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Silence Agreements in Danish Elderly Care: Phantasmatic Asymmetry between Care Managers and Self-Appointed Helpers with a Muslim Immigrant Background

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Abstract: This paper explores the composite of elderly immigrants, self-appointed helpers (*selvudpegede hjælpere*) and care managers (*visitatorer*) in Danish municipalities. Free elderly care is a common good in the Danish welfare state. Instead of using the homecare service provided by the municipality, many elderly citizens with a Muslim immigrant background prefer to have a family member contracted as their self-appointed helper. The self-appointed helper is often a spouse, daughter or daughter-in-law, who ends up having the dual role as both a caring, loving family member and a professional care worker. Due to the special setup with self-appointed helpers working in their private homes, it is difficult for the care managers to follow standard rules and procedures. Instead, it seems to be a public secret that there is a gap between *what we are supposed to do* (according to the law) and *what we actually do*. We suggest seeing this gap as a silence agreement, where care managers, self-appointed helpers and elderly citizens refrain from asking all the critical questions (regarding the provision of care, the quality of care, working conditions, etc.) that no one wants to know the answers to. However, when the silence agreement from time to time breaks down, the relationship between the self-appointed helper and the care manager is haunted by a widespread phantasm where Muslim immigrants are cast as welfare scroungers. Basically, we argue that care managers and self-appointed helpers share a silent agreement but when it is neglected or violated, the latter end up in a vulnerable and marginalized position. The dynamic highlights the ambiguous intimate belonging of Muslim immigrant families and questions to what extent they were seen as legitimate subjects under the state in the first place.

Keywords: care; old age; welfare state; street-level bureaucrats; public secrets; racism; phantasms

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1. Introduction

In the years to come, a larger proportion of the increasing elderly population in Denmark will have a Muslim immigrant background. In 2021, there were approximately 27,000 people with an immigrant or a refugee background above the age of 65 from outside Europe and North America. In 2040, this number is expected to be close to 100,000. Many of these people will need care and assistance in their daily lives. However, elderly care arrangements in immigrant families are often different from those in the majority population. While elderly care is a common good in the Danish welfare state, and all elderly citizens are entitled to help and care from their municipality, for different reasons, elderly Muslim immigrants prefer to get help and support from family members. Many have difficulties speaking and understanding the Danish language, their food preferences may differ from those of the ethnic majority population and they generally have other religious and cultural preferences when it comes to elderly care (Rytter et al. 2021a, 2021b). In their country of origin, where many of them grew up, it is often the tradition that family members take care of each other (Moen 2008; Liversage and Jakobsen 2016; Ismail 2022). In fact, it would be shameful and embarrassing, similar to being abandoned, if the family

would not take care of you in old age. For these reasons, many elderly Muslim immigrants do not want or trust "strangers" from the municipality to help them in their everyday lives.

One option for these elderly immigrants is to have the help they are entitled to be carried out by a "self-appointed helper" (*selvudpeget hjælper*). The Danish Social Service Act provides this opportunity. According to section 94, citizens above the age of 65 with functional impairment can appoint a family member, who is then employed by the municipality, to carry out the daily assignments that would otherwise be the responsibility of a professional homecare worker. The self-appointed helper is thus both a family member and an employed care worker in the elderly care sector of the municipality.

Currently, approximately 2400 citizens in Denmark have a self-appointed helper—the vast majority of them are elderly immigrants from countries where Islam is the dominant religion. Emin, a 92-year-old man, is one of them. Emin came to Denmark from Turkey in the late 1960s. He suffers from kidney disease, is affected by dementia, has impaired hearing and his ability to walk without help is limited. Emin, therefore, needs help during meals, getting dressed and undressed and in relation to personal hygiene. His wife, Fatima, is in her 50s. Fatima is Emin's second wife after his first wife, the mother of Emin's four children, passed away many years ago. When Fatima was still working, different municipal care workers (*hjemmehjælpere*) came to the house to assist Emin, but after a few visits, Emin canceled the arrangement. He did not like the food they prepared for him, and he was uncomfortable with being seen naked by anyone other than his wife. Today, Fatima is employed by the municipality as Emin's self-appointed helper for nine hours a week.

