



Between Care and Contract: Aging Muslim Immigrants, Self-appointed Helpers and Ambiguous Belonging in the Danish Welfare State

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Abstract

In Europe, a growing population of older adults are immigrants from outside Europe and the Anglo-Saxon countries. Often, elderly care arrangements in these families are different from those of the majority populations. In Denmark, a growing number of immigrant families utilize an option in the Social Service Act, under which municipalities can employ a relative to take care of an older family member at home. Due to the special construction of this 'self-appointed helper arrangement,' the caregiver is both a professional care worker, formally employed by the municipality, and a close relative. As such, the arrangement provides a unique opportunity to examine ideas and practices of care at the intersection between the immigrant family and the state. Based on data from interviews and observations among immigrant families (primarily the older adult and the self-appointed helper) and municipal care managers, we explore the consequences of this care scheme for the families, especially the self-appointed helpers. Drawing on the concept of 'lenticular subject positions,' we show how self-appointed helpers in immigrant families and municipal care managers each adopt two different, often contradictory, perspectives or subject positions simultaneously. We argue that the self-appointed helper arrangement constitutes a gray zone in the Danish public health care system, since both care managers and helpers seem to neglect the national legislation and standard procedures concerning public elderly care and care work environment. The consequences are most severe for the self-appointed helpers who end up being in the precarious margins of the Danish labor market.

Keywords: : Care, Aging, Welfare state, Lenticular subject position, Immigrant family, Care manager, Denmark.

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Between Care and Contract: Aging Muslim Immigrants, Self-appointed Helpers and Ambiguous Belonging in the Danish Welfare State¹

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Shirin² is a 39-year-old woman employed by the municipality to take care of her sick 78-year-old mother, Minal. Together with the rest of their family, Minal and Shirin came to Denmark as refugees from the Middle East decades ago. Due to a brain hemorrhage in 2012, Minal is partly paralyzed, unable to speak, and needs care around the clock. Shirin was a student when her mother fell seriously ill. Divorced with no children, she decided to move into her mother's apartment to be available to help her at all times. A municipal caseworker suggested that she could be employed as her mother's self-appointed helper. Since then, Minal's health has deteriorated. Shirin currently works 21 hours a week all year round. Apart from cleaning, her tasks include changing Minal's diapers, attending to her personal hygiene and nutrition, and lifting and moving her around the apartment. When Shirin is not carrying out the duties prescribed in her job contract, she remains an affectionate daughter who cares for her ailing mother.

In this article, we examine care arrangements like the one between Shirin and Minal. These "self-appointed helper arrangements" (in Danish, *selvudpeget hjælperordninger*) are set out in section 94 of the Social Services Act, under which an older adult in need of care can "appoint" a family member who is then employed by the municipality to take care of the person at home (Serviceloven 2019). Originally added in the late 1990s, section 94 was intended for the few older adults who had difficulties cooperating with local homecare units.³ However, our data shows that in major cities, the self-appointed helper arrangement is now used primarily by older immigrants, and their helpers tend to be women, such as wives, daughters, or daughters-in-law.

The number of older immigrants who have been in Denmark for decades is increasing dramatically. In 1990, the number of immigrants in Denmark from outside Europe and the Anglo-Saxon countries above the age of 60 was 4,500 (Ældreforum 2013). As of April 2021, it is approximately 45,400 and according to prognoses, the number of older immigrants are expected to reach approximately 90,000 in 2030 and 132,000 in 2040 (Statistics Denmark 2021). Many, like the families in our study, are refugees and labour migrants from Muslim majority countries, such as Pakistan, Turkey, Somalia, Iraq and Lebanon. Like Minal, older immigrants often do not make use of homecare services or nursing homes provided by the Danish welfare state (Mølgaard and Lindblad 1995; Mian 2007; Wivel 2012). Instead, cultural traditions and religious obligations encourage most families to take care of their older family members at home. Many older immigrants, especially women, may have problems speaking and understanding Danish, and in general, they often find it embarrassing and consider it a failure if their adult children do not take care of them (Ismail 2021; Rytter *et al.* 2021).

The self-appointed helper arrangement thus provides an option for elderly care in these families as well as a unique opportunity for researchers to examine ideas and practices of care at the intersection of the immigrant family and the state. In order to understand the arrangement in its complexity, including

consequences on users' care relations, we include the perspectives of both the self-appointed helpers in the families and the care managers (*visitatorer*) in the municipal elderly care administration.

Overall, we argue that self-appointed helpers and care managers each adopt two different, often contradictory, perspectives or subject positions simultaneously. As the short introduction of Shirin and Minal suggests, it is far from easy to navigate the roles and expectations of being both the caring daughter and the self-appointed helper employed by the municipality, and between the private domain of the family and the public domain of the welfare state. But also care managers sometimes struggle to balance their roles and responsibilities. While most care managers have a background as nurses, their primary responsibility as care managers is to assess older citizens' needs and make decisions about what specific services they can receive. Hence, just as the self-appointed helpers are both family members and employees at the municipality, care managers are both representatives of the municipal administration subjected to legislation and organizational prerequisites, *and* trained as caregivers in the health sector.

