then*

*also interpret for the intercultural issues thereby building these bridges. But every relative can offer translation but does not provide the professional communication that is necessary to build the basis for a correct diagnosis and treatment.”*

(Competence Center für Diversity and Integration, Presidential Department BS)

The two nursing homes used a biographical approach and tried to grasp the inhabitant's needs individually, stating that, if done right, it should no longer matter if someone had a migration background or not.

The home care services both tried to choose caregivers suitable to the client, which included language, culture, etc.

The lack of migrant-sensitive or specific programs was often explained by the lack of demand sensed in their everyday work. However, this lack of use was mentioned to be a pitfall and that it would be dangerous to conclude, that the migrant community did not need support from those services.

*“No one has checked it (if people with migration background were cared for and had no need for dementia care services) yet. That these (people) are all somewhere and they're all involved somewhere. If we find out, I'll be so happy, but as long as I don't know, don't have proof, I won't assume that. And my impression at the moment is, it's not like that. They are not all just taken care of in a club somewhere. I think that's a very dangerous assumption on our part, it's more of an assertion, we even claim that in the meantime, although it's only an assumption.”*

(Verein Fundus)

Some also mentioned concerns that special services might not be the way to go and that exclusive programs might lead to an unwanted separation between people with a migration background and Swiss people. Overall, among the participants there seems to be a consensus that people with a migrant background need to at least be given the opportunity to take part in those services as Swiss people do.

*“I think we need to institutionalize this (care for elderly with a migration background with easier access) much more. Or, it simply has to be clear that if you have a migration background and you reach retirement age, you also have access to support services.”*

(Verein Fundus)

*“So, it is a matter close to my heart that the migrant population also gets more support services and that the relatives also get more support. But we have not got that far.”*

(Alzheimer Basel)

## Administrative and financial obstacles

Concerning the mentioned language barrier, we asked, why only a few of the participants used professional interpretation services. There were three main reasons: Time, money, and administration. Time was a factor that was mostly mentioned in reference to consultations with a GP (also stated previously). A normal consultation with the general practitioner is financially compensated for a maximum of 20 minutes. A carefully performed basic dementia assessment, including a Mini-mental and Clock-Test, without language difficulties was stated to take about 60 minutes. It was often mentioned that services like interpreters could not be accounted for and that because they did not want to bill the patient for it, they did not use interpreters if avoidable. The time limit for a cognitive assessment was a problem for GPs, while limits in financing also were mentioned by other organizations. The Memory Clinic as a hospital was able to use other accounting points and therefore was not affected by this.

Bureaucratic difficulties were mentioned as a barrier for organizations to access the available interpreting services.

*“We have never needed it either, but it is like too complex for a small organization to ask for a translator. I already fear a huge expense. I think it should be possible to work with translators, transcultural translators, relatively easily. That this becomes much lower threshold, that one can request this.”*

(Alzheimer Basel)

Translating written information was considered to be a comparably low effort. Finding trained staff with fitting language skills was said to be a much bigger challenge and seen as a limiting factor.

Care at-home services also mentioned difficulties in accounting for the offered services when clients were suffering from cognitive impairment. They described it to be more difficult to be reimbursed by health insurances, for similar services compared to when someone has physical impairments.

*“And if someone has a problem in cognition, that becomes much less (relation between work and income), there we have to justify much more why we have spent a longer time there than if someone is simply sitting in a wheelchair, then that is not an issue. There we can go for two, three hours every day. But if someone can actually walk normally and could theoretically shower, but can't because of their dementia, we have to do a lot more to get the health insurance to pay for it, and sometimes they simply don't pay.”*

(Spitex Basel)

The financial bottleneck was also mentioned to be an obstacle for families themselves, especially the organization of financial support for example for household services was acknowledged as a challenge. It was described as a fear of being a burden to the system. And even if relatives tried to apply for financial aid, the complexity might be downright difficult even for experts.

*“There are now three completely different structures (providing financial support). We have, yes, the supplementary benefit, then we have the IV (Disability) office, and then we have the long-term care department. From completely different places there is some money somewhere that has to do with care and support for people with dementia. And here we sometimes have difficulties as professionals to understand how this is done, who is responsible for what, what are the exclusion criteria, and what is required for someone to receive this benefit. ... We need a lot of information to be able to give good advice. How are people with a migration background supposed to understand this without help?”*

(Foundation Wirrgarten)

In light of these administrative and financial barriers, different interview partners talked about the central role of the government as a contracting authority when planning and subsidizing those services.

*“Of course, there is often this attitude, ... that people themselves should get this information when they need it. At first glance, you can say that's right, but it's the responsibility of politics or the administration to prepare the structures and, if something like that happens, to know that, okay, yes, we have structures for that and it's not a problem, people can turn to this institution and then it will work.”*

*“And on this topic, i.e. old-age policy and migration, it may not yet be a reality (i.e. an issue of concern), we've been talking about it for ten years, but we're not there yet. And I don't just want to wait until the problems are here and only react then.”*

(Politician, SP Basel- Stadt)

## Discussion

This study examined the situation and various barriers for need-based care of people with dementia and their relatives with migration backgrounds in Basel-Stadt, Switzerland, from the perspective of professionals working in this field. Overall, our findings are in line with the current findings from studies in other countries.

