

A typology of family caregiving for older immigrants: perspectives from care receivers and care providers

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Abstract

Purpose – As populations are ageing and the global average life expectancy is rising, the provision of care for older people is an increasingly salient issue. This paper aims to focus on family-provided care for older immigrants, examining how older immigrants and care providers experience and construct family caregiving.

Design/methodology/approach – Based on interviews with care recipients, family care providers, municipal staff and representatives for migrant organisations in Sweden, this study presents a typology of family caregiving for older immigrants.

Findings – The authors found three caregiving types, namely, solely family-provided care and a combination of family care and public care (predominantly one or the other). The decision to select family-provided or publicly-funded care depends on personal and institutional factors.

Originality/value – The paper makes three empirical contributions to the literature on care provision for older immigrants. Firstly, this study provides insights into the structural and personal factors that shape care-giving arrangements for older immigrants. Secondly, this study examines the perspectives of care recipients and care providers on family-provided care. Care expectations differ between both groups and sometimes result in intergenerational disagreement. Thirdly, in terms of institutional support, this study finds that the Swedish state's notion of individual needs does not match the needs of immigrant elderly and their caregivers. The paper places the care types in a broader discussion about eldercare provision in the Swedish welfare state, which has experienced a decline in publicly funded care services and an increase in family caregiving in the past 30 years. In addition, it addresses questions of dignified ageing from a minority perspective.

Keywords Sweden, Immigrant, Care provision, Family care, Older immigrants

Paper type Research paper

(Information about the authors can be found at the end of this article.)

Received 23 June 2022

Revised 31 July 2023

Accepted 19 March 2024

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The authors would like to thank all study participants who have shared their experiences with us. The authors also would like to thank the Syrian Organisation in Stockholm (Syriska föreningen i Stockholm), the Assyrian Cultural Centre in Botkyrka (Assyriska kulturcenter i Botkyrka), the Cooperation Organisation for Immigrant Associations in Uppsala (Samarbetsorganisationen för invandrarföreningar i Uppsala), Södertälje municipality and Uppsala municipality for their assistance with the research project. The project was funded by the Swedish Research Council for Health, Working Life and Welfare (project number: 2020-01555).

Introduction

Populations are ageing worldwide and global life expectancy continues to rise. Currently, one in six persons worldwide is aged 60 years or older. This ratio is projected to increase to one in five persons by 2050 due to declining fertility rates and increasing life expectancy (World Health Organization, 2020). A considerable proportion of older people has an immigrant background. In 2020, there were 34.3 million older immigrants worldwide, or 12.2% of the global population (United Nations Department of Economic and Social Affairs, 2020).

As the number of older people with an immigrant background is increasing, long-term care for this population is becoming an increasingly salient issue. Although previous studies have provided important insights into the factors that shape the decision to provide family-provided care, few scholars have examined institutional support for family-provided care, individual experiences with family-provided care and the care needs of care recipients and providers in one study. This article aims to integrate these perspectives to provide a more

in-depth understanding of the opportunities and challenges in family-provided care for older persons with an immigrant background. In particular, this article focuses on the understanding and practices of family caregiving, defined as the provision of practical and/or social care and support provided by family members. We examine family caregiving for older immigrants, both from the perspectives of caregivers and care recipients. We find that publicly provided services in Sweden do not meet the needs of the elderly with an immigrant background. This is in line with previous studies that have shown a lack of culturally sensitive and language-tailored services in publicly-provided eldercare in the USA (Han *et al.*, 2008), Canada (Stewart *et al.*, 2006) and elsewhere.

The study is situated in Sweden, a country that has experienced a decline in public funding for health-care services and an increase in family caregiving in the past three decades (Szebehely and Meagher, 2018; Andersson and Kvist, 2015). We address the following research questions:

RQ1. How do older immigrants and caregivers in Sweden experience family-provided and publicly-provided care?

RQ2. What institutional support do older immigrants and their family caregivers need?

These questions are explored through in-depth, semi-structured interviews with care recipients, care providers, municipal staff and representatives for migrant organisations.

