



## Challenges related to providing care for parents with dementia across borders: A qualitative study on transnational carers in Oslo

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### ABSTRACT

Migration requires people to re-define their caring roles, develop new caring strategies and negotiate the scope of care with the family in the country of origin. The main aim of this paper is to identify and describe challenges related to transnational care provided for people with dementia. Transnational caring itself poses many challenges for families but caring for a person living with dementia can be especially difficult.

The qualitative data presented in this article was collected in 2018 as part of a larger study focusing on understandings, experiences and responses to age-related cognitive impairment among families with minority ethnic backgrounds. The data includes seven semi-structured in-depth interviews with migrants in Oslo who were engaged in transnational caring activities for their parents living with dementia.

The participants in our study experienced numerous challenges related to providing care across borders to their parents. Some of the challenges were typical for transnational caring and were associated with care regimes in the countries of parents' and participants' residence, motives for providing care, participants' socio-economic situation and family relations. The other challenges were due to specific care needs of people living with dementia.

A social problem does not exist for a society unless it is recognized by that society to exist.

(Blumer, 1971)

### Introduction

Migrants, like other human beings, do not live in a social vacuum and are connected to other people and places. They often have families in their native countries, which is associated with many socially and culturally constructed mutual obligations and expectations. In most societies, children are expected to provide care for their parents. The scope and forms of care vary depending on the societies' cultures of care (Fine, 2015). However, migration makes people re-define their caring roles, develop new caring strategies and negotiate the scope of care with the family in the country of origin (author; Baldassar, Wilding, & Badock, 2006). For example, a study on transnational Taiwanese families shows that in a situation when hands-on care is difficult or impossible to practice, both migrant children and the parents left behind emphasised such aspects of filial piety as respect for the parents and emotional support (Sun, 2012). Research with Caribbean and Italian migrants living in Great Britain reveals that distance caused by

migration had an impact on the negotiations of care obligations (Reynolds & Zontini, 2006).

The main aim of our study is to identify and describe challenges related to transnational care provided for people living with dementia, including how dementia care is arranged in a transnational context, where parents and children live in different countries. As the number of people with dementia and migration trends separate families, family members may not be available to provide hands-on care. Some of the problems related to providing care to parents living with dementia are common for both children living abroad and those living far away. However, living in two different countries is often associated with potential additional challenges, for example a need to navigate between two different cultures of care and costs associated with time and travel (Zechner, 2008).

Below we will discuss the specificity of dementia, the challenges it poses for the family carers, and focus on transnational caring as our theoretical framework.

### Dementia – challenges for the family carers

Providing care itself poses many challenges for families but caring for a person with dementia can be especially difficult. The World Health

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Organization (WHO) considers dementia as one of the greatest public health challenges of this century (2017). Dementia is a set of symptoms characterised by a decline in memory and other cognitive functions. It affects mental processes, behaviour and the ability to perform everyday tasks (WHO, 2020). Alzheimer's disease causes 60–70% of the cases of dementia, and other types include vascular dementia, dementia with Lewy bodies and frontotemporal dementia (WHO, 2017). According to estimations, the prevalence of dementia in the world almost doubles every 20 years (2015: 47 million, 2030: 82 million, 2050: 152 million) (WHO, 2020). One of the major reasons for the increased incidence of dementia is rising life expectancy (Prince et al., 2015).

Most dementias are progressive, but the symptoms are highly individual, so it is difficult to predict disease trajectory. If someone lives long enough, late stage dementia typically involves 24-h care (Bartley, Suarez, Shafi, et al., 2018). A meta-analysis on differences between carers and non-carers indicates that caring for people living with dementia is associated with a higher level of stress than caring for people with physical impairments (Pinquart & Sorensen, 2003). A systematic review of articles focusing on informal carers shows that caring for the relatives with dementia can be very demanding (Chiao, Wu, & Hsiao, 2015). The challenges are presumed to be so heavy that family carers are often called “the invisible second patients” (Brodaty & Donkin, 2009:217). A study on informal dementia care in eight European countries demonstrated a significant relationship between a higher amount of informal care and negative health outcomes, including psychological health (Bremer et al., 2015). According to a Dutch longitudinal study, family carers of people with dementia are very vulnerable and may not only develop depression but also have suicidal thoughts or contemplate self-harm (Jolling, O'Dwyer, Hertogh, & Hout, 2017). Carers with suicidal thoughts had more severe depressive and anxiety symptoms and reported more health problems than those who did not report suicidal thoughts. In addition, they had a lower sense of competence and mastery, felt less happy and had more feelings of loneliness (Jolling et al., 2017).

## Theoretical framework

In this paper we apply the theory of transnational caring to explore how migrants provide care to a parent living with dementia. Family-related transnational activities of migrants are not a new phenomenon, and migrants have always tried to maintain contact with their families in their native countries by, for example, sending remittances and letters (Vertovec, 2009). In recent decades, technological progress). The development of low-cost means of transport and new communication technologies has intensified transnational activities allowing regular and continuous contact with the family (Faist, 2000).

According to Zontini (2004), transnationalism makes us reconsider our understanding of families and households, based on the idea of co-residency and physical unity. Increasingly, families are characterised by spatial separation, which is caused, *inter alia*, by migration. However, migration resulting in spatial reconfiguration of the family does not cause mutual caring obligations and expectations to disappear. Studies conducted so far among various ethnic groups show that migrants are usually involved in various types of transnational care of relatives who remain in the country of origin (author; Baldassar, 2007; Wilding and Baldassar, 2009; Krzyżowski, 2012; Lunt, 2009; Sun, 2012; Wilding, 2006). In many cases, they have to provide care despite various types of constraints related to the geographical relocation of the family.