Inspired by Ghassan Hage's discussion of 'lenticularity' (Hage 2015; Sparre and Galal 2018), we suggest the concept of 'lenticular subject positions' to capture the complex subject positions of self-appointed helpers and care managers. Hage (2015) introduced the concept of lenticularity as a way to understand the ways that migrants embedded in transnational social fields often inhabit and are engaged in a 'here' and a 'there' (Levitt and Glick Schiller 2004). Like for Hage (2015), our use of the concept is also inspired by the lenticular printing method, which makes it possible to show a set of alternate images that may appear to transform into each other. To grasp 'lenticularity,' you may think of the kind of rulers with colorful pictures sold in many tourist shops: when you move it up and down, you will see a picture in motion, e.g., a dolphin jumping above the water surface or the Queen of England waving at you (just to give two random examples). The figure-ground of the picture changes depending on how the viewer is holding the ruler. By introducing the idea of 'lenticular subject positions,' we suggest a way to understand how both self-appointed helpers and care managers can (and have to) step in and out of different, and to some extent contradictory, frameworks that offer specific rationalities, logics, plots, and perspectives. The self-appointed helper is both a caring family member and an employed care worker, and the care manager is both a bureaucrat who insists on following the rules and someone who looks for pragmatic solutions to support care arrangements in immigrant families.

As we will show, the lenticular subject positions of both the self-appointed helpers and the care managers are at the same time a result of and a precondition for making the care arrangement work. However, the arrangement also creates a situation where both care managers and helpers end up disregarding rules and legislations. In practice, the arrangement is a gray zone in public health care and welfare administration in Denmark. Care managers and helpers often enter into a kind of 'silence agreement,' where they overlook legislation and standard procedures. The consequences are most severe for self-appointed helpers who are subjected to a particular kind of 'precarious inclusion' in the labor market. For example, they receive very little further training, are not entitled to retirement benefits, and have no job security. This is similar to what has also been identified and discussed concerning undocumented migrants in the health sector (Karlsen 2015) and refugees in contemporary integration programs (Jørgensen and Shapiro 2019; Rytter and Ghandchi 2020). The helpers are promised inclusion in the form of formal contracts with the municipality, but in practice, the care arrangement tends to result in further exclusion, vulnerability, and marginalization within the Danish welfare state.

Data collection and research strategies

This article is based on data from our research project, *Aging Immigrants and Self-Appointed Helpers Arrangement (AISHA, 2017-2021)*, which explores implications of the self-appointed helper arrangement from the perspective of both immigrant families and Danish municipalities.⁴ The study is designed as a collaboration between a group of researchers and two Danish municipalities. The authors and the rest of the research group have conducted ethnographic interviews and participant observations among care managers in the municipal elderly care sector and in immigrant families with a self-appointed helper. The focus is on Turkish and Pakistani immigrant families that, for the most part, came to Denmark as labor migrants in the late 1960s and 1970s and Arab families that came as refugees in the 1990s and 2000s (cf. Rytter 2013; Liversage and Jakobsen 2016; Pedersen 2014).

The data sample consists of interviews with 30 older adults and their self-appointed helpers. In this paper, we focus primarily on two cases: the case of 39-year-old Shirin and her 78-year-old mother, Minal, and the case of 55-year-old Fatima and her 92-year-old husband, Emin. We focus on these two cases because they are diverse among our family studies. Specifically, with their different care relationships (daughter-mother and wife-husband, respectively) and the differences in the needs and abilities of the older family members. Our data on these two families was governed by the health status of the older adult and the care resources. In many cases, as in the case of Fatima and Emin, we visited and interviewed both the older adult and the helper several times over a period of approximately six months; while in others, such as the case of Shirin and Minal, we only had access to the helper. In addition, we talked to and interviewed over 40 care managers in different Danish municipalities, and we followed some of them in their work as 'street-level bureaucrats' (Lipsky 1980) in their encounters with immigrant families. Below, we meet Vibeke, Anna, and Lene, who are among the care managers we followed for the duration of our fieldwork and conducted several interviews and observations of their work practice.

Finally, the data set includes a series of workshops in Copenhagen and Aarhus where we invited care managers and self-appointed helpers across Danish municipalities to discuss our initial findings and possible solutions to improve the section 94 arrangement.

Focusing on everyday care routines, we explore the lenticular subject positions of the self-appointed helpers and how they navigate between being caring daughters or wives and employed care workers. Along the way, we introduce the ambiguous position of care managers and how they do their best to administer the section 94 arrangement in a way that is meaningful to them. We end by discussing the implications of precarious inclusion and ambiguous belonging of self-appointed helpers in immigrant families in the Danish welfare state.