As the case with Emin and Fatima illustrates, the self-appointed helper arrangement is not a traditional cash-for-care scheme, such as the one normally found in Europe and North America. Normally, the elderly citizen receives a monthly pot of money based on a formal need assessment that he or she then is free to spend on care services provided by carers in their network, from private suppliers or, as it is often the case in, e.g., Italy, from low-paid female migrant workers (Ungerson 2004). In a study of eldercare among migrant families in Sweden, Forssell (2013) shows how "home care grants" provided by the state often lead to transnational arrangements, where carers are recruited among the elderly citizen's wider kinship network in the country of origin. Lan (2002) discusses how adult children in Taiwanese migrant families in California increasingly employ a non-kin careworker to care for their ageing parents, partly financed by the State of California. Still, the self-appointed helper arrangement is different from these cash-for-care schemes; it is not a matter of pots of money being handed over to the elderly citizens so that they can set up their own care arrangements. Instead, the municipality employs a family member to provide the care.[1] As such, the municipality is responsible not only for the care provided for the elderly citizens but also for being the self-appointed helpers' employer, for the self-appointed helpers' working conditions and working environment (Sparre and Rytter 2021). Similarly, the self-appointed helper must navigate between being both a loving and caring wife, daughter or daughter-in-law and an employed care worker subject to time schedules and documentation demands (Vaaben and Plotnikof 2019), workplace risk assessments and expectations associated with active and healthy ageing (Hansen and Kamp 2016; Lamb 2017; Lassen and Andersen 2016). The special setup with self-appointed helpers working in their private homes taking care of ageing family members makes it difficult for both municipal care managers and self-appointed helpers to follow standard rules and procedures. Rather, it seems to be a "public secret" (Taussig 1999) that there is a gap between *what we are supposed to do* (according to the law) and *what we actually do* (Lipsky [1980] 2010). According to Taussig (1999), a public secret is something that is common knowledge but still difficult or maybe impossible to talk about. Public secrets lead to a strategic situation where everyone knows exactly what kind of questions they are *not* supposed to ask (Rømer 2013, p. 44). Similarly, in his critical discussion of the making of scientific knowledge in Africa, Wenzel Geissler suggests the concept of "unknown knowns" when describing the seldom addressed asymmetrical structural relationship between Western research and their local collaborators (Geissler 2013).

We suggest seeing this gap as a "silence agreement" (*tavshedsoverenskomst*) where care managers (*visitatorer*), self-appointed helpers, elderly citizens and their wider families often refrain from asking the critical questions (regarding the provision and quality of care, working conditions, etc.) that no one wants to know the answers to. It is this silence agreement that makes the self-appointed helper arrangement possible.

In this article, we first unpack the silence agreement and discuss, from the perspective of the self-appointed helpers and the care managers, which aspects of the daily elderly care remain invisible and are not spoken about. Then we discuss what happens when the silence agreement, from time to time, is violated and breaks down—here the consequences and sanctions are much more severe for the self-appointed helpers than the care managers. In the case of such breakdowns, the mutually respectful relationship between the self-appointed helper and the care manager is suddenly haunted by a well-established phantasm (Desjarlais 2019) of the problematic Muslim immigrant having a questionable (suspect) approach to the resources of the welfare state (cf. Anderson 2013). According to Robert Desjarlais, social relationships or encounters are framed and formed by phantasms, understood as "an apparition or illusion; a ghost or phantom; an imaginary construct; a fantastical image or vision; a haunting memory; a fanciful idea; or a cohering fantasy, momentary of lifelong, conscious or unconscious" (Desjarlais 2019, p. ix). There is more to social encounters than meets the eye. In this respect, relationships are always informed by phantasmatic imaginaries. As long as the silence agreement is upheld, the self-appointed helpers and care managers have a common interest (to provide the best possible care for the elderly citizen/family member), but as soon as it breaks down, the relationship changes and is now haunted by destructive stereotypes of Muslim immigrants as welfare scroungers (cf. Andreassen 2007; Anderson 2013; Rytter 2019). The destructive phantasmatic potential inherent in the silence agreement raises some more fundamental questions regarding the extent to which Muslim immigrant women working as self-appointed helpers were seen as citizens with a legitimate belonging to Denmark and the Danish welfare state in the first place.

However, before we come to the analytical parts of the article, we will present the AISHA project and explain how the data were collected.

2. Methodology of the AISHA Project

The article is based on data from the collaborative research project *Ageing Immigrants and Self-appointed Helper Arrangements* (AISHA), carried out in the period 2017–2021. The project explores the self-appointed helper arrangement from the perspectives of municipalities and families with mainly Arab, Pakistani and Turkish immigrant backgrounds. 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 in immigrant families with a self-appointed helper and among care managers in the municipal elderly care sector. Among other things, we have observed and examined direct and indirect relations and encounters between self-appointed helpers and municipal care managers.

Our study sample collected from 2018–2019, included 30 elderly citizens and their self-appointed helpers, as well as more than 50 care managers, health professionals and leaders from Danish municipalities. We followed everyday life in the families and observed encounters between care managers and elderly citizens and their self-appointed helpers. In addition, we conducted focus groups with both care managers and self-appointed helpers. All care managers in our study are women and the same goes for almost all the self-appointed helpers. Usually, the helper is the wife, daughter or daughter-in-law of the elderly person in need of care. Finally, this article also draws on a national survey among 33 municipalities and analyses of quantitative data on elderly citizens with an immigrant background (see Rytter et al. 2021b).