Transnational care provision is especially important for elders living in countries with weak welfare state structures (Kröger & Zechner, 2009). Zechner (2008) conducted a study of female Estonian immigrants in Finland helping older relatives back home. She draws attention to welfare policies both in the country where the relative lives and in the country of immigration. Policies act as facilitators or barriers for transnational caring; for example, a care allowance helps migrants to reduce their working time and to provide hands-on care for relatives

abroad. Restrictions related to travelling abroad while receiving unemployment benefits may act as a barrier to providing care across borders (ibid:39). Transnational carers must operate between two, sometimes very different, social policy systems and care regimes.

Saraceno (2016) analysed the welfare policies in European countries and distinguished five different patterns of responsibilities between the state and the family. ‘Unsupported familialism’ or ‘familialism by default’ is when the family does not receive any financial support and the state does not provide any forms of institutional care. This may evolve into ‘defamilialisation’ through the market, when private resources are used to buy market care. ‘Prescribed familialism’ characterises the systems where the families are obliged by law to provide financial support and care to family members in need. ‘Supported familialism’ occurs when families are supported through the existing policies so they can fulfil their care responsibilities (ibid:316). ‘Supported defamilialisation’ through the market means that the individuals or the families are provided with income transfers so that they can buy market services or the state funds them via the market. ‘Defamilialisation’ through public provision characterises the situation where the family responsibilities are reduced and the state is the main care provider (ibid:317).

Research conducted among Polish transnational carers in the UK shows that systemic differences may modify migrants' beliefs regarding familialism and influence their care intentions (Radziwinowiczówna, Rosińska, & Kloc-Nowak, 2018:16). For example, most of the study participants in the Polish study did not intend to provide personal care for their parents despite being the most desirable form of care in familialistic societies. The researchers coined the term “transnational ethnomorality of care” to describe the situation when both parents ageing at home and their migrant children accept the fact that most of the children's care responsibilities have been transferred abroad (ibid).

Based on Baldassar's distinction between virtual and proximate caring practices, Kilkey and Merla (2014) distinguished four types of involvement in care in a situation of geographical distance: care provided at a distance, delegation of care tasks, coordination of care and care provided in person. The scope and forms of care provided by migrants for dependent relatives are negotiated and depend largely on the type of the existing relationship between family members, and the cultural norms defining the duties of the younger generation to the senior family members (Baldassar, 2007; Krzyżowski, 2013; Zontini, 2006).

Many studies have shown that family care obligations are typically carried out by women (e.g., Brandt, Schmid, & Haberken, 2012). For example, studies conducted among various migrant groups in Australia (Baldassar, Badock, & Wilding, 2007; Wilding & Baldassar, 2009) and Polish immigrants in Iceland (Krzyżowski & Mucha, 2014) show that gender is also an important variable that differentiates involvement in transnational care. Women tend to feel more responsible for providing care for the older family members, often carry a greater burden of care, and in the situation of migration experience a sense of guilt more often than men (Baldassar, 2015). An Australian study on transnational care, involving immigrants from Europe and North America, shows that women focused more on health and emotional issues and men more about financial aspects of care (Baldassar & Baldock, 2000, p. 84).

In this paper, we focus on the challenges related to providing transnational care for parents living with dementia. To the best of our knowledge, no prior study has focused specifically on this group of carers. However, the study examining the crisis of acute and chronic illness in transnational families shows the difficulties experienced by the transnational carers in the situation when their relatives need hands-on care and emotional support (Baldassar, 2014).

Our paper draws on the theoretical framework of transnational care but we also look at care activities through the lenses of intersectionality (Anthias, 2012). We believe that using these lenses affords a better sense of the complexity of carer's experiences, because paying attention to the interconnectedness of different characteristics, for example, gender, age, education, job situation, ethnicity and country of

emigration, can influence migrants' transnational engagement.

## Materials and methods

The qualitative data presented in this article was collected in 2018 as part of a larger study, (Ageing, dementia and the need for care: a qualitative study on experiences and responses to cognitive impairment among families of different cultural backgrounds living in Norway). The overall aim of the study was to explore how age-related cognitive impairment (not diagnosed) and dementia (diagnosed) are interpreted, experienced and responded to within families from different cultural, linguistic and social backgrounds.

### *Study settings, sample strategy and participants*

The research was carried out in Oslo, which has the largest population of immigrants in Norway (SSB, 2017). Initially, the authors were looking for 1) participants with minority ethnic background with family members who had been diagnosed with dementia and who were receiving care at a) their home, b) in a long term care institution, or c) at home, combined with day care centre; 2) participants with minority ethnic background who had not established contact with public health services but provided care for people with age-related cognitive impairment (with or without an established diagnosis); 3) health-care personnel attached to clinics and care homes providing care to people and their families affected by dementia and 4) key representatives from migrant communities. Initially, we planned to use a purposeful sampling strategy aiming at maximum variation in relation to ethnic background, to identify a variety of caring philosophies and practises (Patton, 2002). The first author made contact with several institutions involved in providing care and support for people with dementia and their families (memory clinics, nursing homes, day-care institutions, community-care programmes and dementia coordinators). We changed the sampling strategy to convenience and snowball methods as we experienced various barriers in access to potential participants.

The challenges related to transnational care appeared during the meetings and/or interviews with key representatives of migrant communities in Oslo and with migrant family carers, and different narratives made us aware of a variety of such challenges. There were, for example, situations where parents suffering from dementia were moved to Norway due to difficulties related to the provision of care across national borders, and others told of challenges related to stress caused by parents living with dementia were left alone. Thus, even though initially not a part of the overall focus of the study, we decided to recruit participants who could provide further insight into these challenges. Different channels were used to recruit carers who provided different forms of care across borders. Recruitment information about the project was published on several internet forums for migrants. In addition, private networks of friends and colleagues were used. The first author had several meetings with key persons from minority ethnic groups, informing them of the project aims and the recruitment criteria, which were 1) having a relative diagnosed with dementia abroad, and 2) being involved in any form of care activities related to that person. For this part of the project, we collected data during 1 year.