Care and belonging across state-kinship relations

Anthropological studies of care tend to focus either on the dyadic relation between state and citizen (Mol 2008; Rinker, Bataille, and Ortiz 2020), or on kinship and practices within families, more or less detached from discussions of the state (Thelen and Alber 2018; Thelen and Coe 2019). Care has been discussed as particular forms of work and as an aspect of unfolding life trajectories (Alber and Drotbohm 2015) or as an integral part of the ongoing production of relatedness, kin-work, and mutuality (Buch 2015; Zelizer 2005). Other studies have discussed care as an aspect of intergenerational obligations in transnational family networks (Baldassar 2014; Coe 2011) or have critically observed that women from 'the global south' are filling in the care deficit of 'the global north' (Hochschild 1995), e.g., in the guise of domestic workers (Coe 2017), nurses (Olwig 2015) or au pairs (Dalgas and Olwig 2015). When care and the state are discussed in relation to the family, it is often in the context of more or less creative state-based arrangements where care is sub-contracted to family members (Forsell 2013; Lan

2002; Thelen, Thiemann, and Roth 2014) or from the perspective of the older adults themselves (Ludvigsen 2016; Mikkelsen 2017). However, it is important to pay more attention to how care practices and state regulations intersect and shape each other. Thelen and Alber argue for bringing the state back into the equation in discussions around family care, because “untangling this separation is fundamental to understanding contemporary processes of social organization, including boundary making that leads to diverse forms of marginalization” (2018, 1).

We build on this body of work and examine how domains of the family and the state merge, with self-appointed helpers being forced to navigate between them. The helper, in a sense, comes to embody and personify the state in the midst of the family and thus, as we suggest, comes to inhabit a lenticular subject position. On the one hand, she is subject to ‘care scripts’ (Coe 2017; Oxlund 2018) that emphasize the cultural and religious rights and obligations of reciprocating care between generations within the family (Moen 2008). The families in the study follow Islam and hence care scripts are influenced by the Quranic teachings and Sunnah practices (see Qureshi 2013; Ismail 2021). Almost all older adults and caregivers referred to Islam when explaining why they preferred a self-appointed helper rather than using the municipal homecare service. A number of Quranic verses (*surahs*) as well as accounts of the Prophet Muhammad’s words and actions (*ahadith*, singular: *hadith*) dictate the care responsibility that children have towards their parents. According to a famous hadith, “Paradise is beneath her [the mother’s] feet” (Sunan an-Nasa’i 3104). Muslims are asked to treat older family members, especially parents, with *ihsān*, which implies “that priority must be given to the satisfaction of one’s parents over personal satisfaction and that of one’s spouse, children, and others” and that “obeying one’s parents unconditionally unless they command sinfulness” (Ismael 2021). Thus, Islam understood as a ‘discursive tradition’ (Asad 2009) provides a number of concrete instructions about elderly care, which taken together can be viewed as a ‘care script.’

On the other hand, the self-appointed helper is employed by the municipality and thereby subjected to current trends in elderly care such as a new public management time regime and documentation demands (Vaaben and Plotnikof 2019), workplace risk assessments, and expectations associated with active and healthy aging (Hansen and Kamp 2016; Lamb 2017; Lassen and Andersen 2016; Sparre and Rytter 2019; Rytter *et al.* 2021). In municipal homecare, the focus is very much on physical activity, and care workers are now expected to function more as trainers than carers (Hansen and Kamp 2016). Thus, self-appointed helpers like Shirin and Fatima have to balance demands and expectations from both their family and state institutions (i.e. the municipality).

Similarly, state actors’ practices are shaped in a relational setting (Thelen, Veters, and Benda-Beckmann 2014, 6) with several, sometimes conflicting, roles or demands (Forssell 2013, 91). Care managers are responsible for assessing needs and making sure that older people get the help that they need and are entitled to receive. On the one hand, they are “administrators, information officers and gatekeepers to the welfare state” (Forssell, Torres, and Olaison 2015, 578) expected to follow legislation and objective standards as any other caseworker. On the other, they are trained health professionals who as (former) caregivers sometimes also express care and concern for the older citizens and their helpers.⁵ In this way, they also adopt an ambiguous position, where they either make standardized decisions with reference to legislation, formal rules, and procedures, or they accept solutions which tend to go against regulations in order to secure care for older adults at home.

In addition, care managers have to straddle an ambivalent politicized field where kinship relations and care responsibilities in Muslim immigrant families are sometimes presented as premodern and fundamentally ‘alien’ to Danish practices and ways of life (Andreassen 2007; Hervik 2011; Rytter 2019).

At the same time, policies all over Scandinavia increasingly call for more involvement of family members in order to meet the demands of an aging population in need of care (Ungerson 2003).

Self-appointed helpers and public elderly care

In Denmark, social services for older people are provided mainly by the 98 municipalities that are fully responsible for governance, provision, delivery, and financing of care (Rostgaard 2012). People over the age of 65 who legally reside in Denmark, temporarily or permanently, and are in need of help and support in daily life can apply for assistance (Europa-Kommisionen 2018). Thus, like other Nordic countries (Forsell 2013), the overall responsibility of caring for older citizens rests with the state and not the family. Citizens have the choice between municipal homecare, care provided by a private supplier financed by the state, or appointing a family member or friend as a personal helper, the self-appointed helper arrangement.

Self-appointed helpers are employed by the municipality. They are paid a monthly salary depending on the services they provide for their family members. These services are measured according to the regular homecare system: their time allocation equals what it would take a trained care worker to carry out similar tasks. Services not provided by the homecare and services offered through external partners (such as laundry and grocery shopping) do not result in working hours for the helpers. Consequently, most helpers are employed for 5-15 hours weekly. They are not entitled to retirement benefits, and, if the ageing family member recovers, is hospitalised or dies, helpers find themselves unemployed. In many municipalities, their salary stops immediately or within a few days. They also have to sign a contract saying that they are obliged to report their own sick days and holiday as well as any changes in the citizen's health situation to the municipality. In return, municipalities are responsible for the helpers' working environment and wellbeing.