The article makes three key empirical contributions to the existing literature. Firstly, we provide insights into the structural and personal factors that shape caregiving arrangements for older immigrants. Secondly, we examine the perspectives from both care recipients and care providers on family-provided care, thus providing a more in-depth understanding of care provision for older immigrants. Although scholarship on Sweden has focused on the care experiences of family caregivers with an immigrant background (Kiwi *et al.*, 2018; Forssell, 2004) and immigrant elderly (Heikkilä and Ekman, 2003; Torres, 2006; Hovde *et al.*, 2008), as far as we know no literature has examined the perspectives of both. We will show that the care expectations differ between both groups and sometimes result in intergenerational disagreement. In some instances, the disagreement can be the result of caregivers' acculturation to Swedish caregiving norms. Thirdly, in terms of institutional support, we argue that the Swedish state's attempts to meet individuals' needs do not take the needs of the immigrant elderly and their caregivers into account. As we will show in this article, immigrant elderly's Swedish language proficiency, food preferences, entertainment and social needs are not met by the municipalities' provision of eldercare services.

Based on interviews with care recipients, providers and representatives for municipalities and immigrant organisations in Sweden, the article presents a typology of family caregiving for older immigrants. It includes three types of family caregiving: solely provided family care, predominantly family-provided care and predominantly publicly provided care. The empirical section discusses the structural and individual factors that shape the usage of these three care types, as well as the institutional gaps in care provision for older immigrants.

In the following sections, we discuss family-provided eldercare in Sweden and introduce the research methods. Thereafter we present the research results and present a typology of family-provided care for elderly immigrants. We end with a conclusion.

Care provision for older immigrants

Previous studies have found that elderly immigrants often rely on their spouse, children and extended family as the main caregivers (Martineau and Plard, 2019). In addition, older immigrants in Sweden use public elderly care services, especially nursing homes, to a lesser extent than their Swedish-born counterparts (Songur, 2021). The choice of family-provided caregiving is shaped by structural and personal factors (Ajrouch, 2005; Tavernier

and Draulans, 2018; Andersson and Johansson, 2021). Among others, scholars have explained the higher prevalence of family-provided care among immigrants as filial duty, as children feel a responsibility to care for their ageing parents (Ahmad *et al.*, 2020; Lan, 2002; De Valk and Schans, 2008; Lee, 2007). However, norms and practices of filial care have changed over time, particularly the norm of co-residence (Lo and Russell, 2007; Sun, 2014). In addition, support programs and assistance services that are poorly suited for older immigrants, coupled with care professionals' narrow understanding of the needs of older immigrants, can deter elderly immigrants from seeking public care services (Andersson and Johansson, 2021; Johnstone and Kanitsaki, 2008).

Studies have also shown that a lack of information about public care services, (fear of) discrimination by care providers and social, civic and economic exclusion have hindered elderly immigrants from seeking formal care services (Beganovic, 2014; Tavernier and Draulans, 2018; Ajrouch, 2005). The tendency of immigrant families to choose family care over public care is, therefore, best understood as a consequence of prevailing relations between dominant and minority groups, rather than innate behaviour of minority groups (Hanlon, 2018). In addition, some older immigrants and their family members perceive family care as superior to professional care (Van Wezel *et al.*, 2016).

Although older persons with a migration background share basic care needs with native-born elderly, their care preferences are shaped by their migration experience. This is particularly the case in relation to preferences for food from their country of origin, a desire to share memories and traditions from the country of origin, and to speak one's mother tongue (Karl *et al.*, 2017). The standardised institutional settings of publicly provided care and nursing homes tend to disregard these needs (*ibid.*).

Welfare-state regimes determine the model of eldercare provision – whether eldercare is informal, unpaid or part of familial obligation (conservative), highly marketised (liberal) or sponsored or subsidised by the state (social democratic) (Esping-Andersen, 1990). The Nordic countries provide universal welfare services and allocate a high level of resources for formal care provision (Bettio and Plantenga, 2004). Recent studies, however, have criticised the increasing neoliberalisation of eldercare in Sweden and other Nordic countries, and the resulting deterioration of care (Andersson and Kvist, 2015). Cost-cutting measures in public social services result in increasing privatised paid care, as well as care provision by relatives (Szebehely and Meagher, 2018; Gavanas, 2013). Municipal and regional social policies, as well as personal situations, socioeconomic opportunities, and needs influence how the elderly and their families seek and receive eldercare. In the next section, we discuss the institutional framework for eldercare in Sweden.

Sweden has a social democratic welfare model that aims to provide universal welfare services to all residents. The Swedish welfare model aims to provide “equal access to services and [...] inclusiveness of the care service system, meaning that all people, in principle, use the same services and are treated in the same way in similar care situations” (Anttonen and Karsio, 2017, p. 220). Scholars, however, have argued that universalism in the Swedish welfare regime has weakened over the last decades, including a decline in public care services, an increase in family caregiving and an increase in individual expenses for private services (Andersson and Kvist, 2015; Anttonen and Karsio, 2017; Szebehely and Meagher, 2018). A Swedish study showed that family care (often provided by daughters) was more common among families with less education, while privately purchased care services (often financed by sons) were more common among the higher educated (Ulmanen and Szebehely, 2015). Thus, working-class and lower-educated daughters were affected most by the decline in public care services for older people.