The data that constitutes this particular part of the study includes seven semi-structured in-depth interviews with female migrants in Oslo who were engaged in transnational caring activities for their parents living with dementia. We did not look specifically for females. The participants were aged 30–70 (Table 1). Two of them had underage children in Norway. All the participants had jobs and one studied in addition. Three out of seven study participants came from Poland. Poles constitute the biggest minority group in Norway, and as they are mainly young and middle-aged labour migrants, many have ageing parents in Poland. It was also important for the recruitment of the Polish families that one of the authors was Polish and had an extensive network of contacts in Norway's Polish community that facilitated the recruitment

process.

In order to protect the identities of the individuals who participated in the research, personal characteristics that may reveal the identity of the participants are removed or altered.

### *Data collection and analysis*

The interview guide included a list of broad discussion topics concerning experiences related to the onset and development of dementia, the understanding of dementia, family versus institutional care and available social support. This paper focuses on the challenges related to the transnational care performed by these seven female immigrants.

All the interviews were conducted by the first author in Polish or English at venues chosen by the participants including the office of the first author, the participants' workplaces, a coffee shop and a participant's home. The interviews lasted between 45 and 150 min, and in three cases the first author met the interviewees twice due to time constraints. One participant wanted to meet again after visiting parents in the country of origin in order to provide the first author with the newest information regarding her mother's health and caring situation. All interviews were digitally recorded, and in addition notes were taken during the interviews. In most cases, several short breaks were necessary because the issues raised evoked strong emotions among the participants. Two participants cried during their interviews and needed time to calm down.

The interviews were transcribed verbatim, and the Polish transcripts were translated into English. Thematic analysis was used to gain insight from data gathered (Braun & Clarke, 2006). The interview transcripts were first read three times to get a good overview of the data. They were coded for challenges related to transnational care, and then the codes were categorised and clustered into themes. In the next step, the initial themes were reviewed to confirm the coherence of the data within each theme and a clear distinction between the themes. Subsequently, subthemes were identified within each theme. For example, regarding the theme "care obligations", the three sub-themes "feeling responsibility", "feeling guilt" and "negative social reactions" were identified. Finally, the content of the themes and subthemes was merged into generalised descriptions of challenges related to providing care for parents with dementia across borders.

### *Ethics*

The study was reported to the Norwegian Data Protection Officer for Research (NSD). The researchers followed (institution's name) internal protocol regarding data security. The platform for sensitive data (TSD) was used to store the project data. All respondents gave written informed consent to participate in the study. They were informed they were free to withdraw their participation at any time without giving any reason.

## Findings

### *Overarching challenges of transnational care*

Most participants said they were not surprised when their parents were diagnosed with dementia. The diagnosis came as something expected and was a relief rather than a shock. However, they did not know what to expect in the future. The findings are in line with other studies conducted among family carers to people with dementia whereby relatives experienced the diagnosis as closure and an end to uncertainty. However, they knew little about the future and about their new role of being a family carer (Stokes, Combes, & Stokes, 2015).

Some of the challenges experienced by our study participants were typical for transnational caring and were associated with care regimes in the countries of the parents' and participants' residence, motives for providing care, participants' socio-economic situation and family

**Table 1**  
Sociodemographic characteristics of informants<sup>a</sup>.

Name	Age category	Country of origin	Marital status	Education	Period of stay in Norway	Children
Kasia	40–50	Poland	Divorced	University	>10 years	3 children, one is underage (6 years old)
Ania	50–60	Poland	Divorced	University	<10 years	3 children, one is underage (17 years old)
Inka	40–50	Finland	Married	University	>10 years	No children
Samira	40–50	UK	Married	University	>10 years	1 child
Kate	60–70	US	Single	University	>10 years	1 child
Monika	30–40	Poland	Single	University	<10 years	No children
Ursula	30–40	Austria	Single	University	<10 years	No children

<sup>a</sup> All participants' names are imaginary names

relations. However, our findings show that some of the challenges common for all transnational carers seemed to be even more difficult to cope with when providing care to people living with dementia. Likewise, the already difficult task of providing care to people with dementia was exacerbated by the need to do so from abroad.

#### *Navigating between different care regimes and cultures of care*

Our findings indicate that many challenges related to the transnational caring of relatives with dementia resulted from the care regimes and cultures of care existing in the participants' emigration and immigration countries. Care regimes and care cultures are inter-related concepts often used to describe how care is organised and practised in societies. Kofman and Raghuram define care regimes as “the institutional and spatial arrangements (locations) for the provision and allocation of care” (2009:6) including such economic aspects as whether public support systems are available. Culture of care can be understood as the care practices, values and behaviour produced as a response to national welfare and labour market regimes (Fine, 2015). Cultures of care significantly influence the care regime in any country. The main providers of care are the family, the state and the market. Many countries endeavour to find new solutions and establish a new balance between the family, the market and the state (Bettio & Plantega, 2004; Levitsky, 2014). However, in many societies the family supplemented to varying degrees by the welfare state, is the primary care provider for elder relatives. Levitsky, analysing care responsibilities for society's dependent members in the United States, argues that the ideology of family responsibility is so prevalent, that even such societal changes as women's widespread participation in the labour market, extended life expectancy and reconfiguration of the family forms do not reduce the family's sense of responsibility for care provision (Levitsky, 2014).

Our findings show that the existing patterns of familialism-defamilialisation can facilitate or hinder the provision of care by relatives of people with dementia across national borders. For example, in Poland, where the system is characterised by prescribed and only partially supported familialism, spouses and children, especially daughters, are responsible for the organization of care provision for the parents. The Polish welfare regime promotes women's participation in the labour market but at the same time care is still perceived as a women's activity (Keryk, 2010). The Polish participants in our study struggled with arranging care for their parents, due to several barriers, including the high cost of care services.