In the Social Service Act (*Serviceoven*), services are divided into "personal help and care" (*personlig hjælp og pleje*), "help or assistance for necessary practical domestic tasks" (*hjælp eller støtte til nødvendige praktiske opgaver i hjemmet*) and "food service" (*madservice*) (*Serviceoven* 2019).⁶ Care managers decide care services provided upon routinized systems of care, combining assessments of the citizen's physical and mental abilities with set times allocated for each activity according to the municipality's service catalogue, although they are also obliged to make each assessment individual. Furthermore, in their calculations they have to consider the older citizen's potential for regaining abilities as well as available human resources in the citizen's own network (Aspanil *et al.* 2016; Hansen 2016; Lassen and Andersen 2016). Thus, the final allocation also depends on whether or not the citizen and the helper live in the same household. If they do, the self-appointed helper is expected to do most of the cooking and cleaning as a family member and not as an employed care worker.

As previously mentioned, Shirin made the choice to take care of her mother, Minal. She has been taking care of and living with Minal since 2012. They share a social housing apartment at the outskirts of Aarhus, Denmark's second largest city. Minal does not speak Danish, and following her brain hemorrhage, she has lost the ability to talk. She is unable to dress, shower, move around, clean, cook, or eat and drink. In short, she needs help with every part of daily life. Shirin is employed by the municipality 21 hours a week to help Minal. According to a detailed time-management scheme, time is allocated to her for tasks related to practical help and personal assistance and hygiene. However, Shirin is not obliged to report her actual working hours, because her monthly salary is fixed, unless Minal's care gets reassessed. Her seven days a week are structured in the following way:

Time of day	Activities	Time allocated (minutes)
Morning	Mobility (getting up, moving from bed to wheelchair, etc.)	20
	Personal hygiene (bathing, changing diaper, dressing, etc.)	40
	Preparing food	20
	Nutrition (feeding)	10
Daytime	Mobility (moving around in the apartment etc.)	13
	Excretion (changing diaper etc.)	15
	Preparing food	5
	Nutrition (feeding)	10
Evening	Preparing food	10
	Nutrition (feeding)	4
	Personal hygiene	10
	Mobility (moving from wheelchair to bed)	3
Night	Excretion (changing etc.)	16
Every 2nd week	Cleaning (mother's bedroom and bathroom)	48
Daily average		179.43 min. = 2.99 hrs.

The way Shirin's days and weeks are divided into small bits and pieces of care work and practical tasks reflects a more general trend of new public management and time regulation among care workers in the public sector (Vaaben and Plotnikof 2019). In homecare units, tasks are organized into what is referred to as 'point visits' (*punktbesøg*), which are the number of visits that older people receive during the day from different care workers during eight-hour shifts. Care workers from the homecare would thus have to come to Minal's house three to four times a day for between 16 minutes and 90 minutes. Yet, Minal is too ill to be left alone. If she had been the responsibility of the homecare unit, the municipality would probably have referred her to a nursing home. Shirin, however, obliges Minal's wish to not be left to strangers with whom she is unable to communicate.

Shirin does not think of her time with her mother as split between family care and contracted care work. Nevertheless, there are time slots during the day (and night) when she is formally at work. Not only is her time divided between work and spare time, but the physical space of the apartment is also divided. The toilet and her mother's bedroom are included in Shirin's work contract and have to be cleaned for 48 minutes biweekly, while the rest of the apartment is cleaned by Shirin as a family member, when she is not 'at work.'

But how are the system and the rules understood and practiced among self-appointed helpers and their families? And how do care managers administer and follow up on care provision and the work environment in immigrant families with a section 94 arrangement? In the following, we examine Shirin and Fatima's care work in relation to food and personal hygiene and how it is approached and administered by care managers.

Food and feeding: contradicting demands and expectations

Care managers allocate services according to the older adult's mental and physical abilities, and they are obliged to look into potentials for improvement in these abilities.⁷ In activities related to food and nutrition, tasks are divided into "personal assistance and care," on the one hand, and "practical assistance," on the other. Serving food is a practical task, but the consumption of food (e.g., feeding) is classified as personal assistance. If the helper and the older adult live together, the helper only receives payment for personal assistance tasks. Vibeke, one of the care managers, admitted that "the distinction

between the two is a bit vague because some might eat some meals themselves, while they need help for others." The case of 92-year-old Emin and his wife and helper, Fatima, illustrates how some meals are the responsibility of his self-appointed helper, while others are not. It also illustrates the challenge of applying the logic of regular homecare in families with a self-appointed helper.

Like other labor migrants from Turkey, Emin came to Denmark in the late 1960s (Liversage and Jakobsen 2016). A couple of years later, his first wife and two sons came to Denmark on family reunification. Their two daughters were already married and therefore remained in Turkey. However, in the late 1980s, Emin's first wife suddenly passed away, and instead he married Fatima, who was in her late 20s when she in 1992 came to Denmark. Fatima is illiterate and from a poor family in the same district in Turkey as Emin. In Turkey, she was married and divorced at a young age, so a second marriage in Denmark was a good opportunity despite the age difference between her and her new husband.

