The precariousness of asylum-seekers’ care and support: informal care within and because of the immigration process

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Using ethnographic data, this article aims to analyse the provision of informal care by asylum-seekers in Sweden and how this intersects with the(ir) asylum process. The article argues that asylum-seekers are framed by the Swedish welfare system and immigration authorities as ungrievable and deportable, which not only impedes their access to formal care systems and values, but also creates a strong need for informal care. Further, it is suggested that the informal care provided by asylum-seekers should be included in current debate on informal care and its impact on people’s lives.

Key words informal care • asylum-seekers • deportability • migration

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Introduction

Fatemeh is applying for financial compensation to stay at home with her youngest daughter. Omar retrieves the decision they’ve received on their application. I look at it together with a friend of the family. It has been rejected. It states that the daughter does not meet the criteria specified by the Act Concerning Support and Service for Persons with Certain Functional Impairments. Their friend finds this odd since the daughter has a brain injury.
I ask to see the medical certificate, which states that the daughter has been making so much progress after getting help with her hearing that the doctors want to wait for further measures. (Observational note)

Fatemeh and Omar Khalil fled Syria to Sweden with their four children. After receiving a temporary permit to stay in Sweden, they are trying to obtain financial support to be able to continue providing their youngest daughter with care and support within the family. The first time we met the daughter during this research project, she had great difficulty making herself understood. Occasionally, she suffered sudden seizures, and she required constant supervision. However, the daughter’s situation improved over the following two years. Regardless of the daughter’s improvements, the family still has to provide care round the clock. The care is provided simultaneously as the family is trying to navigate what formal support and care they can or cannot expect due to their changing status as asylum-seekers.

Care and support provided by, for example, family members are commonly known as informal care. Although there is no universal definition of informal care, it is by default to be understood in relation to formal care. Formal care is provided by the public sector or contracted out by the state to the private sector (Szebehely, 2005). Informal care connotes the kind of (often unpaid) care and support regularly provided to a person with a chronic illness, disability or other long-lasting health or care need. It is usually provided outside the formal care system – by immediate family members, other relatives, friends or neighbours (Arber and Ginn, 1990; Larios, 2019). At the same time, it can be argued that most relationships between friends and family members involve some support and care. To distinguish informal care from care taking place in ordinary social life, Revenson et al. (2016: 6) suggest that it depends on whether the act of care is part of what could be considered the ‘normal exchange of support’ or if the care provided is ‘above and beyond that what is typical within a particular relationship’. They suggest that informal care can be distinguished by the latter, meaning that the care is provided over an extended period and on a regular basis. Informal care is often described as unidirectional rather than bidirectional (Andréasson, 2021).

In the field of migration and informal care, scholars have focused particularly on the provision of informal (and formal) care to an ageing foreign-born population. The Swedish Association of Local Authorities and Regions (SALAR, 2021) points out that older people and people with disabilities, together with those with a migrant background, experience unique challenges when trying to obtain social support and services (De Tavernier and Draulans, 2019; Chaouni et al, 2020; Czapka and Sagbakken, 2020). Indeed, asylum-seekers, in particular, often lack the same civic rights as full citizens in a country, making their access to the public care system limited or conditional in various ways (Lobo Pacheco et al, 2016). In turn, limited access leads to a higher risk of social exclusion (Larios, 2019). Another common discussion focuses on care provided by children, for instance, when they act as ‘cultural mediators’, playing the role of interpreter or support person for adult family members in interactions with public authorities (Orellana, 2001; de Block and Buckingham, 2007). This research, however, does not explicitly relate such ‘mediation’ to informal care. Instead, it describes certain contexts where informal care and support are expected. Such perspectives, however, seldom discuss the fact that this expected or taken-for-granted informal care is a result of being involved in asylum application processes and living under threats of deportation.
Consequently, research shows that asylum-seekers often depend on informal care and support from family members, friends and volunteers. However, an analysis of the intersection between the migration experience, asylum process and informal care among families with a migration background is still missing. Asylum-seekers’ life predicaments may simultaneously be limited by different systems within the apparatus of the Swedish state. Their status as asylum-seekers may restrict their access to formal care (except emergency care) and the labour market, and require them to fulfil demands dictated by the migration authorities. Although the ultimate responsibility for care in Sweden lies with the state, the migration process can produce an increased need for informal care, at the same time as the very same processes can hinder people from performing such care. Following this, in the context of their status as asylum-seekers, this article aims to describe and analyse asylum-seekers’ understanding of their provision of care and support, and how it is affected by and intersects with the(ir) asylum process. The article employs a qualitative and ethnographic approach. Asylum-seekers and their families were followed for two years, and data were gathered through interviews and observations. We use the concept of deportability as a conceptual framework to discuss our participants’ experiences as they navigate the Swedish immigration system and the healthcare system.

