Gendered care of ageing migrants and their families in the welfare state:

The case of the self-appointed helper arrangement in Denmark

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Introduction

The focus of this paper is an option in the Social Service Act, under which municipalities can contract a family member to take care of an elderly citizen at home. Due to the special construct of the §94 arrangement, the 'carer' is at the same time a professional care worker, formally employed by the municipality, and a close relative of the citizen in need of care.

The paper examines consequences of this care arrangement from the perspective of municipal care managers, focusing particularly on state-family divides, gender dynamics and problem displacement in need assessments and care provision.

The paper is based on data from a three-year research project 'Ageing Immigrants and Self-Appointed Helpers Arrangement' (AISHA), which explores the implications of the self-appointed helper arrangement from the perspective of the immigrant families and the municipalities. More specifically, data stems from 21 individual and nine focus group interviews with as well as observations of encounters between care managers and self-appointed helpers. In total, I talked to approx. 40 care managers (apart from other municipal actors) across Danish municipalities in 2018 and 2019.

Ageing immigrants and elderly care in Denmark

In Europe, a growing population of the elderly citizens have refugee or immigrant background, and many have their origin in non-Western countries. Often, care arrangements in these families are different from those of the majority populations (Hansen 2014, Moen 2013). In Denmark, only a small proportion of ethnic minority elders live in senior housing, and fewer compared to citizens with non-immigrant background receive home care. Instead, research indicates that immigrant families often take care of

elderly family members at home (Liversage and Jakobsen 2016), and the caregiver is often a (younger) woman.

Such practices tend to clash with, on the one hand, ideals of gender equality and equal rights to education and employment in many European countries (Borchorst and Siim 2008), and, on the other, state demands of employment as part of the social contract in the welfare state (Jöncke 2011). At the same time, municipalities see more informal care arrangements as cost-effective (Ungerson 2003) as well as ways to avoid potential difficulties in providing care for non-Danish speaking elderly citizens with expectations different from those of the majority population (Sparre and Rytter forthcoming).

Theoretical inspiration

Overall, my analysis contributes to the growing literature on care as negotiating boundaries between state and family (cf. Thelen and Coe 2017; Thelen and Alber 2018). More specifically, I also draw on perspectives on gender, equality, and liberal (state) feminism in Scandinavia and beyond (Mahmood 2005; Abu-Lughod 2002; Borchorst and Siim 2008) and perspectives on the double-sidedness and ambivalence of empathy (Bubandt and Willerslev 2015; Hollan and Throop 2011, Wispé 1986).

Care managers make decisions about the specific services granted based on legislation and organizational prerequisites. However, they are also constantly negotiating and defining the threshold between family care and state care (Sparre and Rytter forth.). Furthermore, interviews and observations call attention to a particular dynamic in care managers' interaction with particular family members. The paper demonstrates how care managers slip in and out of their roles as health professionals, administrators, and morally concerned citizens in encounters with especially (younger) female informal care workers of immigrant background.

Public elderly care and the self-appointed helper arrangement

In Denmark, social services for elderly citizens are provided mainly by the 98 municipalities that are fully responsible for public governance, provision, delivery, and financing of elderly care. Similar to other Nordic countries (Forssell et al. 2015), the overall responsibility of care for the elderly rests with the state and not the family, although more informal care arrangements for elderly citizens are practiced widely across the population. All elderly people who legally reside in Denmark, temporarily or permanent, and are in need of help and support in activities of daily life can apply for assistance (Europa-Kommisionen 2018). They then usually have the choice between municipal homecare, care

provided by a private supplier, or a 'self-appointed helper' (§94 in the Social Service Act). The self-appointed helper is employed a certain number of hours weekly, according to a measurement which follows the guidelines in the regular home care system.

The self-appointed helper arrangement bears some similarities to arrangements in other European countries where elderly receive state support to employ directly their own care labour (Ungerson 2003; Forssell 2013). Similar to other countries, arrangements such as the §94 only stand for a small percentage of the overall elderly care provision. However, care workers with migrant background are overrepresented in such arrangements compared to the public professional care sector (Ungerson 2003; Forssell 2013). This is also the case in the Danish context. The majority of elderly with a self-appointed helper arrangement are immigrants from non-Western countries, in particular the Middle East, South Asia and Africa.

Furthermore, the §94 arrangement has a gender bias, in particular in ethnic minority families. Typically, the caregiver is a wife, daughter or daughter-in-law of the elderly person in need of care.

Care managers as bureaucrats: managing the state-family divide

Care managers are as state actors shaped in a relational setting (Thelen, Vetters and Benda-Beckmann 2014: 6) and often with several, sometimes conflicting, roles or demands simultaneously (Forssell 2013: 91). They are "administrators, information officers and gatekeepers to the welfare state" (Forssell et al. 2015: 578) expected to follow legislation and objective standards as any other caseworker, but at the same time, they are also trained health professionals, often nurses, who have been trained as caregivers.