Kasia's mother, who lived in Poland, was entitled to help at home only twice a week yet required 24-h care. There is an insufficient supply of public care services in Poland, and private ones, although available, are expensive and not co-financed by the state (Radziwinowiczówna et al., 2018). The situation forces people to use different types of strategies to care for their parents. Additionally, it was very difficult for Kasia to find a carer due to her mother's aggressive behaviour related to Alzheimer's. Kasia said: “Who would want to live with my mum!”. Due to her mother's extensive care needs and insufficient help from the state, she illegally employed a woman from Russia. However, she was not satisfied with her work because her mother was starving and did not get her medicines. Kasia decided to pay her neighbour to care for her

mother even though the neighbour was only available in the afternoons, but the arrangement seemed to work. Ania coped with the lack of public support and high cost of the private ones by employing Ukrainian women. She explained it was much cheaper to employ a carer from Ukraine than to pay for a place in a nursing home or for private services. Many Ukrainian female domestic workers in Poland work illegally and are referred to as “invisible carers” (Kindler, 2008; Peterson, 2007). They do not pay taxes, and, thus, are not included in the social insurance system and have no access to social benefits. Ania explained that one of the carers developed very high blood pressure and needed regular treatment and so had to return to Ukraine. Ania's experiences illustrate how unregulated employment of carers on-site may add additional stress to transnational caring resulting from the fear of intervention of the authorities:

Once, my mum called the police...She reported that her grandchildren got lost.... The poor Ukrainian woman was terrified because she worked illegally. She called me, and said “the police is already here”. I decided to talk to him...I told him that my brother was responsible for my mum but he had to leave for a week. I also explained that my mum was talking about my children who were not kids any more...I hoped that he wouldn't check that Ukrainian lady. On the other hand, even in Mother's block of flats there are so many old people who are taken care of by Ukrainian women. It is a well-known phenomenon in Polish society. The authorities turn a blind eye to it because they have no choice. We need carers.

All Polish participants talked about the very high costs of institutional care in their country. If the older person cannot afford to pay for a place in a nursing home, the children and grandchildren are obliged to cover the costs. Further, not many public care institutions are suited to the needs of people with cognitive impairments. The private nursing homes that provide services for people with dementia are very expensive. Kasia, for example, being a single mother, worried a lot about her adult children having to pay for her mother's stay in a nursing home.

Ania, Kasia and Monika all experienced the collision of two different care regimes and care cultures when discussing the situation with their Norwegian friends and colleagues. Monika, for example, explained that her colleague did not understand her difficulties in providing care across the border:

The first question I was asked by my colleague was “don't you have nursing homes in Poland? I answered: But it is about my mum. It is very difficult to explain to people here that my mum is so important for me.

The participant explained further that it is not a common practice in Poland to “send” parents to care institutions. She referred to the norm of reciprocity of care in the families, an important element of Polish culture.

Ursula was from Austria yet shared some of the experiences of the Polish carers. Her parents lived in a small village where the family was expected to provide care for their elders. She explained:

I think it depends on the region. In the city or the capital, it would be

totally fine, I guess, to place parents with dementia in a nursing home. But in the village...if my father would be in the institution, people would say that children don't care. I think it is not that accepted yet. It is still normal that the family take care of them as long as possible. Maybe you can have a person that comes during the day. But to go to the institution like nursing home? No.

Ursula's experience shows that local context may influence the expectations regarding family's involvement in care.

Not all the participants worried about care arrangements for their parents. Samira from the UK was satisfied with home care provided for her mother by the Scottish National Health Service. In Scotland, people living with dementia and their carers are offered person-centred, coordinated and flexible support ([Scotland's national dementia strategy 2017](#)). Samira's mother was entitled to free care due to her limited financial resources. Public carers stayed with the mother when Samira's sister was at work and every day drove her to the activity centre where she played games and was served food adapted to her needs. Samira had no doubt that her mother received the best possible care. She regularly called her mother and sister and, in this way, supported them emotionally, perceiving her role as complementary to the care provided by the state and by her sister.

The experiences of a Finnish interviewee, Inka, are related to the Scandinavian model of care, existing in the Nordic countries ([Esping-Andersen, 1990](#)). Inka was sure that her father was getting proper care because of the way the public care system is organised in Finland. She explained:

I think it is quite similar to here (in Norway) so it is not a problem. It is very common to give it (care responsibility) to the state. For example, my grandmother, she was put in a care home for people with Alzheimer's. It is too difficult for the family to provide care for a long time.

The Nordic countries are characterised by defamilialisation through public provision, or optional familialism, where the caring family is supported by the state and is given the option to be partially relieved from caring responsibilities ([Leitner, 2010](#)). The state is the main care provider and relieves the family from caring tasks. There is also strong social support of this type of solution ([García-Faroldi, Miguel-Luken, & Ayuso, 2017](#)). Therefore, Inka was not worried about all the practicalities related to care provision. She contributed to the care by providing emotional support for her father and by spending time with him and doing things he enjoyed.

In many countries with more family-oriented regimes, or as some would say neoliberal, especially in eastern and southern Europe, there are not enough long-term care (LTC) institutions and home services ([Lamura et al., 2008](#)). There are only 11.8 beds per 1000 population aged 65 years old and over in LTC institutions in Poland, compared to 57 in Finland, 46.2 in Norway, 45.6 in UK and 33.4 in US ([OECD, 2017](#)). A lack of sufficient public care services together with expensive private care, gendered care responsibility and strong norms of generational reciprocity can potentially reinforce traditional care models, as there are no alternatives to informal family care. According to Levitsky, the ideology of family responsibility mask any potential alternatives ([Levitsky, 2014:167](#)). As our findings indicate, in some situations even grandchildren are forced by law to contribute financially to their grandparents' care, and migration does not abolish or reduce financial obligations within the family. Transnational families have to meet the challenges related to care deficits in their countries of origin.