Since 2009, older persons and their family members have more freedom to choose care providers (Andersson and Kvist, 2015). Municipalities can decide if they allow private and for-profit companies to employ family caregivers, also called next-of-kin employment

(Brodin, 2018). In some municipalities, family caregivers can be paid for their services. In those cases, caregiver companies hire them and oversee the caregiving arrangement. The employment of family caregivers has been criticised because it is associated with low wages, weak social security, lack of formal training and lack of evaluation of the quality of care services (Brodin, 2018). A study in Stockholm found that the majority of employed family caregivers are immigrant women coming primarily from non-European countries (Brodin, 2018). The option of next-of-kin employment is therefore possibly at the expense of female family caregivers.

Some municipalities offer financial support, usually maximum of 4,000 Swedish crowns (approximately €400) per month. Data about employment of family carers and family financial support is unavailable, although the Swedish National Board of Health and Welfare and the Swedish Family Care Competence Centre estimate that the majority of economic compensation recipients are immigrants (Forssell *et al.*, 2014). The prevalence of immigrants among recipients of economic compensation reflects the difficulties faced by immigrants to enter the Swedish labour market.

In addition to economic compensation, some municipalities offer psychological support to family caregivers, such as counselling with trained professionals, a hotline for family caregivers or group support. Some also offer temporary respite care services, which enable family caregivers to recuperate or pursue their own activities. Temporary respite care services are only offered to main caregivers for older people. Psychological support and temporary respite care services are usually provided in Swedish, which may pose a linguistic barrier for immigrants.

Culturally sensitive care services can mitigate cultural-linguistic challenges in public care provision for older immigrants (Jönson *et al.*, 2018; Hadziabdic and Hjelm, 2020). In some municipalities, older immigrants can receive home care services in their native language. On the one hand, the provision of culturally sensitive care services can be a relief for family carers, and have a positive impact on the health and well-being of older immigrants (Kiwi *et al.*, 2018). On the other hand, international studies have warned about problematic implementation of culturally-specific care provision, such as inherent cultural racism in this type of provision and dismissal of structural problems by reframing these services as a lifestyle choice (Johnstone and Kanitsaki, 2008; Jönson *et al.*, 2018).

Methods

The authors obtained approval from the Swedish Ethical Review Authority to conduct the research. The first author conducted semi-structured interviews with caregivers, care recipients, municipal staff and migrant organisation representatives (total $n = 35$) and a group interview with 30 visitors in a senior day centre, between February and November 2021. Caregivers and care recipients were main informants in this study. Municipal personnel and migrant organisation representations helped in putting the first author in contact with potential participants and provided background information about available publicly-funded and community-based care services. The participants were recruited in the greater Stockholm and Uppsala area. These regions were selected due to their large immigrant populations. The interviews were conducted either in person or by telephone, lasting between 25 and 80 min. Most interviews were conducted in Swedish, and migrant organisation representatives assisted in translating for participants who did not speak Swedish.

The interviews addressed the following topics:

- types and reasons for family care provision;
- caregiving support from municipal social services;
- experiences with and opinions about family care provision;

- challenges of family care provision; and
- institutional support needs.

The interviews were recorded digitally after obtaining informed consent and summarised. More detailed summaries were written for two unrecorded phone interviews. The first author translated the interview responses into English. We use pseudonyms to protect the identity of the interviewees.

The first author created the typology of family care as follows: Firstly, the interview data were sorted by whether or not study participants provided or received family and/or municipal care services, and to which extent. This analysis resulted in three types of care. Secondly, the author categorised reasons for family care, support from municipal services and institutional support needs under these three types. Thirdly, the author analysed participants' personal experiences to illustrate each of the three care types.

There are three limitations in this study. Firstly, the older people in the study were in relatively good health and managed their everyday activities with no or little help from publicly funded service providers. They need less care than older people with complex health conditions, such as people living with dementia. Secondly, we only recruited informants who used or provided family care. Thus, we did not collect information about older immigrants who used solely public care. Thirdly, it may be possible that the presence of representatives for migrant organisations or municipalities who translated in group interviews could affect the answers of participants. Nevertheless, the presence of these representatives was necessary to build trust between the researcher and study participants.