3. Public Secrets and Administrative Grey Zones

There are grey zones in all political systems and in bureaucratic administration. A grey zone is "an area or situation marked by ambiguity or porous boundaries" (Frederiksen and Knudsen 2015, p. 2), but the metaphor also illuminates a clear cut between black and white, as well as wrong and right, which is then mediated by a borderland in-between, the grey zone. According to Michael Lipsky, in public administration there tends to be a gap between "what we are supposed to do" (according to the Social Service Act and other legislation) and "what we actually do" (to make it work in our everyday practices and administration of the care arrangement) (Lipsky [1980] 2010). Any administrative system needs flexibility. If employees start to follow the rules rigidly, the system collapses. That is also why it is often a serious weapon in union conflicts between managers and employees in the public sector if the employees threaten to start working by the rules; that will inevitably stall the system or make it fall apart altogether.

The same goes for the self-appointed helper arrangement. To make the system work, both self-appointed helpers and municipal care managers must be willing to close their eyes and ignore fundamental challenges and problems with the care arrangement. By zooming in on the grey zones of the mutual silence agreement, we come closer to an understanding of the relations between the state and the family as they are imagined and played out in encounters between municipal care managers and self-appointed helpers in Muslim immigrant families. We will first present three challenges that face the self-appointed helpers, followed by two challenges that face care managers at the municipality granting and administrating the section 94 care arrangement.

3.1. The Work Colonizes Day and Night

The self-appointed helper carries out tasks and care work that normally would be the responsibility of professional care workers (*social- og sundhedshjælpere* and *social- og sundhedsassistenter*) from the municipal homecare. Municipal care workers visit several elderly citizens throughout their working day. They carry out tasks related to personal hygiene, cleaning and food provision depending on the needs of the specific citizen in his or her private home. They are expected only to provide the help and assistance that the elderly citizens have been granted by the care manager according to the Social Service Act and the municipal service standards.

Self-appointed helpers are employed to carry out the same assignments as a care worker from the municipal homecare, but they only attend to one citizen—an elderly family member. When, for instance, the assignments of preparing dinner (10 min) and helping the family member to the toilet (15 min) are completed, the self-appointed helper is off work. She is still at home in the vicinity of her elderly family member, but now she is there as a caring wife, daughter or daughter-in-law.

In a previous article (Sparre and Rytter 2021), we presented 39-year-old Shirin who takes care of her mother, Minal, who is partly paralyzed and has lost the ability to talk due to a stroke she had in 2012. Shirin is allocated 21 h per week to help her mother. Table 1 is an illustration of Shirin's weekly work assignments:

Table 1. Shirin's working hours.

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

Table 1. *Cont.*

Time of Day	Activities	Time Allocated (Minutes)
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 diaper, etc.)	16
Every 2nd week	Cleaning (mother's bedroom and bathroom)	48
Daily average		179.43 min = 2.99 h

However, when you work in your own home and your task is to help and take care of your own mother, it can be difficult to separate work and free time. Shirin, of course, helps her mother when she needs help. She will not insist on strictly adhering to the contract and only help her mother go to the toilet when she is supposed to, according to the agreement with the municipality. Instead, Shirin will listen to her mother and help her when needed. For this reason, Shirin has to be available all day; her nights are colonized too as she must get out of bed and help Minal whenever she needs help.

Furthermore, self-appointed helpers find it difficult to go on holiday or take time off during weekends. The case of 46-year-old Bushra illustrates this very well. Bushra takes care of her mother, Nimra, who suffers from dementia. The municipality has employed Bushra for 31 h per week, but helping her mother takes up all of Bushra's time. Besides taking care of her mother, Bushra is also preparing food for her 81-year-old father. Bushra is under a lot of pressure, even though her husband and five children do their best to help her out. Bushra explains that she has not been on holiday for the last four years. Before Nimra's dementia reached its current stage, Bushra tried to continue attending social events such as weddings. After several episodes where Nimra used inappropriate language, and was aggressive or rejected to come along, Bushra, her husband and her father stopped bringing Nimra with them. Instead, the family split up and Bushra stayed at home with her mother.

In general, the official care arrangement and part-time employment take up all of the self-appointed helper's time and affect their private life. It becomes difficult to say no or have other people from the family or municipality take over. Furthermore, the elderly family member always gets worse and needs more help and care as time goes by. What may have started as small tasks only a few hours a week often ends up taking up all of the self-appointed helper's time both day and night, as is the case for Shirin and Bushra.

3.2. Physical Injuries and Work-Related Health Problems

The self-appointed helpers work in the private homes of their families, which are often also their own private homes. The place is seldom suitable for assignments involving citizens who are severely physically challenged. For the same reason, we have met several helpers who struggled with physical injuries or problems related to their jobs.

Tasks such as lifting and helping elderly family members from the bed to the toilet, couch or wheelchair or helping them move around in the house or apartment can be tough on the helpers' hips, knees and backs. Sometimes, care managers notice or foresee problems related to such heavy tasks. One example was provided by the care manager Anette, who recalled a previous meeting in the home of a 54-year-old man, who had married a woman who was 20 years younger than he was and from Pakistan, his country of origin. Due

to illness, he could not get up and walk around in the apartment without the help of his wife. Anette was quite shocked when visiting the couple; the young wife was literally carrying her husband around on her back in the apartment. Anette decided not to offer her the job as a self-appointed helper because she assumed that the young Pakistani wife, entering Denmark on family reunification, would not be able to stand up to her husband and say no when he asked her to carry him around in the apartment for many years to come (Sparre 2021a).