Their primary responsibility is to assess needs and make sure that the elderly person gets the help that he or she needs and are entitled to receive. Their decisions build upon a meticulous system combining assessments of the citizen's physical and mental abilities with the time offered for each activity according to the municipality's service catalogue, although care managers are also obliged to make each assessment individual. In addition, they are responsible for employing the self-appointed helper. Before contracting a potential helper, care managers have to make sure that she is mentally, physically and practically capable of carrying out the tasks.

Self-appointed helpers are paid a monthly salary calculated based on the services they provide for their family members. The measurement follows the regular home care system, insofar as their time allocation equals what it would take a trained care worker e.g. to help a particular elderly citizen to the toilet. Services not provided by the home care as well as

services offered through an external partner (such as laundry service and grocery shopping service) do not result in working hours for the helpers. Consequently, very few helpers are employed more than 5-15 hours weekly. They are not entitled to retirement benefits, and if the ageing family member recovers, is hospitalised or dies, helpers are out of job and back to square one without a job. In many municipalities, their salary stops immediately or within a few days.

Care managers are aware of these rather unfavourable employment conditions for the helpers. These conditions are, however, also what makes the arrangement economically favourable for the municipality:

> Well, the §94 arrangement is the cheapest solution for the municipality, rather than having the home care out there. After all, §94s are considerably more flexible than the home care. Then you can ask, if this is good or bad, right, because if they are not allowed [by the elderly to carry out a task], they will come back later. Or maybe they even *live* together with the elderly, so they are much more flexible. But I also think that some way or the other we make mini-senior homes in a lot of private houses. Is this what we should do? Is this what we want? (Hanne - AV, Aarhus).

Economically, the §94 arrangement is a good solution; in a cost-effective way it assists families, who otherwise refrain from using public elderly care facilities. Also, as the care manager indirectly suggests, some of these elderly might not be the easiest persons to provide care for, which then spares the municipality for potential disagreements with the elderly and their families.

Many care managers, like Hanne, are however, critical of the arrangement. Their concerns mainly focus on the lack of rehabilitation and the risk that a helper does not notice important danger signals when it comes to the elderly's health situation. Care managers are also sometimes worried about helpers' work environment, particularly if they have to move an elderly around. However, they have very limited ways to ensure that the care work comply with the ideas and norms on which the legislation rests, and as I have argued elsewhere, they often turn their blind eye to it (Sparre and Rytter forth.).

Care managers also cannot change the fact that many helpers work more or less around the clock, mainly due to what care managers see as norms and expectations in the families. Being a self-appointed helper often "collides a little with being a family; the old culture that you help each other is still there – for better and for worse", as Vibeke (HA, Ishøj), another care manager put it. Thus, most of the time, care managers' focus on assessing needs and assigning care services in accordance with standards and legislation, and they leave it to

the families whether or not this would be a suitable arrangement for the helpers. However, sometimes they had other concerns.

Care managers as caregivers: young wives and daughters/daughters-in-law

Sometimes, however, care managers' care extends beyond the elderly and the administrative and legal procedures. Vibeke, said:

> Basically, it is an economically cheap arrangement. Then you could of course say that it has some other costs – if the daughter-in-law is not integrated and does not get a job. How is it on the longer term? (Vibeke - HA, Ishøj)

This view reflects a widespread unease among care managers when it comes to long-term societal costs and not least life prospects and wellbeing of the especially younger female self-appointed helpers. This is an example of how another care manager, Annette, governed for the sake of a young wife, the helper of her much older sick and ageing husband:

> I have one example with a married couple and what they do for each other. We ended up declining their application to employ her as his helper, because … he was 54 and then he had married a woman who was 20 years younger. And he had married her, because she was supposed to take care of him. She was sitting there beside his chair, ready to jump up. […] In fact, he got really angry, but because we couldn't reach an agreement [about what he could do himself and what he needed assistance for], the case was decided and she was rejected as helper, because she wouldn't be capable of putting her foot down" (Vibeke - LM, Aarhus).

Annette here describes an assessment meeting in an ethnic minority family. After visiting the couple, the care manager decided that the woman would not be able to put her foot down and say no to her husband. Thus, instead of paying her only for the activities that he *really* needed assistance for, the care manager decided to reject the application altogether. She was concerned about the well-being of the woman who might become "even more isolated and detached from Danish society". However, care managers have no warrant for rejecting §94 applications with reference to the wellbeing of the helper. Instead, they have to prove that the helper would be unable to deliver the required services, due to either physical constraints (e.g. back injury) or other commitments such as educational activities or another employment.

This unease is even more widespread if the helper is a young daughter or daughter-in-law. Another care manager, Hanne, explained how she recently had rejected an application, where a father wanted to employ his daughter as self-appointed helper. The daughter was a

student, and Hanne rejected the father's application because his daughter would not be able to provide care and assistance at the specific time spans needed. This is how Hanne describes the case:

> Many of them, I think, are forced into this by the family. That this is something you do. Earlier this week I closed down a §94 case, and I chose to write a letter to them saying that it is not possible for me to employ his daughter. Luckily! Because she cannot deliver the help he needs day and night (Hanne - AV, Aarhus).