Interview sample description

In this section we will describe the study participants' sociodemographic background, care role and the type of care received or provided. The first author interviewed 35 informants, comprising of care recipients ($n = 12$), caregivers ($n = 19$) and municipal staff and migrant organisation representatives ($n = 10$). Four participants were both caregivers and care recipients. Two participants worked as municipal staff and were also caregivers. For these six participants, we counted their roles individually.

Out of the 26 interviewed care recipients and caregivers, 22 were female and four were male. Three of the interviewed men were caregivers. Thus, care recipients and caregivers were predominantly women. The age of the caregivers in the study ranged from early 30s to mid-80s, whereas the age of the care recipients ranged from mid-60s to mid-80s. The participants came from Iran ($n = 12$), Finland ($n = 4$), Iraq ($n = 5$), Syria ($n = 1$), Turkey ($n = 2$), Angola ($n = 1$) and Spain ($n = 1$). Seven caregivers lived together with the care recipients, and five of them took care of their husbands. Eleven caregivers lived in the same city as the care recipient. Seven care recipients had at least one child who lived in the same city.

A group interview was conducted during an information day in an Arabic-speaking senior day centre organised by a migrant organisation. Two-thirds of the participants were female. The age of the participants ranged from early 60s to late 70s. Due to the group setting, we were unable to collect the country of origin and family care arrangements for each participant. The group members discussed family care and publicly funded service provision.

Sixteen participants received or provided family care as the sole form of care provision. Five participants had family care at first, and then received home care service or moved to a nursing home when their health condition had deteriorated or when the family caregivers' life situation had changed. One caregiver took over the care for his mother due to a lack of safety equipment for municipal caregivers at the beginning of the COVID-19 pandemic. The

remainder received primarily home care services from the municipality, in combination with family care; or, they lived alone and received social support from their family members.

Family caregivers in the study tend to assist older relatives with everyday tasks, such as cleaning the apartment, buying groceries, cooking and accompanying older relatives to doctor appointments and social and religious activities. Living arrangements and geographical proximity between care recipient and caregiver can affect the degree of support from family caregivers. Whether or not care recipients receive public care services, and to which extent, also influence the care they receive from the family. The type of family caregiving in turn affects the care recipients' and caregivers' needs for institutional support. In the next section, we will present the typology of family caregiving based on the interview data.

A typology of family caregiving for older immigrants

We identify three types of family caregiving:

1. family caregiving as the sole form of care provision;
2. receiving public home care services, but relying heavily on family care; and
3. receiving primarily publicly funded care, with limited family care.

These categories, however, should be seen as fluid, rather than fixed. As we noted earlier, family caregiving arrangements may change as the conditions of care recipients and/or caregivers change. [Table 1](#) provides a summary of these three types of family care provision. In addition to these three types of family caregiving, a smaller number of older immigrants in this study lived alone and did not receive day-to-day family caregiving or public home care services. Their family members provided only social support. Because they primarily managed everyday tasks by themselves, we have excluded them from the typology of family caregiving but we do present their perspectives as this is a salient form of support for older persons with an immigrant background.

Table 1 A typology of family care

<i>Perspective</i>	<i>Care type</i>		
	<i>Solely family-provided care</i>	<i>Combination of family care and publicly funded care</i>	
		<i>Predominantly family-provided care</i>	<i>Predominantly publicly-provided care</i>
Personal experiences of family care	<ul style="list-style-type: none"> ■ Culture and traditions: <ul style="list-style-type: none"> – Expectation of reciprocity ■ Lack of trust in public care: <ul style="list-style-type: none"> – Care provided by strangers ■ Dissatisfaction with public care ■ Geographical proximity: <ul style="list-style-type: none"> – Co-residence or – The one who lives the closest usually provides most care – Relocation when necessary 	<ul style="list-style-type: none"> ■ Family caregivers perform tasks that are not covered by home care services ■ Insufficient home care ■ Geographical proximity: at least one relative living nearby provides care 	<ul style="list-style-type: none"> ■ Do not want to burden their children ■ Need more care than the family caregivers can provide ■ Family caregivers are not care professionals ■ Family care is provided once in a while ■ Geographical proximity: relatives live nearby or far away
Needs for institutional support	For family caregivers: <ul style="list-style-type: none"> – Information about available support – Financial support – Support after a relative has passed away 	For family caregivers: <ul style="list-style-type: none"> – Financial support for family members who perform most care work – More task flexibility for home care staff 	For care recipients: <ul style="list-style-type: none"> – Publicly funded care services in their native language, familiar food and entertainment in their native language

Source: Table by authors

In this section, we will present the results and analyses of the three types of family caregiving. We will thereafter present the findings about the role of family caregivers as solely social support.