In the above case, no contract was signed, but it is a general challenge for self-appointed helpers that they must help elderly family members move around in their homes. They risk injuries or more long-term physical problems. However, the problem with work-related injuries among self-appointed helpers is not something that takes up much of the care managers' time. The reason is that helpers rarely report the injuries. Their difficult working conditions and working environment are not reflected in the general statistics of employees' wellbeing in the municipality. Not only work-related injuries but also ordinary sick days are dramatically underreported in the statistics because if the self-appointed helper reports to the care manager that she is sick, the municipality will have to send a replacement. The replacement will have to be a care worker from the homecare team, but the families (and especially the elderly family members) do not want a care worker who is unable to communicate with the elderly family member or does not understand his or her cultural and religious preferences. So instead of calling in sick, self-appointed helpers do the job or find a replacement within the family network. Against the rules, they keep silent regarding injuries, ordinary sick days and the fact that other family members sometimes step in and provide help and care to the elderly citizen.

The care managers are well aware of this structural barrier. In one of our focus group interviews, the four care managers joked about the self-appointed helpers: "they must be the healthiest employees in the municipality—they are never sick!". The joke obviously addresses the self-appointed helpers' lack of interest or willingness to report illness and sick days, but it is also a critical self-reflection regarding their own passivity since they as employers simply ignore a fundamental structural problem with regard to the section 94 care arrangement which all of them know exists.

3.3. The Lack of Colleagues and the Precarity of Helpers

Finally, the job as a self-appointed helper is unusual due to the helpers' isolation, lack of colleagues and precarious lack of job security. Self-appointed helpers are employed for the number of minutes and hours that their elderly family members are entitled to. Unless they have relevant health education, their payment follows the minimum salary—currently approximately DKK 128 (approximately EUR 17) per hour. There is no possibility of negotiating the salary within the elderly care sector, nor are there any opportunities for advancement. They are self-appointed helpers and that is it.

Furthermore, they have no job security. The contract as a self-appointed helper will be terminated within a few days if the elderly citizen is hospitalized. However, there seems to be some flexibility, since it will be administratively difficult to terminate the arrangement just to enter into it again when the citizen is discharged from the hospital. It is the responsibility of the self-appointed helper to report to the municipality if the elderly citizen is hospitalized. This, however, does not seem to be a top priority when an old father or mother ends up at the hospital. The mutual flexibility in relation to hospitalization is part of the silence agreement between the municipality and the self-appointed helpers. If the elderly citizen, on the other hand, dies, the employment is automatically terminated. The death of an elderly family member not only leaves the self-appointed helper with a personal loss and grief; they also lose their jobs.

Despite the difficult work environment and lack of job security, Danish labour unions show little interest in supporting the self-appointed helpers as a specific category of employees in the welfare state and elderly care sector. Historically, the unions have been a significant actor in regulating salary and working conditions in the Danish labour market.

It is the union *FOA—Fag og Arbejde*—that organizes social and health workers in the elderly care sector. However, we have not met any self-appointed helpers who were organized in the union or heard of any care managers who had encouraged their employees to join a union. The reasons could be that the unions have little (if any) focus on the relatively small group of self-appointed helpers and that neither the self-appointed helpers nor the care managers see and recognize them as 'real' or ordinary care workers. In many respects, they differ from other jobs in the (relatively) regulated public sector of the Danish welfare state.

Instead, the self-appointed helpers end up being a group of employees who work at home (with their elderly family member), receive a low salary and have a poor chance of taking holiday or having some free time in the evenings or the weekends. In this respect, the self-appointed helpers are part of a more general trend of emerging niches in the labour market that are filled with precarious labourers who have fewer rights, less security and receive less recognition than the rest of the labour market (Hirslund et al. 2020; Spanger and Hvalkof 2020). Often these new jobs on the Danish labour market are filled by immigrants, such as Philippine au pairs caring for children in upper-middle-class families (Dalgas and Olwig 2015; Bach 2017), farmworkers from Eastern Europe or Ukraine (Skvirskaja 2015; Lovelady 2020a; Lovelady et al. 2020), Polish or Baltic construction workers (Lovelady and Arnholtz 2016; Lovelady 2020b) or Syrian and Afghan refugees who have to follow job-training programmes where they "learn" to work in order to receive their "integration payment" (*integrationsydelse*), a salary way below the minimum wage (Rytter and Ghandchi 2020; Shapiro and Jørgensen 2021). With regard to the self-appointed helper arrangement, it is predominantly Muslim immigrant women who become self-appointed helpers, working at home and taking care of their ageing husbands, parents or parents-in-law (Rytter et al. 2021b).