Gendered care and problem displacement

As the examples show, from time to time care managers switch perspective. They mainly take the position of the detached bureaucrat or health administrator when deciding the needs of the elderly citizens and the working hours and care responsibilities of the self-appointed helpers. They govern for the sake of the elderly's wellbeing and right to care.

However, sometimes they switch perspective and express more concern for the wellbeing of the self-appointed helper than of the elderly citizen. This is when they suspect that especially younger women "are forced into this by the family". In such cases, the care managers take drastic decisions to protect the self-appointed helper. Put differently, the care of the care manager extents to include the helper.

This was the case when a care manager decided to reject the application of the young wife. And it is the case when they express concern about young people (especially daughters or daughters-in-law but also younger wives) being 'parked' in the families as care workers with no access to Danish education or 'the real' labor market. This is a particular kind of 'problem displacement' where the care managers suddenly give more attention and care to the self-appointed helper than the ageing citizen.

A way to approach this problem displacement is to see it as a form of gendered care: female health professionals and ethnic majority women caring for a 'sister' – showing their solidarity and empathy. If we then approach such decisions through the idea and concept of care as empathy, we will come closer to an understanding of the dynamics and consequences of encounters between female ethnic majority health professionals and (younger) ethnic minority women.

Empathy and othering

Empathy differs from sympathy. "Sympathy, one might say, gives purchase on identity to achieve compassionate communion. Empathy, meanwhile, is a form of vicarious insight into the other that insists on one's own identity. Empathy involves, therefore, a double movement

of the imagination: a stepping into and a stepping back from the perspective of the other, at once an identification with an other and a determined insistence of the other's alterity" (Bubandt and Willerslev 2015: 7, see also Wispé 1986).

In these particular encounters that care managers have with younger immigrant women and their families I see their relationship with the helpers as pervaded by ambivalences and reflecting the inescapable ambivalence in empathy. They strive to identify with them as 'sisters' or 'daughters' in a national community by imagining their lives and futures, but the ways many of them encounter and talk about the mostly immigrant (Muslim) women reflect a specific Western liberal discourse of individually, gender equality and ideas of liberating the oppressed (cf. Mahmood 2005; Abu-Lughod 2002). In other words, through "empathy [they] strive[] toward identification, yet do[] so while (re-)producing radical alterity" (Bubandt and Willerslev 2015: 29). These women need to be "saved" from their families and "culture" in order to be "liberated" (cf. Abu Lughod 2002). For this reason, care managers' words and actions sometimes disclose what Nils Bubandt and Rane Willerslev term the "dark side of empathy"; they risk doing more harm than good, because their empathy may foster stigmatization and marginalization rather than empowerment. In other words, while care managers are motivated by a wish to undo difference and include these women in what they see as independent Danish/European women and citizens, they sometimes end up doing difference, but are able to construct it as liberating because they draw on specific ideals of equality and individuality.

In other cases, where this kind of empathy and identification is not at play, care managers seem to do the opposite by withdrawing perhaps a little bit more than they would have done in Danish majority families. They leave it up to the family to organize themselves, because they see these elders as having less need for state care because they "'still' have kin support (Thelen and Coe 2017: 11-12). As I have argued elsewhere, it seems that many of the care managers approach the families with certain ideas and expectations as to family care in immigrant families, which in some cases result in them accepting rather extreme working conditions for the helpers.

Conclusion

As I have argued elsewhere (Sparre and Rytter forth.), care managers inhabit an ambiguous position, where they oscillate between the framework of legislation, economic restraints and municipal decisions, on the one hand, and the care, empathy and sympathy that they as "street-level bureaucrats" (Lipsky 1980) and health professionals have towards the population they are supposed to control (Hoag 2011: 88), on the other. Both dynamics

described above – 1) care managers decisions to reject the application in order to "save" an immigrant woman from care obligations, and 2) care managers accepting care arrangements which do not always comply with rules and regulations – reflect the care and concern that health administrators often have towards their clients. These concerns may be legitimate and based on previous experiences, but in these cases, they also seem to rest on specific dominant ideas of Arab/Muslim immigrant families (Simonsen and Kofod 2010, Hervik 2011). The families are seen, discussed and approached as radically different from Danish families. As a result, a family member (often a wife or daughter) is seen 'unsuitable' for the position as self-appointed helper. However, in many cases these family members will continue to do care work for their elderly family members without being paid for it.

In the near future the Danish welfare state will have to come up with new models to care for the growing number of elderly citizens with immigrant and refugee backgrounds who refuse public elderly care such as home care and nursing homes. These models might build on care schemes such as the self-appointed helper arrangement. It is, however, vital to come up with models that address the special needs of immigrant families in order to secure equal rights and care of these ageing citizens and work to improve the inclusion and belonging of citizens with immigrant backgrounds in the national community and the welfare state.

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