Today, Fatima is in her 50s and employed as Emin's helper nine hours a week. Emin suffers from kidney disease and has to go to the hospital for dialysis three times a week. He also needs to be careful about his diet. On top of this, he is affected by dementia, has impaired hearing, and limited balance and walking abilities. He needs assistance during meals and in almost all activities related to dressing and personal hygiene.

Fatima has never learned to speak Danish properly, and Emin and Fatima have no children together. Officially, she has been employed as his helper for about two years, but she has been assisting Emin for more than four years, during and in between her shorter and longer periods of factory work, cleaning jobs, and job training. While Emin is a respected man who sometimes provide financial help to poor families in his village of origin, Emin and Fatima live in a social housing apartment and are sometimes struggling to make ends meet, especially if they want to afford summer vacation in Turkey. Their only steady income is his public pension and her part-time salary.

When Fatima was still working, different municipal care workers (*hjemmehjælpere*) came to the house to assist Emin, but after a few visits, he cancelled the arrangement. Emin did not want anyone but his wife to see him naked (a reservation among immigrant families informed by specific moral-cultural codes that we discuss in a subsequent section in this paper). He also had bad experiences with the food: "Some Arab [care worker] made stupid food . . . bread with cream cheese and unfried sausage!" After that, Fatima started preparing his food, and two years ago, she became his helper. In fact, it was her caseworker (*sagsbehandler*) at the job center who suggested the arrangement. Fatima was unemployed and had difficulties holding on to jobs outside of the house due to her care responsibilities.

Recently, Fatima asked for a reassessment because the care work demanded more of her. Many of the other helpers we followed pointed out that the municipal time allocation signaled the lack of recognition of the huge amount of care work they carried out. Anahita, another self-appointed helper with immigrant background who cares for her blind husband said: "The responsibility you have as a self-appointed helper is really huge, and the municipality allocates far too few hours taking into consideration the kind of work we actually carry out and the hours we spend on this." Some helpers, like Fatima, tried to get a reassessment, but most other helpers accepted the conditions. In fact, many are happy that this kind of arrangement exists. It gives them some kind of financial compensation and an opportunity to meet the expectations of their older family members who wish to have them carry out the care work themselves.

While Fatima does get some rest and time for herself when one of Emin's sons takes him to the hospital for dialysis, the nine hours she is employed a week do not come close to covering the time she spends

assisting her husband. During the reassessment meeting at the couple's apartment, the care manager, Anna, asked about the meals. Fatima answered that she prepares all her husband's meals and sometimes even feeds him. She also gets up at night if Emin is thirsty. Fatima seemed to be aware that Emin is supposed to do as much as possible himself. Anna stressed that it is very important for Emin to help himself if he wants to maintain his physical abilities. At some point during the meeting, Emin's daughter-in-law, who was also present, served tea. Immediately, Fatima poured tea for Emin, added sugar and stirred. Anna, the care manager, stopped her: "We just talked about you doing less for him, and yet, now you are stirring his tea!"

As this incident illustrates, it can be a challenge to think and work in a supportive (*støttende*) but not compensatory (*kompenserende*) way. In general, care managers often see that rehabilitation of older adults is a problem in families with a self-appointed helper and even more so in immigrant families. According to care manager Helle, "the focus on rehabilitation is almost non-existent. There are *very few*. I might have met a couple [of helpers] where I sensed that the daughter had a focus on this, but no, it is virtually non-existent." Thus, despite the fact that all state-funded elderly care is expected to be provided according to the current paradigm of healthy aging where the caregivers help older adults help themselves (Lamb 2017; Ludvigsen 2016; Mikkelsen 2017), this is often not the case in families with a self-appointed helper, and care managers have very limited ways to ensure this. Many Muslim immigrants, e.g. from the Middle East, are raised in a context where getting old means that you are entitled to care and support from your children (cf. Moen 2008; Ismail 2021; Liversage and Jakobsen 2016). While many older ethnic majority Danes are motivated for rehabilitation by prospects of maintaining their abilities and retaining their independence, especially independence from their own family (Christensen 2020; Hansen *et al.* 2015), Emin and many of the other older immigrants in our study do not have the same aspirations of independence and mobility. Care managers do comment on this during reassessments, but they also quietly accept that this is how care is provided in many of the immigrant families.⁸

Only the appointed helper must provide the care

According to section 94, only the person employed and approved as self-appointed helper by the municipality is allowed to carry out the tasks. Minal is paralyzed and rarely leaves her bed. She also needs special food. Shirin is allocated a certain number of hours for "the practical task" of preparing the food and "the personal assistance task" of feeding her mother – a total of 59 minutes per day. However, the bureaucratic logic makes very little sense for Shirin as she rarely leaves her mother. When Shirin needs to go to the grocery store or has an appointment outside the home, she asks her sister or brother to look after their mother. Her sister lives with her husband and children in a town one hour away and often visits her mother and Shirin on weekends. Her brother lives close by and visits them on a regular basis. Although the siblings, according to Shirin, have difficulties understanding Minal, who is unable to speak, they do prepare food and feed her if Shirin is not there. They also sometimes carry out other assigned tasks. This, however, violates Shirin's contract with the municipality. Only the person employed and approved by the municipality is allowed to carry out services paid for by the state. Thus, even though Shirin's siblings are not paid for their help, they cannot provide assistance if it relates to the tasks assigned to Shirin. However, in cases such as Minal's, where the tasks are many and have to be performed in the morning, during the day, in the evening, and at night seven days a week, most helpers only manage the tasks with help from other relatives (cf. Ismail 2021; Rytter *et al.* 2021). The care managers suspect that tasks are sometimes distributed between family members, and even though this violates the contract, they seem to quietly accept this. As Vibeke explained: "Well, we do not go to the homes of older citizens to observe what is going on without making a prior appointment – so we don't really know whether it is Ahmed who takes care of his mother or if it is his wife. There is no control."