4. Administration of the Care Arrangement

It is not only the self-appointed helpers who have to accept and navigate within the silence agreement; the same goes for the care managers. In the following, we will focus on the ability and effort of care managers and municipalities to regularly follow up on the care provided to the elderly citizens and secure everyday rehabilitation of the elderly citizens, which has become a requirement in elderly care in Denmark in recent years.

4.1. Follow-Up and Re-Assessment of Needs and Care

Results from our survey in 33 municipalities show that many municipalities distinguish between, on the one hand, following up (*opfølgning*) on an established care arrangement and, on the other hand, re-assessment (*revisitation*) where care managers visit elderly citizens and their self-appointed helpers to decide whether they need to adjust the care provided by the municipality. Many municipalities report that ideally, they contact the elderly citizens once a year or every second year. Some municipalities have a follow-up visit two to three months after the start of the care arrangement and after that, they visit the family once a year. The purpose of the visit is to evaluate the physical condition and wellbeing of the elderly citizen and decide whether the self-appointed helper's time allocation corresponds with the needs of the elderly citizen. A less explicit aim of the home visits is also to monitor whether the self-appointed helpers are providing the help and care they are supposed to.

A general challenge in many municipalities is that each care manager often has very few cases with self-appointed helpers. Care managers explained to us that they have an overload of tasks, which is why they must prioritize, and often the section 94 cases end up at the bottom of the piles. This is because care managers assume that the self-appointed helpers as caring family members will do their utmost to provide good care. Another reason for not prioritizing these cases is that, due to language barriers, visits to immigrant families are often difficult to arrange and require an interpreter, who might not be available. Thus, for several pragmatic and structural reasons, care managers often end up neglecting their responsibilities of follow-up and re-assessment of needs and care.

One municipality reported that they had decided to do a sample. They selected 4–5 families, assumed to be representative of elderly citizens with an immigrant background and a self-appointed helper. This sample was their way to live up to their responsibilities to provide follow-up and re-assessment. Obviously, this helped ease the workload of the care managers, but it did not necessarily help the elderly citizens and their self-appointed helpers.

4.2. Everyday Rehabilitation

Since 2015, it has been an integrated aspect of municipal elderly care to encourage, train and help elderly citizens to do their best to keep their bodies in the best possible physical condition. This is part of the more general trend in elderly care and ageing societies to improve the efforts made by the elderly people themselves (Lamb 2017), often referred to as "help to self-help" (*hjælp-til-selvhjælp*), a new paradigm suggesting that old people should be helped to help themselves keep their bodies in good shape and look after their wellbeing (Aspanil et al. 2016; Oxlund et al. 2019). This has resulted in a redefinition of the professional identity of care workers: they used to be seen and see themselves as "carers", but today they are often conceptualized as "trainers" (Hansen and Kamp 2016) who are supposed to coach and train citizens in how to get out of bed, put on their clothes and prepare their own meals. It is a specific way to express and prove your active citizenship; the elderly citizens may no longer work and pay taxes, but they are still obliged to do physical exercises and take the medicine prescribed to them (Ludvigsen 2016).

However, these ideas often seem to clash with ideas of elderly care in Muslim immigrant families, where elderly people, to some extent, have done their part by bringing up their children and, probably, getting them married (Moen 2008; Liversage and Jakobsen 2016; Ismail 2022). Now they can lean back and expect to receive help, care and love in late life from their adult children. The conflicting ideals are noticed by the care managers. Here Lone explains:

> "The arrangement challenges the mandatory rehabilitation procedures (*rehabiliteringsforløb*), in which you have to clarify whether the citizen is able or will be able to do more him- or herself. Among 'the ethnic' (*de etniske*), we encounter other cultural ideas. That someone must wait on and serve them. That you cannot make demands on them. Both the young and the elderly have these ideas. Strictly speaking, the rehabilitation procedures are mandatory, but it is a huge apparatus with an interpreter and everything to put in place, which is why 'the ethnic' are often exempted." (Lone, care manager)

The challenge of rehabilitation is a general problem in families that have a section 94 arrangement, but, according to several care managers, the problem is even more significant in immigrant families. Vibeke elaborates:

> "In general, the helpers—and especially those with a refugee or immigrant background—have difficulties with working in a rehabilitative way. It is mandatory by law that we work to maintain skills and not just do everything for the elderly citizen. They *must* do what they can themselves. But often the self-appointed helper works in a compensatory way. They have another approach to elderly people; that they need to be served and carried through life." (Vibeke, care manager)

The welfare state's agenda of everyday rehabilitation is, of course, related to an ambition to ensure high quality and optimize elderly citizens' wellbeing in the late stages of life. However, an economic rationale is also salient. Elderly citizens who take care of their health and physical condition will be less expensive for the municipality and welfare state in the long run. It is, however, difficult for the care managers to ensure that elderly citizens with a self-appointed helper are provided with care and assistance according to national requirements and the rehabilitation law.