#### Care motivations

Despite different motivations, all participants in our study felt responsible, to some extent, for providing care for their parents living with dementia. The motivations to provide care result in different outcomes for carers and their well-being ([Brodaty & Donkin, 2009](#)). The ones motivated by a sense of guilt or moral obligations tend to

experience more negative consequences ([Pyke & Bengtson, 1996](#)). Feelings of guilt appear when individuals fail to meet this societal obligation. Strong moral pressure about caring for dependent relatives often results from a traditional care regime, relying primarily on the family ([McCleary & Blain, 2013](#)). The Polish care model, described in the previous section, is one example of a familialistic care regime.

The feeling of guilt is relatively common among transnational carers, because due to physical separation they have limited abilities to fulfil caring obligations ([Baldassar, 2015](#)). Most societies prioritise physical presence and hands-on care for parents. According to our findings, a feeling of guilt was experienced by most of the participants, albeit of varying intensity. A Polish interviewee, Ania, explained how she felt that she neglected her mother:

I feel terrible. I was there for her for a while and I had to come back to Oslo. I do feel I neglect my mother although we employ a carer.

In Poland, people judged her because she left her mother with dementia alone, and the negative social reactions intensified her feeling of guilt.

The Finnish participant, Inka, felt somewhat guilty because she was not with her parents and could not support them on-site. However, she explained that her personal problems made it impossible for her to engage in care as much as she would like to. Inka knew that her father was cared for but believed that, as a daughter, she should be there more often and support her parents emotionally. Not all participants experienced a sense of guilt related to transnational caring, due to the different definitions of caring and how it was exercised. Kate from the US described her contribution to caring, saying hands-on care was not the only form of care, but related it to the fact that she engaged with and spoke to her mother on a regular basis:

I didn't feel like I wasn't contributing at all. We were in contact several times a week. I never felt like I was deserting my mother.

Kate expressed confidence that she did what she could in her situation, living far away from her mother and felt that the emotional ties were strong and were nourished through the telephone calls.

Some participants perceived care in terms of moral obligation, resulting from the culturally defined norm of reciprocity. Their intention was to "pay back" parents who had brought them up and supported them for many years. In the literature, reciprocity and altruism are identified as the main motives for providing care to parents ([Kohli & Künemund, 2003](#)). Our findings also show that these motives made most of our participants postpone the decision to move parents to a nursing home. As expressed by one of the Polish participants, Kasia, "We decided to wait until the last moment". She viewed care provided at home as the best for the person with dementia and related this to the norms of reciprocity and altruism. By providing the best possible care, Kasia wanted to repay her mother for the help she had received from her in the past. However, Kasia believed that if the person was so ill that she/he was not aware of what is happening to her/him, it would be possible to place her/him in a nursing home. She explained that this was due to her conviction that all people have the right to stay at home as long as their condition allows for it.

Samira from the UK also referred to the norms of reciprocity and altruism when explaining why she had decided not to place her mother in a nursing home: "This [sending parents to an institution] is so cruel, it is so inhumane. It is such a brutal thing to do to somebody who brought you up". Our findings suggest that the desire to fulfil the norm of reciprocity, characterising care regimes based on familialism, was very strong, despite the challenges related to the provision of care across the border and increasing care needs related to the progressive nature of dementia.

We identified one more reason why some study participants were involved in transnational care activities despite the many difficulties related to it. As mentioned earlier, in such countries as Poland characterised by deficits of state institutional care and relatively low

pensions, older adults cannot cover the high cost of private care. In such situations, family support and participation in care is not a matter of choice, and even if they live abroad, the system forces them to financially contribute to caring. Children are obliged by law to pay alimony or cover the cost of caring if parents live in poverty. Thus, intersectionality (Crenshaw, 1989) and its applicability in the studies of transnationalism (Anthias, 2012), reveal how factors including gender, financial situation and the native country's care regime/care culture intersect and influence transnational migrants' experiences.

#### *Role conflict: having caring responsibilities in two countries*

The transnational carers in our study talked about the challenges related to having *caring responsibilities* both in Norway and in the country of emigration. They were concerned about the time and the finances they had to spend on providing care for their parents living with dementia. According to Finch and Mason's (1993) study on kinship in Great Britain, the family responsibilities are more the products of continuous negotiations than the results of rules and obligation. This is because the responsibility to care for parents is often limited by other obligations, resulting, for example, from women's entry into the workforce. Previous studies show that carers experience stress due to the need to reconcile caring with other such social roles as work and child raising (Brody, 1981; Cassie & Sanders, 2008). Most of our participants experienced some difficulties related to the reconciliation of work and care provision. However, they seemed to look at that role conflict as something completely normal. It did not evoke strong emotions during the interviews, except for the situations where the participants talked about the experiences with employers' negative attitude towards their transnational care activities. One of the Polish participants, Kasia, worked at a nursing home and did not tell her main manager about her mother's illness. She explained, "I was afraid of her reaction. She may think it would affect my work". She wanted to live in Poland and fly to Norway every week to conduct her shifts at work, but her employer did not agree to such an arrangement and threatened her with dismissal. Kasia's shift arrangements would easily have allowed her to travel regularly to Poland. Monika experienced what she perceived as very negative reactions from her employer when she had to fly to Poland due to her mother's deteriorating health:

I didn't ask for a few days of vacation in Greece. I asked for a short leave because of my mother's health problems.

Monika was very disappointed that her employer did not try to support her efforts to see her mother. The employer, on the other hand, explained that it was difficult to find someone to replace her in the kindergarten. Monika cried during the interview and hoped that the employer would be more understanding in the future.

Kate, whose mother lived in the US, did not experience any work-related problems that might negatively influence her care activities. Her bosses were supportive and she could work from home when she visited her mother in the US four times a year. She explained:

You know what would be really hard for me? If I had had a different job and I hadn't been able to travel, I don't know how I would have coped. I would probably resign or take an extended leave of absence.