Type 1: family caregiving as the sole form of care provision

The majority of the interviewees received or provided solely family care. From the caregivers' perspective, caring for older relatives was part of their culture, as has been found in previous studies (De Valk and Schans, 2008; Herat-Gunaratne *et al.*, 2020). Tahani (caregiver) reasoned that respect and care for older family members were part of the cultural values she grew up with in Iraq, and therefore she considered it as natural to take care of older parents:

I think for us it's a natural thing. We don't take it as: 'Oh, I have to throw away my life to take care of [my older parents].' It's just part of our culture. We perceive it as we are obligated to do. They are our family.

Caregiving for older parents may also be an expression of gratitude for the care that the parents had provided in the past. Soraya's (caregiver) mother moved from Iran to Sweden to help her with childcare years ago. In return, she takes care of her mother now:

I was the one who came [to Sweden] first. It was a long time ago. When [my mother] visited us, the children were small. She was very young then. She decided to take care of my children. She actually stayed for my sake.

Soraya appreciated that her mother moved and stayed in Sweden for her and her children. She took care of her mother to reciprocate the care given by her mother to her children. Care among immigrant families is, therefore, best described as *circulating* – to be given and returned – in the families across generations over time, and sometimes at multiple sites as immigrant families relocate to a new place (Baldassar and Merla, 2013).

Some caregivers noted that the cultural values of caring for older relatives among immigrant families are better compared to native Swedes. Yusuf (caregiver) said that even after his mother moved into a nursing home, he and his brothers still visited her every day. During their visits, they even socialised with other (non-immigrant) residents:

There were many [residents] who did not have anyone who visited them. When they saw us, we became friends. [...] We helped as much as we could, so not only [helping] my mother.

Family caregivers, including Yusuf, may feel a sense of pride from providing care for sick and older relatives, as well as a feeling of moral superiority over non-caregiving family members (Ahmad *et al.*, 2020).

Caregivers may have conflicted feelings about family caregiving when they imagine themselves as future care recipients. Ava (caregiver) and her sister faced challenges in balancing everyday life, work and caring for their older mother because she refused public home care assistance. Based on this experience, Ava is open to receiving home care services when she can no longer manage by herself. Ava's view is an example of immigrants' cultural acculturation regarding caregiving. Changes in family caregiving practices may happen as a result of immigrants' cultural acculturation in the country of residence (Wong *et al.*, 2006; De Valk and Schans, 2008). Difficulty in balancing caregiving and everyday life, limited social support from the extended family as a result of migration and the availability of public care may cause caregivers to reduce or withdraw from family caregiving as the only form of care.

Lack of trust in public care can also be a reason why family caregiving is preferred over public care. Some participants viewed public care as receiving care from strangers. The presence of care workers in the home could be experienced as a delicate situation, in

contrast with a feeling of familiarity and safety from receiving family care (group interview). Tahani (caregiver) explained that her family opted for family caregiving for their sick grandmother because they could not trust if a care worker, who was a stranger to them, would do the job properly. Concerns about receiving care from a stranger at home are understandable because home is a private place and laden with family values (Milligan and Tarrant, 2018). The act of receiving and giving care entails a complex negotiation of trust and disclosing vulnerabilities (Conradson, 2003). For Tahani and her family, it was difficult to trust a non-family member to take care of a loved one. When public care does not meet the expectations of family members, they may take over caregiving duties for older relatives. Caleb (caregiver) decided to discontinue the public home care services for his mother because the worker did not take necessary health and safety precautions at the beginning of the COVID-19 outbreak. In these examples, family caregiving was thus preferred due to lack of trust and dissatisfaction with the quality of public care. While concerns about receiving care from a stranger at home and dissatisfaction with public care are not exclusive for immigrant families, differences in the philosophy of care between immigrant families and the receiving country's general elderly care system may become a strong motivation for family care provision (Han *et al.*, 2008; Weng and Nguyen, 2011).

Regular provision of care requires bodily proximity. In the context of family caregiving, this requires geographical proximity between care recipients and caregivers. Those who receive and provide solely family care usually either live together or live in the same or an adjacent apartment building. If they do not co-reside, the family member or relative who lives the closest to the care recipient provides the most care. Anneli (caregiver), for instance, took care of her former husband when his health condition deteriorated because his daughter from another marriage lived far away. The caregiver or care recipient may relocate if they live far away and family caregiving is preferred. When his father became ill, Hamza (caregiver) took care of him because they lived in the same city. When Hamza was no longer able to balance work and caregiving, he moved his father to another city so that Hamza's sister could take over. When family caregiving is the sole form of care provision, co-residence, adjacent living or relocation may be necessary to ensure regular provision of care.