The article is structured as follows. First, we briefly describe how informal care, as a phenomenon, can be understood in the context of Swedish society and internationally. Then follows a description of the conditions that asylum-seekers encounter when applying for asylum or residence in Sweden, and what this entails in terms of their ability to access formal care. Next follows a section on methods and research design, followed by the findings section. Finally, in the conclusion, the threads are brought together and the aim of the article is addressed in a theoretical and summative manner.

Background and literature

Informal care internationally and in Sweden

Internationally, we see an increasing refamilisation due to fiscal constraints on care budgets, ageing populations and changing family patterns (Jegermalm and Sundström, 2017; IACO, 2018; Dahlberg et al, 2018; EIGE, 2019). An increasing refamilisation means that more responsibility is put on families to take care of significant others in need of care and support since the public care apparatus is required to target the people with the greatest needs. Informal care is understood as a significant societal resource that involves between 10 and 25 per cent of the total population in different countries, depending on how informal care is understood, defined and measured (Zigante, 2018). For example, in some Southern European countries, the family is considered the minimum social unit of society, creating a clear set of societal expectations of and obligations on family members to take care of one another. In other countries, such as Sweden, the individual is considered the minimum unit. There is no formal obligation for individuals to take on care responsibilities, as these responsibilities rest with the welfare state and, ultimately, the municipalities (Andréasson, 2021). Nevertheless, people in Sweden may, of course, feel obliged to provide informal care.

It has been estimated that as much as 80 per cent of all long-term care in Europe is provided by informal carers, with about two thirds of this care being provided by women (Zigante, 2018). Correspondingly, family carers can be seen as the backbone
of long-term care in the US, providing an estimated 34 billion hours of care annually, encompassing more than one in five Americans (NAC and AARP, 2020). Informal care can include a wide variety of support, for instance: providing practical support, such as domestic work and personal care; emotional support; and administrative support, such as coordinating care and interacting with various public authorities (Jeppsson Grassman, 2003). In scholarly debate, informal care has often been explicitly related to the care of older people and people with different kinds of disabilities, as well as partners’ and parents’/children’s care for their loved ones, as with the youngest daughter in the Khalil family, already mentioned. In the wake of new legislation in Sweden in 2009, however, the National Board of Health and Welfare Sweden (NBHWS, 2016) has emphasised that available support includes all carers.

As such, scholarly debate on informal care has focused less on its relationship with the asylum process and the precariousness that typically surrounds people entangled in the process. Since migrants move between different national contexts with varying understandings of and approaches to formal and informal care, and since they often have less access to formal care, it becomes relevant to discuss how informal care is viewed and understood in the context of an asylum application process.

**The migration process and its precarity**

The prospect of seeking asylum in Sweden is challenging in many ways. Several researchers have pointed out the obstacles that face those wishing to immigrate to Sweden and the difficulties inherent in, and related to, navigating the asylum process (Sager, 2011; Sager and Öberg, 2017; Andréasson, 2021). Between 2014 and 2016, about 270,000 individuals and families arrived in Sweden seeking asylum (Swedish Migration Agency, 2021). This was a significant increase in asylum-seekers, which led to long waiting times, crowded asylum camps and stressed reception providers, such as migration authorities, social welfare offices and health services. Such concepts as ‘system collapse’ and ‘breathing space’ were used by politicians to motivate a new law (2016:752) on temporary restrictions on the ability to obtain a residence permit in Sweden. This law also eliminated the possibilities of family reunification for many migrants. Simultaneously, a new Swedish public rhetoric emerged that described migrants/asylum-seekers as problems and threats to the Swedish economy, rather than assets to society (Sager and Öberg, 2017).

Further, the tougher socio-political climate increased the demands placed on asylum-seekers, forcing them to care for themselves to a greater extent, without any, or only limited, support from authorities and other public support systems. However, some help is still available. As an asylum-seeker, you can receive access to housing and between SEK12–71 (approximately €1–7) per day, depending on age and whether food is included with the housing. After receiving a temporary or permanent residency, you can seek help from the municipality. However, you are expected to manage on your own, first and foremost, by finding a job and somewhere to live, and providing for yourself and your family. For some, this tougher climate has manifested through the highly individualised asylum process, requiring applicants to prove themselves worthy of the right to stay in Sweden (see the discussion on civic integration later). For others, failure to obtain asylum or a residence permit forces them into hiding and having to care for themselves, without access to even the most basic rights, such as healthcare, welfare benefits and a roof over their head.
(Nordling, 2017). Some people in hiding are pushed into a state of limbo, where they are not either able to return to their country of origin or allowed to stay in Sweden. Thus, asylum-seekers are left to fend for themselves and their loved ones, without sufficient support from what is otherwise, in an international comparison, considered a generous welfare system (Lundberg, 2017). As such, based on existing literature, we argue that the asylum process itself contributes to, or even generates, a need for informal care among people with a migrant background in Sweden because they are not always entitled to the formal care and support (normally) provided to citizens.