Nurses from the municipality have suggested that Minal should be given a tube-feeding formula because she cannot swallow food correctly. Yet, she has refused the offer, and despite the risk of choking, Shirin continues to feed her mother. From one perspective, this situation could be viewed as neglect of care. However, instead of dismissing Shirin as a self-appointed helper because the municipality cannot guarantee Minal's safety, the care manager has accepted the family's decision without further objections. The only alternative would be to lose contact with Minal altogether. The care manager, Lene, said this about this general dilemma: "We have had many immigrant families where we've thought that the older citizen would actually have benefited from living at a nursing home. But they don't do that, even though the task of caring is in fact too comprehensive, right?"

Naked bodies and personal hygiene: differing care scripts

Muslims in general attach great importance to filial piety, and it is often considered shameful to assign elderly care to professionals outside the family (Ismail 2021). In addition, many older Muslim immigrants prefer the caregiver to be a close family member because they do not want 'strangers' to see them naked. According to dominant religious and cultural moralities, a person's *awra* (intimate parts of the body) are considered private and to be revealed only to close kin such as spouses, sons, daughters, and daughters-in-law (Ismail 2021). As we have observed in our study, different families have different priorities. Some older men prefer their sons to help them, while older women often ask their daughters. It is also common that daughters-in-law provide this kind of care in the patrilocal household. Older Muslims might also have specific requests regarding washing and intimate hygiene such as daily showers and washing before prayer.

Emin and Minal have similar requests, and neither of them wants strangers to see them naked. These ideas, however, go against the logic of state policies. Unlike activities related to food and cleaning, the personal hygiene of older adults with reduced abilities is the responsibility of the state and *not* the family. According to care managers, you cannot expect family members to take responsibility for such intimate tasks. "That is exactly why we [the municipality] offer help, so that husband and wife can continue to be husband and wife," as another care manager explained. In contrast to many other nationalities (both European and non-European), most ethnic majority Danes prefer a professional care worker to assist them with intimate hygiene, because they do not want to burden their children (Christensen 2020; Oxlund, Grøn, and Bregnbæk 2019). As such, the ideals and norms originating in what can be termed an Islamic care script differ significantly from the care script prescribed by the Danish welfare state and common practice in many ethnic majority families. Here, the more intimate parts of an older person in need of care becomes the domain of the state. In families with a section 94 arrangement, the helper thus receives payment for all activities related to personal hygiene, and the state has the overall responsibility for the provision and quality of the care.

For this reason, the municipality is also responsible for the work environment of self-appointed helpers who carry out such tasks. Of the 184 minutes Shirin is employed daily, 117 minutes are spent on physical demanding "personal help and care", including relocating her mother from the bed to the wheelchair, helping her move around in the apartment, changing her diapers, and assisting her with personal hygiene. Most of the nine hours Fatima is employed are assigned for similar tasks. It is therefore crucial that helpers are physically capable of supporting and relocating older family members. Care managers must ensure that they do not have physical problems or limitations when they are employed as self-appointed helpers. They take this responsibility very seriously, both for the sake of the helpers and because the municipality might risk extra expenses due to compensation and sick leave if the helpers hurt their knees, shoulders, or back.

Care managers, along with physiotherapists and occupational therapists, do their best to teach newly employed self-appointed helpers how to assist their older family members in an ergonomically correct way so they can protect their own bodies. However, the older adult might already be used to and might expect a certain way of receiving care. Emin's immediate answer to the care manager's question of how much his family does to help him is clearly illustrative: "My family brings me sandwiches and other things, and if I ask them to stir my tea, they do so!" Some helpers do try to assist in a supportive and non-compensatory way, but their attempts are often not appreciated by their older family members. Unlike among older citizens born and raised in Denmark (Christensen 2020, 156), these older immigrant adults are not to the same extent concerned to become a burden to especially younger family members. In contrast to majority Danes, older immigrants do not seem to connect notions of personal dignity with independence and "fending for oneself" (Christensen 2020, 31). Thus, in order to treat their older family members with *ihsān* and thus live up to the Islamic care script, Fatima and other self-appointed helpers in Muslim immigrant families often end up providing help and care which conflict with the municipality's approach of active aging and help to self-help.