Type 2: receiving public home care services, but relying heavily on family care

Municipalities offer social services for older people so that they can continue living a dignified life at home. The services include meals-on-wheels, cleaning, laundry services, assistance with personal hygiene (such as bathing and going to the toilet), transportation services and a safety alarm. The types of services, length and frequency are based on individual needs. We found that older people who received home care services combined these with family care to a varying extent. Participants who received home care services reported a division of care between home care workers and family members. Leila (caregiver), for instance, usually wrote down instructions and a to-do list for home care workers who assisted her mother. Family members helped older people with tasks that were not covered by home help services, such as accompanying them to doctor appointments or religious services. In this way, family care and public care complement each other. However, unclear boundaries of care work between home care workers and family caregivers can cause a strain on the provision of care for older people (Abrams *et al.*, 2019). Mona (caregiver) expressed her frustration regarding this issue:

For example, my mother-in-law had heart palpitations. [The home care worker] called us when they were supposed to call an ambulance. Why did you call us?! You are the home care worker! So I had to go there quickly. I told my husband that it became more work for me than before [when she was the sole carer].

In some cases, family caregivers performed most care work as they felt that home care services were insufficient. Jasmin (caregiver) noted that her disabled husband received

only two hours of home care services per day. She estimated that she carried out about 80% of the care work at home. Anneli (caregiver), who took care of her sick former husband, picked up the slack when the home care worker was not around, such as reminding her former husband to eat, tidying up at home or letting the nurse in during home visits. Mona reported that home care workers often had to call her during home visits and ask her to communicate with the care recipient due to language barriers:

My problem with [public] home care services is that they send someone who cannot speak her [mother-in-law] language. Then they would call and ask, 'Please, can you translate?' It is demanding.

Language barriers can create challenges in communication between care recipients and formal care providers. When care recipients and public care providers do not share the same language, the responsibility to facilitate communication falls on family caregivers.

In addition to cultural distance in the form of language barriers, some older immigrants did not like Swedish food. Three caregivers reported that they still cooked for older relatives because the food cooked by home care workers or meals-on-wheel food was unfamiliar to them. As Hamza shared:

They [Hamza's mother and father] did not accept the meals-on-wheels food. They refused to eat the food because it was far from our food culture. So, I had to either bring food home to them or I sometimes cooked for them.

The cultural importance of food for older immigrants is sometimes overlooked by public care providers as they cater to the general population (Herat-Gunaratne *et al.*, 2020). When meals that older immigrants receive as part of publicly funded care services differ from their "food culture", as Hamza put it, family caregivers prepare meals.

As we have seen here, family caregivers continue to play an important role in the care provision for older immigrants, rather than simply complementing the provision of municipal home care services. The reliance on family caregiving, despite receiving public care services, can be a result of insufficient allocation of public care services as well as language barriers and food preferences.

Some older immigrants lack information about rules and regulations about public elderly care provision, which may negatively affect the care that they receive. Participants in the group interview were unaware that they should notify the social services administrator if their health conditions had deteriorated. If they fail to do so, a municipally-funded home care provider may not be able to perform all necessary tasks in the allotted time frame, and family members may take on caregiving responsibilities beyond their capabilities.

Type 3: receiving primarily publicly funded care, with limited family care

In this type, care recipients received primarily public care, whereas family care is received to a lesser extent and less frequently than solely-provided family care. Participants in the group interview did not want to burden their children, especially if they lived far away. In these cases, publicly funded care provision can facilitate older people's wish for independence and unburdening their children (Ajrouch, 2005).

When the needs of care recipients exceed the ability and capacity of family caregivers, public care is sometimes necessary. The decision to change the form of care provision can be difficult for both the care recipient and the caregiver as it involves a negotiation of cultural practices of care (Kiwi *et al.*, 2018). Hamzah (caregiver) and his sister had a disagreement with their father about moving him into a nursing home, after no longer able to provide adequate care at home. They tried to recreate the familiarity of home in the nursing home by decorating the place with familiar furniture and photographs, but he still disapproved and they became estranged from their father. Hamzah regretted that they were unable to make amends with their father before he passed away. Physical and psychological exhaustion from caring for sick elderly relatives, along with a

lack of support from the extended family as a consequence of migration, may also cause caregivers to give up caregiving at home (Kivi *et al.*, 2018). The inability to provide necessary care, despite a wish to care for sick elderly relatives, can create a rift in intergenerational family relationships and cause caregivers to feel inadequate.