5. Silence Agreements

To sum up, the self-appointed helpers' working conditions are characterized by a work-life imbalance, where many end up working 24–7 without holiday or sick days. Furthermore, they often have a physical working environment with many lifts and working postures that place strain on their knees, hips, arms and backs, and they lack colleagues and co-workers from the municipal elderly sector to talk to. Finally, they have no job security or possibilities of upgrading their qualifications.

Likewise, it is difficult for the care managers to live up to the legal requirements of follow-up consultations and re-assessment of care arrangements with a self-appointed helper. This is particularly a problem in immigrant families where the elderly often does not speak and/or understand Danish very well. The fact that the helpers work at home complicates care managers' formal procedures. Care managers also tend to neglect their responsibility to ensure rehabilitation of the elderly citizens, partly because it is difficult to carry through with employees such as the self-appointed helpers who are not trained care workers, but many also explain it away by blaming the families' cultural and religious idiosyncrasies and special wishes when it comes to elderly care.

So basically, both the care managers and the self-appointed helpers seem to agree that there are structural aspects of the care arrangement that are unsolvable. Instead of stating this explicitly, there tends to be a public secret (Taussig 1999) that no one should ask critical questions regarding these problematic issues. Both care managers and self-appointed helpers seem to oscillate between two positions: As for the helper, she is on the one hand a caring wife or daughter, who might have put her own education or career on hold to stay at home and help her elderly family member and, on the other hand, she is employed as a care worker and needs to comply with the rules and regulations of the municipal elderly sector. In interviews and conversations with us, care managers too moved between a formal bureaucratic logic, where they refer to the Social Service Act and all the rules and regulations they are supposed to follow in their daily work, and what they actually do in order to make pragmatic solutions for the elderly citizens and their self-appointed helpers—and to some extent to ease their own workload (see Sparre and Rytter 2021). Both self-appointed helpers and care managers oscillate between "what we are supposed to do" and "what we actually do" (cf. Lipsky [1980] 2010).

It is the grey zone of the silence agreement between the care managers and the self-appointed helpers that makes the care arrangement work as an alternative to the ordinary homecare service in the welfare state's elderly care sector. However, in our national survey, we found several examples of what happens when the silence agreement from time to time breaks down. This is often the case when self-appointed helpers step out of the grey zone and lose the balance between being a caring daughter and a dutiful contracted employee. According to the care managers, this happens when they give too much priority to the intimate belonging and interests of the family, and thereby neglect the norms, rules and regulations of the municipal elderly care sector, representing the more abstract welfare state.

In this respect, a breakdown of the silence agreement has very different consequences for care managers and self-appointed helpers, respectively. The next section will give some examples of this dynamic.

6. Violation and Mistreatment

The care managers generally comply with and contribute to the production and reproduction of the silence agreement. However, they are also aware of cases with self-appointed helpers and immigrant families who violate the silence agreement to such an extent that they can (will) not accept it anymore. The cases we have collected in this respect cover a spectrum ranging from unintended violations of the contract to regular mistreatment of the elderly citizens who the self-appointed helpers are supposed to help and care for.

We start with two examples from our survey that illustrate these dynamics. Both cases concern self-appointed helpers who decided to go on holiday, leaving the elderly citizens back home. They never reported the holiday to the municipality and therefore, received a salary they were not entitled to. The first case is from a municipality on Zealand. The self-appointed helper went to Lebanon, while another family member took care of the elderly citizen. The municipality received an anonymous tip that something was wrong. This led to a cancellation of the self-appointed helper's contract since no one other than her was allowed to provide the treatment and care that she was employed to provide. In this case, the rules were violated, but the elderly citizen received help and care after all. We have several examples of similar "family replacements", where the self-appointed helper set up an alternative care arrangement without notifying the municipality when they from time to time went on holiday outside Denmark (Rytter et al. 2021b, chp. 9).

The second case is from a Danish-Turkish family living in Greater Copenhagen. An elderly man had his daughter-in-law as his self-appointed helper. Still, she decided to take a three-week holiday in Turkey with her husband and children. The old man was left at home alone with no help or support, and it turned out that he could not take care of himself. The municipality discovered the neglect and arranged for the man to go to a day-care centre for elderly citizens on a daily basis, where he could get his meals and the help he needed. In this case, the contract with the self-appointed helper was also terminated.

Both cases concern self-appointed helpers who do not comply with the rules when it comes to reporting holidays. However, the two cases differ in the way the elderly citizens were affected by it. In the first case, another family member took over and provided help and care instead of the self-appointed helper. In the second case, the elderly citizen was directly mistreated.

The second kind of mistreatment is when the elderly do not receive the help and care they need and are entitled to. One such case was reported from a municipality in Jutland, where a Danish-Iraqi man was employed as his wife's self-appointed helper. He probably did his best but did not seem to acknowledge or understand that she needed much more professional help and care than what he could provide. Here the municipality stepped in and took over. The husband did his best, but the wife was still mistreated.