Kate would not have been able to cope emotionally with her mother's illness if she did not have the possibility to visit her regularly. The type of job she had allowed her to work from home and from a distance, as long as she was able to access internet/skype and the like. Inka from Finland worked part time and did not experience any difficulties related to reconciling work with transnational care provision.

The participants who worked in the service sector experienced less flexibility related to the time and place of work. Referring to intersectionality as our analytic tool, our findings show that the interplay of cultural capital (Bourdieu & Passeron 1977), financial situation and type of job affects the experience of conflict between the role of an employee and the role of a transnational carer.

Talking about their children evoked strong emotional reactions in the interviewed women. Two participants had underage children and both talked about experiencing a role conflict between being a mother and being a daughter of a person living with dementia. They were typical representatives of the sandwich generation (Miller, 1981), being sandwiched between ageing parents and underage children. Having caring responsibilities in two countries presented additional challenges including high costs of travelling between two countries and lack of time. Ania from Poland was a mother of three children, including one underage, and considered her role as a mother more important than the role of a daughter. She said:

What about a single mother like me? I would have to choose whether I feed my children or my mum. I don't have a choice, I have children.

Ania explained that financially, socially and time-wise she would always choose the children over her mother. Kasia experienced a similar dilemma as a result of simultaneously supporting her dependent child and dependent mother. She was the only daughter and obliged by law to contribute financially to the cost of care provided for her mother. She told us about the reason of her worries:

I can't spend all my money on my mother as the Polish state wishes. If I did, I would lose my child in Norway. Barnevernet (Child Protection Office) would intervene.

Kasia had had to deal with Barnevernet before, when she was warned that the youngest child could be taken away from her because of her financial situation. She felt controlled by both the Polish and the Norwegian state, and it was impossible to satisfy the requirements of both systems. As a result, being a single, immigrant mother, having a low paid job that she was dependent on, Kasia experienced an on-going role conflict. Referring to the theory of intersectionality, the findings show how the interconnectedness of various characteristics describing migrants' position in the host country influence their transnational caring.

Our study shows that middle-aged women may experience a dilemma related to competing social obligations, which is in line with previous studies on family caring (Brody, 1981; Cantor, 1983; Levitsky, 2014). Transnational caring may intensify the on-going role conflict experienced by carers due to differences in parental and childcare regimes and in the gender politics between country of origin and country of migration. For example, the Polish participants who were socialised to believe in familialism and traditional gender ideologies encounter culture clashes when living in the Norwegian gender egalitarian society.

#### *Challenges related to geographical distance*

The participants in our study primarily performed care from a distance. Distance is one of the most important factors deciding migrants' capacity to engage in transnational caring (Baldassar et al., 2007; Zechner, 2008). Transnational migrants cannot provide continuous conventional hands-on care due to their physical absence. Research conducted so far shows that relatives often provide support by means of telephone conversations, skype or e-mails (Baldassar, 2007; author; Krzyżowski, 2012; Wilding, 2006). As we saw with Kate from the US, internet and related communications can function as a channel of psycho-social and informational support.

In the case of dementia, distance constitutes an especially significant barrier to participation in care. With the development of the illness, people with dementia require care that demands physical contact with the carer, and even virtual contact is likely to become more and more difficult. Our findings suggest that the participants' experiences of distance were shaped by the intersection of various categories such as family structure, family relations, the stage of the parent's dementia, type of job abroad, culturally based expectations, care systems and financial situation.

Ania and Kasia from Poland said they lived constantly in stress from being far away as they felt they needed to check on them regularly. Ania explained how difficult it was for her to manage the situation:

She needed to talk to me regularly because she forgot that I called her 10 min earlier and she was feeling abandoned... It was on my mind all the time: call your mother, call your mother.

For Ania, distance constituted a significant barrier in contacting her mother. Telephone calls were the only available type of communication with her. For Ania and some of the other participants, distance was interrelated with such system barriers as inflexible jobs, working from home and lack of money to travel to the home country to visit parents.

Kasia had no siblings or other close relatives in Poland where her mother with Alzheimer lived. Thus, care activities could not be redistributed within the family, and she was considering moving her mother to Norway. However, it turned out to be very complicated due to existing legal regulations, which hindered the mother's official move to Norway. There were several other factors she considered as barriers; for example the lack of competence in English and Norwegian might hinder the mother's adaptation to a new society. Furthermore, Kasia was renting a fully equipped flat in Oslo and was afraid that her mother could destroy something during her episodes of aggression, as she had no financial means or insurance to cover the cost of any potential damages.

Ania's case shows that even though migrants are allowed to work across the borders, existing systemic and financial barriers do not facilitate caring for family members. As a result, her mother remained in Poland and she tried to find effective coping strategies to respond to increasing care needs from a distance. She travelled more often to Poland and arranged care on-site by taking her mother for medical examinations, buying medicines and arranging for a carer. She also employed someone that would clean her mother's flat.

Study participants used different strategies to participate in care despite the distance separating them from their parents. In some cases, these women delegated care to siblings, who either provided hands-on care or coordinated care by informal or formal carers. Studies on transnational practices and experiences of immigrants from Australia (Baldassar et al., 2007) and Poland/Great Britain (Kordasiewicz et al., 2018) show that frequently the child who lives close to the parents performs the primary care duties. These participants discussed all the details regarding care needs and care provision with siblings or other informal carers. Any in-person care was often provided by the participants during the holidays or short visits. However, all participants said they visited their parents as often as they could and invested a lot of time and effort when they were there. Kate, for example, looked for a good nursing home for her mother, took her to specialists and helped her adapt to life in the institution. Monika visited her parents every other month. During her short visits, she paid the bills, bought coal for winter, talked to care services in Poland, wrote applications and prepared documents related to the organization of care for her mother.