The evolution of immigration policy described earlier is related to a similar development evident throughout Europe and internationally, often described as an increase in so-called ‘civic integration’ policies (Borevi et al, 2017). ‘Civic integration’ includes a trend whereby the help or support offered to migrants is more a matter of ‘self-help’, consisting of demands to learn the language of the country, perform specific citizenship tests or, importantly, settle in the ‘right’ places, and seek work outside the family. These demands are explained as helping the migrant integrate into society, but migrants unable to fulfil them are met with financial sanctions and, by extension, deportation. According to research, such policies are considered as more a disguised form of migration control than as actual help aimed at the individual or family (Goodman, 2011; Ahlén and Boräng, 2018). One particularly notable civic integration measure has been to urge migrant women to take work outside the family, often resulting in them being steered into precarious work (Farris, 2017). Working under poor conditions and with the threat of deportation, asylum-seekers perform (care) work that the middle class no longer want to do themselves, such as social reproductive labour (Farris, 2017; Mulinari, 2018). Civic integration can be related to the issue of informal care not only because this work rarely counts in this discourse as enough proof of work to receive a permit to stay, but also because the conditions resulting from poor working conditions without social rights can create or increase the need for informal care.

**Conceptual framework**

In this article, we analytically use the concept of *deportability* when addressing the unclear, uncertain and precarious conditions associated with the asylum application processes (De Genova, 2002; Sager, 2011). Deportability is used to capture the constant risk asylum-seekers face of being wrenched from their daily life due to their status as non-citizens. Asylum-seekers are forced to live under the threat of deportation and suffer the effects of living under constant uncertainty. Deportability also tends to create precariousness, in that people are excluded from being able to demand or to exercise their social and human rights (Sager and Mulinari, 2016). An increased precariousness is based on the notion that society generally becomes more uncertain in terms of, for instance, more temporary jobs, temporary housing or temporary residency (Khosravi, 2017). In the context of migration, Sager and Öberg (2017) argue that there is a continuum of deportability manifested as a social structure (producing precarity), not only as an issue of legal status. This continuum includes legislation and immigration policies on residency, work permits, family reunions and, sometimes, access to care and support. Due to the lack of rights and the civic integration demands imposed during and after the asylum process, the process itself...
potentially increases the need for informal care. These demands also push people away from their families and friends, and into precarious work. Consequently, we argue that the asylum process contributes to a need for informal care, while simultaneously complicating the ability to perform such care.

In the context of asylum-seeking, people can be understood as being framed as deportable (Butler, 2009). Butler (2009) uses the concept of frames to describe how people are framed like a painting, meaning that they are socially positioned in a certain way within social structures. According to Butler (2009), an epistemological framework determines what lives are deemed ‘grievable’ or expendable. Migrants considered deportable, we argue, can be understood as being epistemologically framed as ‘ungrievable’. When framed as ungrievable, people are not regarded as worth grieving for or keeping within the national borders; instead, through social structures (that is, immigration policies, legislation and so on), they are framed as expendable enough to deport. This framing leads to them being given fewer rights and receiving less support than people deemed not deportable, that is, grievable. However, framing should not be read as static or unchangeable. It is possible to reframe people into becoming grievable (Butler, 2009). It could, for instance, be possible to reframe people considered deportable into fully grievable human beings or to frame people as grievable regardless of their position in the asylum or immigration process (see Björngren Cuadra, 2015). Since people are framed as ungrievable by the welfare system, however, it is possible to imagine other actors (for example, organisations, family and friends) taking on a greater responsibility to provide help and support when needed. Deportability thus affects not only the person being put in a deportable position, but also the people and contexts around this person (Sager and Öberg, 2017). Deportability reproduces a vulnerability, including of their families and those who need informal care. In this sense, deportability can be understood as being socially ‘contagious’ or transferrable.

In this article, we use the concept of deportability as a framework for a discussion unpacking our participants’ experiences as they navigate the Swedish immigration system and the healthcare system. We focus on how they perform and understand informal care in a context that essentially frames them as ungrievable, paying interest to how it affects their life situation and social relationships.