One participant (Farah) was strongly against family care because family members were not trained professionals. She had worked as a manager for private companies that employed family caregivers and for companies that provided home care. Based on her experiences as a manager, she argued that older people who received home care services were happy to meet and interact with people outside the family circle. When her mother became ill, she employed a home care worker to take care of her mother. She visited her mother only when the worker was not there. This provides another nuance in the choice between public care and family care. Farah's opinion was based on years of experience working in the care industry. She learned that care should be provided by professionals, rather than family members. Three participants, meanwhile, took over care responsibilities precisely because they had worked as nurse assistants or home care workers. This suggests that previous experience as care workers and care managers may contribute to the decision to select family care or public care, including the decision about who will provide the care.

Solely social support provided by family members

Older people who are in fairly good health do not need family caregiving or public care services to manage their everyday lives. Four older participants in the study reported that they generally managed everyday tasks by themselves. Family members primarily provided social support. Emilia (care recipient), for instance, was 80 years old and had arthritis in her hand, but she did not need home care service. She cooked for herself, kept her home clean and kept socially active by participating in local migrant organisation and church choir. She viewed that she managed quite well by herself. Her daughter who lived in the same city called her regularly and visited her occasionally.

Unlike public places, the home represents a place where older people can have greater control and independence, as well as a place to nurture their self and identity (Milligan and Tarrant, 2018). The ability to manage everyday by themselves, without or with limited support from the family, can enhance older people's sense of independence, which can contribute positively to their well-being. However, without the physical presence of family members daily, regular communication via telephone with their families became important for some older people in this study. For example, Daniela's (care recipient) daughter lived in another city, but she talked with her daughter every day by phone. To be active socially in immigrant organisations, senior day centres and religious communities was another way for older immigrants to reduce loneliness.

As we mentioned earlier, older immigrants may move from one care category to another over time. Although Emilia and Daniela are able to take care of themselves at this time, it is likely that they will move into category 1, 2 or 3 if their health deteriorates. Or they may seek solely publicly provided care, depending on their personal situation.

Needs for publicly funded support for family caregivers and care recipients

The Swedish Social Services Act stipulates that municipalities should offer support to care recipients and informal caregivers. Municipalities, however, have the authority to decide on the types of support they offer, such as financial support, individual counselling, support groups and temporary respite care services. We found that support for caregivers was needed most when family caregiving was the sole form of care provision; nevertheless, limited information about available support can hinder family carers from seeking support. In Table 1 we summarise the different needs for institutional support based on the types of family caregiving.

Financial support for family caregivers was often brought up by care recipients and caregivers when we asked about support that was needed. The financial support would compensate for caregivers' time and effort, such as cooking older immigrants' favourite meals. Some municipalities that offer financial support, discontinue the support if a care recipient receives home care services from the municipality. Mona (caregiver), who had taken care of her sick mother-in-law for years, said that she could no longer receive financial support after her mother-in-law received home care services. She, however, continued to do almost the same care work as before, including giving insulin shots, with the exception of cleaning the apartment and washing the dishes, tasks performed by a home care worker. She wished that the municipality could still provide financial support as she continued to take care of her mother-in-law. Financial compensation, however, ignores structural challenges faced by immigrant families, as a higher percentage of women with an immigrant background as family carers to older people may be a result of their exclusion in the Swedish labour market (Forssell *et al.*, 2014; Brodin, 2018). For some caregivers, financial compensation makes it difficult to find flexible work that allows them to care for older family members.

Caregivers often mentioned that it was difficult to balance informal care, paid work and their own lives. Lack of time for self-care could lead to stress among family carers. For Gabriela (caregiver), whose work involved providing support for older people, it could be emotionally draining to care for her mother at home. Most participants in the study had limited information about available support for caregivers offered by municipalities. Only three caregivers were aware of these services and none had sought support from municipal services.

Although some care providers in the greater Stockholm and Uppsala area offer care provision in the native language of care recipients, this option is limited in the support for family carers. Ava (caregiver), for instance, asked the municipality about temporary respite care services. She was informed that the municipality did not have staff who could speak the native language of her mother, so she decided not to request the service. Temporary respite care can give primary caregivers a chance to recover and pursue their own activities. A concern about leaving a relative with someone who does not speak the language can prevent caregivers from seeking this type of support and can affect their own social life.