Another case in a municipality in the southern part of Jutland concerned a middle-aged couple from Bosnia. The husband's old mother came to Denmark for family reunification, and the wife was afterward employed by the municipality as her self-appointed helper. One of her assignments was to help the old mother-in-law get out of bed and into a wheelchair every morning. After lunch, she should be helped back into bed. However, when the care manager from the municipality visited the family, she realized that the elderly woman never actually left her bed, and due to the neglect, she now suffered from pressure ulcers. The care managers also questioned whether she actually was served proper and nutritious meals. This concern led to a change in the contract and care arrangement. The care manager demanded that an ordinary (professional) care worker from the municipality visited the family every morning and at noon to make sure that the woman was moved from her bed to the wheelchair and back again. The other tasks continued to be carried out by the daughter-in-law. The care manager explained that it was her impression that the mistreatment was a result of the wife trying to comply with the wishes of her mother-in-law, but that she, as a responsible care manager, had to react and change the care arrangement.

When we compare the last two cases, the first one is a case where the care assignments are overwhelming for the self-appointed helper, and in the second case, it is more unclear why the self-appointed helper chose not to fulfil her contract. Nevertheless, the care manager gave her the benefit of the doubt and helped the family set up a more sustainable care arrangement. In both cases, we see an elderly citizen who does not receive proper treatment, but the care managers' evaluations of the motives behind the neglect are different in the two cases.

7. Social Fraud and Welfare Scroungers

As mentioned earlier, the self-appointed helper is at the threshold between the private and the public, between bureaucratic logic and family care and between a contractual relationship and an emotional relationship; they are expected not to be too intimately connected to any of the two domains. In this respect, the care arrangement constitutes and challenges the boundaries between the family and the municipality (state), between well-defined assignments and more diffuse emotions, love and affect within the family. For this reason, we are cautious not to categorize the violations or mistreatment by the self-appointed helpers as "social fraud". The care managers, however, are less cautious about using this diagnosis in certain cases.

One prominent example of fraud was presented in the national press. In September 2010, several stories were reported in Danish media about 24 self-appointed helpers in Odense municipality who had received DKK 1.5 million in salary which they were not entitled to. The case motivated municipalities all over the country to revisit their section 94 cases and discuss how they could improve their communication with the employed self-appointed helpers regarding their rights and duties.

However, the case from Odense is an illustrative example of the grey zone of the care arrangement. In fact, an employee from the elderly sector in Odense municipality explained that many of these cases of "fraud" were self-appointed helpers who had taken their elderly family members with them on holiday outside Denmark without knowing that this was a violation of their contract. The rules were undoubtedly violated, but it was never intentional, and the helpers continued to perform the help and care they were supposed to. Due to the media scandal, Odense municipality terminated the care arrangements, but soon after, many of them were actually re-established because the need was there and because the alternative to the self-appointed helper would be a much more expensive ordinary homecare service provided by the municipality.

Social fraud is also on the agenda in other cases when, for instance, the self-appointed helper has another job that obviously collides with the care assignments. In such cases, the care manager and municipality can (rightfully) start to suspect that the elderly citizen is being neglected or that someone else is providing the help and care. In one case from a municipality in Greater Copenhagen, the authorities discovered that one of their self-appointed helpers had started working full-time in another job and that she had, therefore, handed over the care assignments to her sister without informing the municipality. In other words, she had subcontracted the care assignments to her sister. This, however, was not acceptable and the care arrangement was terminated.

In another case from a municipality on Zealand, the daughter-in-law was the self-appointed helper in the family. However, the municipality discovered that she also had a full-time cleaning job with working hours not compatible with her assignments as a self-appointed helper in the morning, at lunchtime, in the afternoon and in the evening. Confronted with this enigma, the daughter-in-law explained that she went home during her lunch break to help her mother-in-law with lunch and to go to the toilet. Despite this, the care manager still suspected that something was wrong; she actually considered contacting the municipality's "social fraud unit" (*enhed mod social bedrageri*). The idea was that they should secretly follow the daughter-in-law and see whether she did return each day during lunchtime. If not, the care manager would terminate the arrangement.

8. Conclusions: Phantasmatic Asymmetry and Ambiguous Belonging

Due to demographic developments, the number of elderly citizens with a Muslim immigrant background is rising. Many prefer to be helped and cared for by family members instead of making use of the public welfare scheme where different homecare workers visit the elderly citizens day and night. Therefore, the option of having a family member employed as a self-appointed helper through the municipality is attractive. In this respect, the section 94 care arrangement becomes a prism that highlights numerous dilemmas and paradoxes in elderly care and the relations between Muslim immigrant families and the

welfare state. Basically, it is impossible for both the self-appointed helpers and the care managers to live up to the legislation and to administrate and work by the rules (cf. Rytter et al. 2021b).

The care managers are perfectly aware that when it comes to the self-appointed helper arrangement, they must navigate between "what we are supposed to do" and "what we actually do". They take a pragmatic approach, a flexibility that makes the care arrangement work in the families. The neglect of their responsibility to secure and monitor the care and rehabilitation of elderly citizens and the work environment of the self-appointed helpers can often be excused or explained away as a consequence of their general workload and their many cases and responsibilities. They must ensure that help and care are provided to numerous elderly citizens, which means that the special care arrangement of self-appointed helpers is given less attention than it actually deserves.