A study on Polish transnational carers in Iceland and Australia shows that they tried to maintain their relatives' lives and support them emotionally through virtual communication (Krzyżowski, 2015). In addition to all their efforts when visiting, these women regularly called their parents to compensate for their absence and inability to provide care in person. However, some of them said that their parents were reluctant to exchange upsetting or emotionally difficult information. Monika, whose mother was not able to talk on the phone, described her worries related to limited contact with her parents:

*When you live abroad, the telephone is the best way of communicating with your parents. But I can't really verify whether my father was honest with me or not. It makes me worry a lot... I suffer because I can't be there. I can't fly to Poland whenever it is necessary. My mum's disease showed me that I am stuck here. I can't just go and visit my mum because I work in Norway. Helplessness is the worst in this situation.*

She explained further that her father did not want to worry her because she was living far away from home. Monika knew that he was hiding information regarding her mother's health because her cousin would call when something was wrong with her mother. Ursula, whose parents were living in Austria, experienced similar problems, resulting from incomplete communication with her parents. She explained that she tried to find out whether they needed help but her parents preferred to deal with the situation themselves:

They won't tell you when they have appointments at the doctor, what the doctor said, etc. I tried to find out what type of dementia it is, what kind of medicine my father gets and what is the prognosis. You know, they always try to protect us, the children.

They never called her with any updates related to her father's illness. Thus, even though she was trying to help her parents cope with the situation, the distance made it impossible. To address this, Ursula planned to get an overview of the parents' situation during her summer holiday. She had decided to talk to her father's doctor about the prognosis and how she could help. According to Carling (2008), lack of access to information about non-migrants' daily life puts migrants in a very vulnerable situation as they can only imagine what life on the other side is like.

Studies on Italian transnational families and on Polish female transnational carers who provide care to their relatives left behind show that avoiding difficult topics and negative emotions during the conversations between family members "across the borders" is a common practice (author; Baldassar, 2007). Although the main function of this emotional separation is to protect the relatives from "potential guilt feelings" (Baldassar, 2014), there is always a risk that they will feel excluded from normal family life and the possibility to help. Therefore, although technological developments have made it possible for migrants to stay regularly in touch with their families and to maintain many of the everyday responsibilities and routines, the geographical proximity in many situations continues to be irreplaceable.

#### *Family relations and family dynamics*

Family conflict is one reason for migration and may make migrants limit their contact with their families in the country of origin. The participants in our study had diverse family situations and sometimes very complex relations with their parents. Research shows that the nature of past relationships between family members influences the scope and forms of transnational care (author; Baldassar, 2007; Zontini, 2006). The most important factor is the relationship with the person who needs help. A recent study on perceived relationship closeness in couples navigating Alzheimer's shows that relationship closeness can shape the experiences related to AD (Gallagher & Beard, 2020). Couples with high closeness described their experiences as a composite whole in contrast to the couples with low relationship closeness who described their experiences with AD as distinct to each party (Gallagher & Beard, 2020).

As many as five out of seven participants reported difficult relationships with their parents prior to dementia diagnosis. Only Kate and Inka talked positively about their relationship with their parents and did not convey any problems that influenced their care activities. Kasia never had a good relationship with her mother as "she (the mother) is manipulative, she has always been like that". She perceived that the mother became even more manipulative as the dementia progressed. Thus, Kasia's difficult relationship with the mother before Alzheimer's, and associated changes in the mother's personality, made it challenging for her to visit and provide care for her mother. Kasia did not have many good memories related to her mother that would reward her for her efforts and thus had an ambivalent relation to the principle of reciprocity.

Ania described a very difficult relationship with her mother throughout her life. In her case, the emotional costs of limited care provision were relatively small. Ania explained how she was trying to

provide good care for her mother even though she was not emotionally involved:

I am doing everything to improve the quality of her life. I would like her to feel good and comfortable as much as possible in her situation. However, I am not concerned about her the same way that I am concerned about my children. I am not very emotional about it...I am trying to be pragmatic.

The quote indicates that the participant was ready to fulfil her caring obligations while also trying to be emotionally distanced. Ania's experiences shows the importance of prior relationship in caring dynamics.

Monika had a very difficult family situation, which stressed her a lot. Her father suffered from ataxia, and the mother had taken care of him before she developed dementia. They lived in a small village in Poland far away from health and care institutions. The participant explained: "Suddenly my father realised that he knew nothing about everyday life". The eldest and mildly mentally disabled sister and the father did not understand the situation, in Monika's view, so she did not consider them capable of caring for her mother. This placed a huge burden on Monika's shoulders, who expressed her worries regarding her father being the main carer to her mother:

I don't trust my father enough to leave him with my mum. He can help her but he needs to be guided by someone.

She was feeling responsible for the whole family, but she did not know how to support them across the borders. That overwhelming responsibility, resulting from the family's inability to cope with the situation, made Monika's life abroad very stressful. Monika's experiences resulted from the intersection of various characteristics: the familialistic care regime in Poland, the family's lack of coping with the mother's illness and the participant's internalised moral obligation to provide care for the parents.

Ursula said that her parents, especially her mother, did not want to talk about any problems relating to her father's Alzheimer's. Both parents pretended that everything was OK or were unwilling to involve their children or receive any help. The mother used to say, "Well, it is my problem (father's illness) and I have to handle it and no one else can help me". This was very frustrating for Ursula as living abroad limited her possibilities of helping her parents. Her parents expressed that it was the children's duty to contact them and did not inform the daughter about the progression of her father's health. However, calling her parents was also problematic. As Ursula explained, "If you don't call, it is wrong. If you call, it is still wrong because you may call too often". She had a strong sense of duty to care for her father, but she did not cope well with the situation due to her family dynamics and transnational life that limited contact.