Johanna (caregiver), who was a Swedish Finn, experienced that the support for family caregivers after the care recipient has passed away is limited. She needed psychological support the most after her husband whom she took care of had passed away. Rather than receiving psychological support from the municipality, she received it from a Finnish group and a Finnish-speaking church community. This indicates a gap in the support for caregivers offered by municipalities, as well as the importance of ethnic and religious groups in supporting immigrant family caregivers.

Caleb (caregiver), whose mother used to receive home care services, wished that home care workers could be more flexible. He gave an example where the worker refused to help put away dirty cups because it was not his job. From the family caregiver's perspective, the flexibility of formal care workers in carrying out their tasks can help reduce the burden of the family carer. However, as formal care workers are already under time pressure for doing their job (Meagher *et al.*, 2016), they may not have time to go beyond the assigned tasks.

When we asked the care recipients what institutional support they needed, they requested public care services in a language they understood, cultural activities and familiar food. Although she was still able to manage everyday by herself, Emilia (care recipient) thought about the time when she would need more support. The municipality where she lived had a Finnish-speaking nursing home, but she worried that demand would increase due to the rise of Finnish-speaking elderly.¹ She wished for more Finnish-speaking nursing homes and for workers who can speak her native language. Reflecting on his father's situation in the nursing home, Hamza (caregiver) wished that the nursing home could provide television channels in the language his father understood and offer familiar food once in a while. As immigrants

comprise 20% of the Swedish population [[Statistics Sweden \(SCB\), 2020](#)], this creates a large demand for ethnic-specific care provision. Diversity within the immigrant population, however, complicates the fulfilment of this demand. One care recipient, for instance, argued that Finns used to be the biggest immigrant group in Sweden, but now there are various groups and the municipal resources have become divided. Ethnic-specific care provision and the possibility to employ family carers were mentioned as alternatives in the interviews. When the public care system is unable to provide acceptable care services, family caregivers bear the responsibility to provide alternatives ([Herat-Gunaratne et al., 2020](#)).

Conclusion

The typology of family caregiving that we have presented in this article showcases different care constellations for immigrant elderly. The choice of care type depends on personal circumstances and preferences (geographical proximity to family members, ability and desire to provide care, cultural preferences) and institutional factors (dissatisfaction with publicly provided care services, preference for care provision by care professionals). These factors combined shape the decision of care recipients and family members to select a particular type of care.

Care needs of immigrant elderly are similar to native-born elderly. Loneliness, a lack of flexibility in homecare workers' tasks, concerns about the lack of protective equipment during the COVID-19 pandemic and dissatisfaction with the quality of publicly-provided care are common challenges in eldercare. Some of the factors, however, are specific for elderly with an immigrant background. The expectation of filial care, the need for information and services in the native language of immigrant elderly and a desire for culturally specific food and entertainment indicate that immigrant elderly have specific care needs. When these needs are not met by the institutionalised health-care system, elderly immigrants and their family members may prefer family-provided care. In addition, family members may deem family care of better quality than publicly provided care.

In this study, we have identified several needs for institutional support that family caregivers and care recipients observed. They either deemed that this support was missing or insufficient in publicly provided services, and they felt that they needed this support to provide or receive family-provided care. Institutional support for family caregivers, such as information about available publicly funded support and financial compensation, is needed by family caregivers who provide sole care or partial care for older family members (types 1 and 2). Meanwhile, institutional support for care recipients, such as culturally-specific information and services, is needed by older immigrants who receive primarily publicly-provided care (type 3).

Care provision for elderly immigrants is a particularly salient issue in the Swedish welfare state. Although the state aims to provide universal welfare services for all its residents, it is evident that it is not succeeding. With the decline in funding for public services, including eldercare services, family members are filling the care gap. Although municipal agencies offer services to alleviate the care burden for family members, some immigrant caregivers and care recipients are not aware of these opportunities due to language barriers or limited dissemination of information. These issues show the importance of culturally- and linguistically-tailored health and social services for elderly immigrants ([Han et al., 2008](#); [Stewart et al., 2006](#)).

Note

1. Swedish Finns are a national minority in Sweden, along with Sámi, Tornedalers, Roma and Jews. The Swedish government's minority policy ensures that members of these groups can use their languages in public and private settings. Some nursing homes have Finnish-speaking staff, they serve culturally appropriate food and celebrate national holidays ([Hadziabdic and Hjelm, 2020](#)).

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