Even though a wide range of dementia care services was available, only a few services were specialized for people with dementia and migration backgrounds. The amount of contact between the interviewee and patients/clients with a migration background varied from daily to almost none, depending on the organizations they represented. The connection of the migrant community to a general practitioner does not differ from the one in the Swiss community. However, post-diagnostic services such as advisory and support services and care at home services only report half of that and it seems to decrease even more when looking at stationary care like nursing homes (Hungerbühler and Bisegger 2012). This post-diagnostic gap was also found in other countries (Nielsen, Nielsen et al. 2020). Nielsen (2020) showed that this gap mostly seems to apply for services focusing on personal care or support and that services that

for example helped with technical aids were less affected by this gap. Therefore, it seems that obstacles become more relevant when personal contact is part of the offered service.

While the amount of people lacking a dementia diagnosis is already high in the Swiss population (Alzheimer- Schweiz 2021), people with a migration background are perceived to be underdiagnosed even more often. We also found a discrepancy on who diagnosed dementia. On one hand, GPs report to find it difficult to diagnose dementia when patients have a migration background (Giezendanner, Monsch et al. 2018) and therefore prefer to assign them to the specialist in the Memory Clinic. On the other hand, interviewees working in post-diagnostic dementia care services reported that people with a migration background less often have been diagnosed by a specialist. This discrepancy is mirrored in actual literature (Sagbakken, Spilker et al. 2018, Dodd, Pracownik et al. 2020). Whether it is a GP or a specialist who establishes the diagnosis, the person making the diagnosis must be transcultural educated to allow adequate and fair evaluation. Knowing the different concepts of illness is important to implement the necessary steps to assure a good quality of the diagnostic and culture-sensitive assessment involving the patient and their proxies. To allow a fair evaluation it is also important to do the diagnostics in the patient's mother tongue, which includes a lingual and transcultural interpreter and adjusted diagnostic tools in language and culture. There also needs to be knowledge of how to evaluate the scores respecting age, gender, educational years etc. If these conditions cannot be fulfilled, it is advisable to redirect the patient to someone who can, for example, the Memory Clinic, which is not only specialized in diagnosing dementia but as a hospital also has the resources to adapt to patients' needs.

In light of the demographic numbers compared to the reported percentage of people with a migration background using dementia care services, it is unlikely that there might not be a need for dementia care services in the migrant population. In line with the perceptions of our participants, most of them are cared for at home (Alzheimer-Schweiz 2019) and provision of care is mostly handled inside the families. While for some care inside the family is implied by cultural and religious reasons, described as a filial duty (Kong, Deatrack et al. 2010, Tezcan-Güntekin 2018, Nielsen, Waldemar et al. 2021), others for example second-generation migrants who are more familiar with new social norms can be in dilemma between the cultural obligation from their country of origin and experiences from the new country (Mogar and von Kutzleben 2015, Czapka and Sagbakken 2020). This change of mentality was also described in the interviews. Despite the assumption of care services that family carers profit from a wide support network inside the family, sickness and the care for the affected is often kept inside the closest family, and care, therefore, falls onto the back of only a few family members and sometimes overstretches the familial resources (Ulusoy and Grassel 2010, Nielsen, Waldemar et al. 2021). Therefore, it could be implicated that there are other reasons for not reaching out for help than just cultural expectations and it is crucial to identify those reasons, so those who need help can access it before the decompensation of the family system. While language stood out as one of the main obstacles, other socio-economic factors such as education and financial situation emerged to be more important factors when looking at unequal access to dementia care than cultural or religious differences (Czapka and Sagbakken 2020).

In our interviews, we also talked about the barrier in accessing dementia care that was originating from the offered services themselves or more from a lack of migrant sensitivity in those services, which as elaborated in the following have also been found in other studies in other countries (Czapka and Sagbakken 2020, Nielsen, Nielsen et al. 2020). During the diagnostic process sensitivity, equal conditions for all patients (culturally and linguistically validated tests, interpreting services, etc.) is important and their absence can pose very difficult situations for physicians, patients, and their families all the same (Sagbakken, Spilker et al. 2018, Czapka and Sagbakken 2020) and can lead to a delay of diagnosis. In our interviews we also found that the emergence of cognitive decline also depends on the abilities before the onset of disease (e.g. reading etc.), allowing their absence to be noticed. Further, a lack of knowledge about dementia and the dementia care services in the migrant population can hinder them in reaching out for help (Kenning, Daker-White et al. 2017, Nielsen, Nielsen et al. 2021). This lack of knowledge could origin from a lack of understandable (language and content) information being available (Czapka and Sagbakken 2020, Nielsen, Nielsen et al. 2020, Nielsen, Nielsen et al. 2021), which most of the interviewees confirmed to be a problem, as most information materials were only available in the national languages and written information itself was seen as to high-threshold. However, some information materials are available (Alzheimer Switzerland 2021) but do not seem to be implemented broadly in the everyday work of dementia care services. One reason might be that professionals do not know about those materials, which was also mirrored in some of our interviews (Kohn, Tov et al. 2013) Besides translating the written information, the option of having consultations in the patient's/client's language is very important. Interpreting services offer a valid option to overcome that barrier (HEKS 2021, AOZ 2021). However, their usage was reported to be very rare in our interviews and literature (Czapka and Sagbakken 2020), as their financing is not supported by insurance and falls onto the shoulders of the patient or the organization. Due to these administrative and financial problems, interpreting services are only used by bigger players like hospitals.