Again, the care managers are aware of the problem: "Sometimes they get squeezed between what the citizen (*borgeren*) would like them to do and what they are actually contracted to do," as Lene expressed it. However, care managers also do not have the time and resources to regularly follow up on work environment matters. As Vibeke explained:

One of the things we discuss a lot is work environment. And I must say that we're not doing it properly. [...] We need to make other rules for these things, how we do it – follow-up meetings and further instructions if we sense that something is not right. I have, for example, been in a Turkish family where the daughter injured her back. Even though we instructed her not to do this and instead do that, she just lifted! And in principle, she is employed by us, right, as to insurance and things like that. It's difficult.

Care managers provide follow-up assessments of the care received by the older person but usually only once a year.⁹ Such meetings allow just a glimpse of the actual practices in the home. Most care managers interviewed for this research admitted to be pragmatic in this regard. Despite their worries and concerns about the wellbeing of the self-appointed helper, Lene, among others, admitted that sometimes she "compromises [on the safety of the self-appointed helper] although this is not the right thing to do." Of course, not all helpers ignore the advice they are given, and many do take care of their bodies. However, in practice the municipality does not have the resources and organizational structures to control this. Unfortunately, work accidents can happen, but the self-appointed helpers rarely inform their care manager about their injuries and physical problems. Many of the helpers we talked to complained about pain in their neck, back, and arms. Fatima, for example, at some point sustained a slipped disc in her back. But none of those we talked to ever reported work-related injuries to the municipality. Thus, although self-appointed helpers must abide by the standard rules and procedures for the physical work environment and the municipality must ensure that this is also the case, the reality in many families with this arrangement is different. Many helpers employ inexpedient work postures due to both entrenched habits and apartments not designed for older people in need of heavy and physically demanding care work.

The self-appointed helpers do not complain about their working conditions to their employers – maybe because they essentially see their care work as a private matter and task for the family rather than as a job for the municipality. Since no one complains, there are no incentives for the care managers to make further inquiries.

Conclusion

In this article, we have presented and discussed the self-appointed helper arrangement in Danish municipalities from the perspective of both self-appointed helpers and municipal care managers. The arrangement provides an option for elderly care among older immigrants who do not want to make use of public homecare services or nursing homes. Within the field of anthropology and aging, it provides a unique opportunity to examine ideas and practices of care at the intersection of the immigrant family and the state. We have primarily focused on two immigrant families: Shirin, who is self-appointed helper of her mother, Minal, and Fatima, who is the helper of her much older husband, Emin. Their experiences and perspectives have been discussed in relation to the understanding of the three municipal care managers.

We utilized the concept of 'lenticular subject positions' (Hage, 2015) to capture situations in which self-appointed helpers as well as care managers step in and out of different and to some extent contradictory frameworks that offer specific rationalities, logics, plots and perspectives. Positioned at the intersection of family and state, we find that the self-appointed helper is often forced to balance different demands and expectations in her care work. She is split between being employed care worker and a caring family member (spouse, daughter, and daughter-in-law) that help her aging relative out of love, respect and care. Similarly, the care manager find herself caught in the push and pull of the legislative frameworks, economic restraints, and municipal decisions, as well as the care and empathy that she as health professional have towards both the older citizens and their caregivers. The care manager alternate between being a health administrator who insists on following the rules, and someone who looks for pragmatic solutions to support care arrangements in immigrant families.

Due to increasingly stricter laws and regulations regarding homecare assistance and work environment, the requirements of the arrangement have become impossible to live up to for both care managers and self-appointed helpers. Consequently, care managers often end up disregarding rules because they have no other solution at hand. They observe and assess care work, which does not comply with the legislative guidelines, and in many cases, they turn a blind eye to it. Some justified this by saying that the self-appointed helper arrangement is the only way to provide some kind of care assistance to families who otherwise refrain from using public facilities for elderly care. Others talked about aging immigrants as having less need for State resources because they "'still' have kin support" (Thelen and Coe 2019, 290).

Also, the self-appointed helpers more or less deliberately disregard the rules. They hand over tasks to other family members, and few live up to the demands of rehabilitation and ergonomically correct working positions. Just like the care managers, they end up breaking the rules because they are impossible to live up to. We maintain that the notion of lenticular subject position allows us to acknowledge the tensions associated with care work under the current care regimes. As discussed in this paper, we show that both self-appointed helpers as well as care managers are caught up in a lenticular subject position as both a caring family member and an employed care worker with simultaneously different, often conflicting demands and expectations. Thus, in practice, care managers and self-appointed helpers enter into a form of 'silence agreement' where both parties refrain from asking questions that they do not want to know the answer to.

Another, more structural, dimension of the lenticular subject positions is the general relationship between the self-appointed helper and the state. The arrangement promotes a particular kind of precarious inclusion of the helpers in the Danish labor market. Anthropologist, Marry-Anne Karlsen (2015) introduced the concept "precarious inclusion" to discuss how undocumented migrants in

Norway, despite their legal status, have access to different kinds of health care services. The undocumented migrants are legally placed outside the scope of welfare legislation, while at the same time humanitarian exceptions are built into the system to relieve tensions between the welfare state's commitment to basic security and immigration law enforcement. Similarly, Mikkel Rytter and Narges Ghandchi (2020) demonstrate how Afghan refugees in mandatory three-year integration programs in Danish municipalities are sent into internships at private companies, only to regretfully realize that at the end of one internship the next one awaits. Their inclusion in the labor market is at best insecure and precarious.