On the contrary, when the self-appointed helpers stretch the limit of the silence agreement to such an extent that the care managers no longer can or will accept it, they face severe sanctions and consequences. In other words, it is the care managers who take action when the intimate belonging of a self-appointed helper is viewed as problematic. We have presented several cases where the pragmatic flexibility of the care arrangement is suddenly re-interpreted by the care managers as deliberate neglect of the work contract and as social fraud. This shift emphasizes the asymmetries of the mutual silence agreement: the self-appointed helpers—the Muslim immigrant women—are the vulnerable party in the relationship.

When the silence agreement breaks down, we hear in our interviews and focus groups how care managers tend to switch to a "culturalist" discourse, where the helpers' neglect of assignments is presented as self-fulfilling prophecies. Suddenly, they are no longer presented as appreciated employees, but mainly as immigrant women determined by their cultural (Middle Eastern or South Asian) background and religious (Islamic) orientation (see also Sparre 2021a). They are seen and presented as members of Muslim immigrant families who deliberately appropriate resources from the welfare state that they are not entitled to (Rytter 2019).

It is this sudden change in the social situation between the care manager and self-appointed helper that we suggest interpreting as a haunting phantasm. The mutual respectful relationship is suddenly dominated by the spectral image of the Muslim immigrant as a problematic welfare scrounger. If the self-appointed helpers step out of the grey zone of the silence agreement, they are inscribed in an orientalist texture where Muslim immigrants are presented as radical others. The breakdown comes to exemplify how: "racialized minorities carry what might be termed the 'burden of representation', as they are seen to represent the capacities of groups for which they are marked and visible *per se*" (Puwar 2004, p. 62).

As long as the silence agreement is in effect, the self-appointed helpers enjoy the privilege of being unmarked and invisible (Sparre 2021b). On the contrary, when the silence agreement is terminated, the helpers become hyper-visible as a specific kind of problematic Muslim immigrant. The dynamic illustrates the kind of ambiguous belonging to the welfare state that is possible for the Muslim immigrant populations (Thelen and Coe 2019; Thelen et al. 2014; Sparre 2021a). Their actions, physical appearances and relationships are always at risk of being haunted by the phantasm of the welfare scrounger and singled out as "not-quite-real" Danes (Rytter 2010), a segment of the population that, like parasites, enjoys the welfare benefits that they are not entitled to.

It is obviously too simple and misleading to conclude that all Danes or that the structure or the employees in the elderly sector are racist. It is similarly naïve to insist that there is no racism in Denmark or in the administration of the welfare state. Instead of choosing between these two extreme positions, we suggest paying attention to the subtle dynamics of local encounters, where street-level bureaucrats (care managers, social workers, police officers, school teachers, etc.) suddenly slip into a "culturalist" discourse that presents Muslim immigrants as people who, due to their foreign background and religious beliefs, tend to neglect Danish laws and by illegitimate means appropriate resources and welfare

benefits which they are not entitled to. This, we claim, would never have been the case if the self-appointed helper had an ethnic Danish background. Rather, the encounter is formed by a phantasmatic asymmetry that questions the Muslim immigrant woman's legitimate belonging to the Danish nation and welfare state. In this respect, the breakdown of the silence agreement ends up contributing to the ambiguous belonging and general stigma of Muslim immigrants.

Future research needs to pay more attention to the way that relationships and encounters between Muslim immigrants and street-level bureaucrats are haunted by asymmetrical phantasms and culturalist assumptions of "us" and "them", majorities and minorities in Danish society. This kind of research will, hopefully, provide more sophisticated analysis and understanding of racism and othering in the egalitarian Danish society and welfare state.

We end the article by returning to Bushra, the 46-year-old Danish-Pakistani woman introduced earlier, who takes care of her old mother who suffers from dementia. Today, Bushra is contracted 31 h per week but works day and night to help and provide care for her mother. Thus, she is an example of a more general trend in the families we followed during the AISHA project: what often started out as a manageable task of helping an elderly family member a few hours a week may over time become unbearable as the condition of the elderly family member gets worse. Bushra, for example, has not taken any holiday in four years. Not only is Bushra in a precarious situation due to her working conditions and working environment as a self-appointed helper; but she, like other Muslim immigrant women in similar situations, also risks further stigmatization, sanctions and exclusion if she is "caught" receiving help from other family members in caring for her mother.

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Note

[1] The self-appointed helper arrangement is popular among Muslim immigrant families. However, the majority population is also involved in taking care of their ageing parents, and due to reduced homecare coverage in Denmark, there is a political wish to involve family members more in the care and support of elderly citizens (Rostgaard et al. 2022). However, many still prefer a professional homecare worker to provide everyday personal care services such as assistance with bathing, grooming and dressing (Christensen 2020).

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