This can lead to an underestimation of the need for support and consequently to absent redirection to available services. Having a diagnosis is often an important key to access to dementia care services and their financing, and therefore is one of the first barriers during the process of dementia.

Interviewees and literature mentioned the importance of a key person, who could function as a person of trust and help manage challenging tasks and establish a connection to the suitable professionals where needed (Ulusoy and Grassel 2010). In Denmark, primary care dementia coordinators take over this role (Nielsen, Nielsen et al. 2020). But it could also be a GP in Switzerland in light of their important role in the healthcare process. Such a role as a dementia coordinator is something that we did not come about during our interviews. Also, it is important to include the social network of migrant communities as a valuable resource in navigating the care structures available in the country (Pflugger, Biedermann et al. 2009, Olbermann 2012). Participants rarely reported educating their staff in transcultural competencies. Therefore, working with people from other cultures or who speak another language can be challenging for professionals (Nielsen, Nielsen et al. 2020). Also challenging is the cultural insensitivity of the staff in situations where they may fail in understanding the

specific family functions and appear to take over or impose their views on them (Nielsen, Nielsen et al. 2021). This lack of migration sensitivity in the offered services might lead to people with a migration background not feeling welcome or seeing the offered services as unfitting for themselves/ their family members. Different materials have already been developed including guidelines on transcultural dementia care (Alzheimer- Europe 2020) or auxiliary material for professionals when working with dementia patients and their families with a migration background (Demenz und Migration, 2021, Migesplus 2021).

## Limitations

Our study focused on the canton of Basel-Stadt and therefore might not be representative for other parts of Switzerland. It is to be expected that they differ from the reality in more rural regions or those with a lower or higher percentage of people with a migration background. Also, we only talked to professionals working in the thematic field and did not evaluate the opinion of the affected and their families. There is no objective data from the services on the migration background of their customers/ patients. Thus, the numbers given during the interviews were mostly estimations.

## Concluding Remarks

To overcome the barriers reported in this study and to aim at equal access to dementia care for all residents in the country, different solutions have been mentioned in the interviews or are suggested in the literature. We underline these recommendations within four sub-headings: improving overall dementia care, addressing gaps in education and training related to dementia care, closing the financial concerns, and calling for research on this particular topic for this specific population.

### **1. Dementia care:**

- Screening- and diagnostic- tools and scores have to be culture-sensitive and linguistically adapted and easily accessible also for primary care professionals to ensure a timely and fair diagnostic process.
- Tools for evaluating the need for care and support also have to be culture-sensitive to ensure detection of needy individuals and their families.
- Information material about dementia and dementia care services has to be linguistically adapted (language, culture, language level) to patients' needs.
- Transcultural interpreters are to be used on all levels of dementia care (diagnostics, support, care ambulant, and stationary).
- Multicultural resources in staff should be valued and benefitted from. For example, by keeping a list of language skills to use for easy and short translations in everyday business.
- Establishing the role of a dementia coordinator/ case manager who can coordinate between patients/ families and the involved organizations.
- Introducing structures focusing on the needs of people with dementia and migration background. (e.g.: Mediterranean floor, flexibility in food, day structure, etc.)

- Allowing different levels of involvement of relatives in the care of their loved ones according to their respected needs.

## **2. Education and training:**

- Transcultural and interprofessional courses should be implemented in the educational curriculum of all disciplines from early on.

- Reenforcing the exchange between disciplines and organizations by the organization of round tables to share knowledge and information about who's doing what.

- Coworking with migrant communities to better inform about dementia and dementia care.

## **3. Financing:**

- Changing legal basis to allow reimbursement by health insurances of transcultural interpreting services for stationary and ambulant care services.

- Extending the political brief for migration-sensitive dementia care to support existing and new projects to focus on the needs of the migrant- community.

## **4. Research:**

- Further studies to explore the needs of the migrant- population by directly working with the affected families. (better understanding obstacles and needed adjustments).

- National studies for a more complete picture of the situation in Switzerland.

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## **Ethics approval**

The project was submitted for evaluation to the Ethics Commission (EKNZ) and found to not fall under the law for human research in Switzerland. Hence, no ethics approval was required, however, the commission judged the study protocol to be ethically sound.

## **Competing interests**

Authors declare that they have no competing interests.

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### Tables

Table 1: Interview partners and their respective fields of work

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