In this article, we show how immigrant women who, like Shirin and Fatima, become self-appointed helpers are subject to a similar kind of precarious inclusion in the labor market and thus are subject to an ambiguous belonging in the welfare state in general. Several years of employment have heavily impacted their lives, wellbeing, and future prospects. As self-appointed helpers, they are included in the labor market as a (special kind of) care worker, but at the same time, they are not really included. They are required to be available around the clock seven days a week, but they never meet any colleagues, and they have little (if any) contact with the municipality. They are not required to have any formal qualifications and, apart from instructions in basic hygiene and lifting techniques, they do not receive any further education or training. This means that they have no new formal qualifications to put on a resume when their contract ends. If the aging family member recovers (an occurrence that is highly unlikely), is hospitalized, or dies, the self-appointed helper is often left without a job. In fact, in many municipalities, the self-appointed helper stops receiving salary immediately or within a few days. Given that these helpers have no economic insurance and no or limited formal education, their employment opportunities remain stifled.

However, the helpers are to some extent complicit, since they rarely complain about their situation. This lack of willingness or inability "to make claims to reciprocal exchanges" is both an indication and a precondition of their ambiguous belonging to the welfare state (Thelen and Coe 2017, 287). Still, in the near future, the Danish welfare state will have to come up with new models of welfare innovation to secure equal access to "care with dignity"¹⁰ like that of the Danish majority citizen for the growing number of older immigrants and refugees. These models might build on a reconfigured arrangement involving the self-appointed helper, yet an arrangement where employment conditions and working environment are comparable to that of care workers in the municipal home care. Overall, we suggest that municipalities take their employer responsibility more seriously by offering e.g. yearly staff development interviews and formal skill development courses, and that they take steps to improve physical and social working environments for self-appointed helpers in private homes.¹¹

Notes

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² All names have been changed in order to protect the right to anonymity of our interlocutors.

³ Personal communication, Danish Ministry of Health, May 2018.

⁴ In Denmark, public elderly care is regularly subject to changes. For example, new recommendations by the independent state appeals board (*Ankestyrelsen*) have recently resulted in adjustments of the procedures for assessing needs and allocating time for older citizens with a section 94 arrangement. This article is based on data on how the arrangement was practiced and administered by Danish municipalities in 2017-2019.

⁵ In another paper, Sparre (2021) demonstrates how care managers slip in and out of their roles as health professionals, administrators and morally concerned citizens in encounters with young female caregivers with an immigrant background in particular. She shows how female health professionals and ethnic majority women tend to care for young self-appointed helpers as ‘sisters’ or ‘daughters’ in the nation and thus sometimes taking drastic decisions to protect and ‘save’ them from care work in the family.

⁶ <https://www.retsinformation.dk/eli/lta/2019/798>, accessed 22 February 2021.

⁷ The process is usually termed ‘Reablement’ (*rehabiliteringsforløb*) and is a form of rehabilitation, more specifically – “a time-limited, person-centred, home-based intervention for older people who are at risk of functional decline” (Aspiral et al. 2016: 574). Reablement is very much in line with the paradigm of active and healthy aging. In Denmark, it is regulated by section 83a (*‘et korterevarende og tidsafgrænset rehabiliteringsforløb’*) in the Social Service Act. Care managers in Danish municipalities are obliged to consider reablement for all older citizens, including those with a self-appointed helper.

⁸ Municipalities are obliged to follow up on section 94 arrangements once a year. A new assessment might result in an adjustment of the time allocation due to change in the abilities of the older citizen concerned. We only heard of very few cases in which a care manager, after a follow-up meeting, decided to dismiss a self-appointed helper due to neglect of care or deliberate violations of the employment contract with the municipality.

⁹ Usually, care managers have case responsibility and follow the same older citizens and self-appointed helpers as long as these arrangements last. However, their managers and colleagues are often involved in major decisions regarding the services that are offered or declined.

¹⁰ Danish Ministry of Health, <https://www.sst.dk/da/opgaver/videnscenter-for-vaerdig-aeldrepleje>, accessed 19 April 2021.

¹¹ Based on the insights from the AISHA project, we recommend the following improvements of the section 94 arrangement: 1) Municipalities should treat self-appointed helpers like any other employee group in the organization, for example by offering yearly staff development interviews. Helpers would then have an opportunity to review their tasks and work-life balance as well as a chance to discuss possibilities for further training and work opportunities in the municipality once their older family member has passed away. 2) It would benefit both the helper and the municipality if the self-appointed helpers attended mandatory, formal skill development courses in e.g. lifting and moving people, first aid, and signs of pressure sores and infection, and if they received a certificate on completion of such courses. This would ensure that older citizens received a care standard closer to that required in regular homecare, and the helpers would have proof of their skills and experience if they wish to continue working within the health and care sector. 3) Self-appointed helpers would also benefit greatly from improved physical and social working environments in private homes. In order to ensure that helpers assist older citizens in an ergonomically correct way, prescribed tools and facilities should be an indispensable rule and not something the helper should have to discuss with the older citizen or any other family member. Furthermore, municipalities should support self-appointed helpers in their need to take time off on a regular basis by employing two rather than one helper. The two helpers might

share the tasks, or the second helper could be an approved substitute ready to take over in case of illness or vacation.

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