The findings suggest that in most cases the nature of already established family relations and family dynamics shaped the way the study participants were involved in care provision for their parents; this is in line with previous studies on transnational caring (author; Baldassar, 2007). However, in the case of two participants, the relationship with their mothers improved significantly after the latter became ill and the Alzheimer changed the mothers' personalities. Ania, for example, admitted that the relationship somehow improved, "It is a miracle that Alzheimer's has changed my mum with time". She was referring to the fact that her mother became a very nice, polite and friendly person. The other participant, Samira, also observed many positive changes in her mother's behaviour:

She is such a funny person. She has never been like this. I never had a good relationship with my mother... That's because of the fact that she was a very difficult woman when I grew up. She wasn't a nice woman at all.

The participants admitted that what they saw as positive changes in their mothers' behaviour and personality were very surprising and

made their contacts and care provision across the borders much easier. Personality and behavioural changes are not uncommon in Alzheimer's (Terraciano & Sutin, 2019; Robins Wahlin & Byrne, 2011) and can precede other clinical manifestations of the condition.

#### Challenges related to dementia

Most participants expressed their uncertainty as to whether they were providing the best possible care for their parents with dementia and used the Internet, books and brochures to deepen their understanding of dementia. Previous studies on family carers of people living with dementia show that they are entangled in uncertainty and isolation (Brody & Donkin, 2009; van Wijngaarden, van der Wedden, Henning, et al., 2018). As our participants did not live with their parents, they were unable to observe the development of their parents' dementia, and it was difficult for them to arrange proper care across the borders. Participants' worries resulted also from a lack of control over the situation and over the parents' illness and partially from lack of knowledge/competencies regarding dementia care. For example, they did not know to what extent they should listen to their parents' wishes. As a result, they experienced on-going negotiations between the role of a loving daughter who would like her parents to be happy and the role of a responsible daughter who knew that people with severe dementia demand special care, preferably provided by professional health workers. Kasia explained how she, as a daughter and carer, felt divided and insecure regarding how to respond to the needs expressed by her mother:

What is more important in that case? My mum's needs? Her happiness? Or my feeling of duty and common sense?

She said her mother warned her that she would commit suicide if she were moved to a nursing home. As a result, Kasia decided to organise hands-on care for the mother as long as she was able to stay at home. Kasia believed that it would be more morally acceptable to place the mother in a nursing home when she had no awareness of what was happening to her.

One of the biggest challenges for the participants was the progressive nature of dementia. They expressed worries about the future that caused stress in the present. Ursula and Kate, for example, worried that their parents may not recognise them next time they met. Ursula explained, "I don't know how fast the illness develops so maybe he doesn't remember me...". The future was full of uncertainties for most of the interviewed women. Inka did not want to think about the future "because it is not so encouraging". Like other study participants, Samira was aware that the family might be unable to provide care in the future. She explained that, "It is not about the money, but it is about having the capacity to look after her". Lack of knowledge about dementia and its development was reported by most participants, which was in line with previous studies. A systematic review reports the need for more information and knowledge about the diagnosis, progression and symptoms of dementia, health and behavioural problems related to dementia, methods of managing the care of the relatives with dementia, including medications and availability of care services (McCabe, You, & Tatangelo, 2016).

All participants said they provided care for their parents living with dementia during short visits to the country of origin. In that way they were able to contribute with hands-on care in periods, but, on the other hand, these periods became very demanding. Samira described her experiences related to providing hands-on care for her mother. When she visited two or three times a year, she replaced her sister, the main family carer:

It is so difficult (providing hands-on care) that I can go there maybe 2–3 times in a year. I stay there like 2–3 weeks. Even after 3 days I am exhausted... One day she knows who you are and another day she doesn't. It is very frustrating, very depressing.

Samira emphasised both the physical and the emotional burden, and



her statement illustrates the weight of informal care in dementia. She explained further how difficult it must have been for her sister to care for the mother every day. Samira was convinced that carers need support in order to be able to provide care and protect their own health. According to previous studies, family carers of people living with dementia report the need to address their own psychological and physical health (McCabe et al., 2016). Carers need both formal and informal care support to protect their own health. None of our participants was a member of any support group for carers. For most, however, providing intense care during the short visits was a very stressful and exhausting compensating practice as they were trying to make up for their absence.

## Conclusions

Family ideology travels across borders and providing care for the ones left behind is actively pursued by many migrants. Caring for parents across borders requires many sacrifices from migrants, especially women, who often have caring responsibilities in two countries.

State arrangements can create barriers or facilitate informal care across borders. In countries with un- or insufficiently-supported familialism, the families experience a considerable struggle to ensure proper care for their relatives. Ensuring such care is very challenging for transnational migrants, especially the ones who need to navigate within two different care regimes, characterised by different gendered roles and expectations layered by class statuses. Dementia rates have increased worldwide and spatial mobility is experienced by many families, so there is a need for social policies that seek to reduce existing systemic barriers to promote and facilitate transnational caring. Due to a lack of resources, such as language competence and education, some migrants may not be aware of their rights regarding the care for relatives in their country of origin. However, having knowledge about such entitlements may not be enough if their employers are not flexible and do not facilitate migrants' visits abroad in order to provide care.

Our findings illustrate how the intersection of gender, social and economic class, and the care regimes in the country of origin and the host country differentiates the challenges related to transnational caring. Some categories are mutually reinforcing. Low income single mothers coming from countries with familialistic care regimes may experience caring for an ageing parent with dementia in a significantly different way from women who have access to greater resources, come from countries characterised by supported familialism or defamilialisation, and have flexible jobs allowing them to work in different parts of the world and surplus income to do so. Relationship closeness is another important factor that shapes carers' experiences with transnational caring for people living with dementia. It influences the scope and forms of care and it affects carers' well-being. Our findings show that transnational caring for people living with dementia is nearly untenable even for better off women with flexible jobs and is a very trying experience regardless of the availability of state support.

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