Methods and research design

The article builds on a longitudinal ethnographic project in which different aspects of migrants’ and asylum-seekers’ experiences and life predicaments have been sought. Data were gathered mainly through interviews, informal conversations and participatory observations. In total, 35 current or former asylum-seekers contributed their stories, constituting the basis of our data collection and analysis. While their countries of origin vary, they correspond largely proportionally to the groups of people who arrived in Sweden at the time of the fieldwork (2015–21), mainly from Afghanistan and Syria, though also from Eritrea, Lebanon and other countries (Swedish Migration Agency, 2021). A few were initially unaccompanied young people (16–19 years old), while others arrived with their families (consisting of one or two parents with children). The formally and individually interviewed participants varied in age, stretching between 16 and 65 years old. Some families also had younger children, though these minors were not interviewed for ethical reasons. The participants
had different legal statuses: some had been granted permanent residence; some were awaiting a decision; and some were awaiting deportation. They all shared the experience of the Swedish asylum process.

Concerning epistemology, a relatively open-ended approach and research design were employed when conducting the study (Maxwell, 2004; Hammersley and Atkinson, 2007). Ethnography was approached as a relational philosophy of research (Anderson-Levitt, 2006; Skukauskaite and Green, 2012). We participated in the daily lives of our participants for an extended period, listening to them and observing what happened in their interactions with family members, public authorities and others. Consequently, the analysis presented in this article is to be understood as the outcome of an intersubjective process between the researchers and the participants.

We met with the participants repeatedly during the empirical work, often monthly. All participants were interviewed formally on at least two occasions. Repeated informal talks and observations were also undertaken during fieldwork. This approach allowed us to capture their changing understandings of their life situation and predicaments, and how relationships evolved due to, for example, informal care. The first interview was semi-structured, in the sense that our questions dealt with specific themes, including the participants’ background, their escape to Sweden, their experience of Swedish public authorities, their interactions with civil society, their status in the asylum application process and their family life. We asked the interviewees about their situation in Sweden and how it impacted their families and loved ones. We also asked how the asylum application process was understood and about care and support from others. Follow-up interviews were usually less structured and designed to clarify any uncertainties. The interviews lasted between 45 minutes and three hours, and were recorded and transcribed verbatim.

We also conducted observations and took part in the daily life of the participants, including meetings with officials and social encounters with friends/family. This approach was seen as conducive to establishing relationships of trust and unravelling various aspects of ordinary daily life that might otherwise be forgotten or perceived as trivial (see Fangen, 2005). Additionally, observations also made it possible to resume discussions initiated in interviews and to ask the participants to develop their thoughts on what happened during observations in follow-up interviews (see also Banik, 1993). Observational notes were taken immediately after observations and contained both descriptive information and, in a separate column, initial analytical ideas and reflections. Methodologically, we intended to capture the participants’ subjective experience of providing and receiving support related to their experiences of the Swedish immigration and asylum-seeking context. We read the transcriptions and observational notes several times to familiarise ourselves with the data, and then sorted and coded the data (Hammersley and Atkinson, 2007). The analyses were conducted in a dialectical process, moving between data, previous research and central theoretical concepts; based on this process, the data were sorted into themes (Hammersley and Atkinson, 2007).

Further on in the writing process, the themes were gradually refined through the dialectical process of moving between reading and writing within ethnographic research (Hammersley and Atkinson, 2007). Quotations presented in the findings were selected mainly based on them capturing both subjective experiences and the structural prerequisites surrounding these experiences. All names and places mentioned
have been anonymised to ensure confidentiality. Formal ethical approval was secured from the Regional Ethical Review Board (2018/239-31).

Findings

The findings are presented in three sections. First, we discuss how the participants understand informal and formal care within an asylum context. Second, we focus on how the asylum process itself serves to frame the participants as ungrievable, pushing them into precarious life situations that increase the need for informal care. The final section focuses on a specific tendency to want to spare relatives from pain and suffering, and how these actions can be interpreted as informal, paternalistic care influencing family relations.

Providing care and support

In this section, we look specifically at how the participants described the need for care and support, and their provision of it. Some of the participants have access to formal care. Nevertheless, they are all engaged in simultaneously trying to take care of their family members and navigate their asylum-seeking processes. We meet the Khalil family again. Here, Omar, the father, deals with his daughter’s medicines:

Omar collects the bag with all the medicines their daughter needs. He shows them to us and explains their use thoroughly. Omar provides her with the medicine because it’s mainly he who accompanies her to the hospital. He talks about how hard it is to get a good night’s sleep, as they must monitor their daughter round-the-clock. Omar looks tired. (Observational note)

This type of round-the-clock care, which is not usually part of ordinary parental responsibilities and is not provided by public healthcare or social services, is an illustrative example of informal care and how it may intersect with parenthood (see Szebehely, 2005). However, as with other participants in the study, what complicates the Khalil family’s issue is their status as newly arrived in Sweden. They must not only provide extended informal care, but also navigate and understand the healthcare system, the social services and the Swedish Migration Agency. This is evident in the introductory quotation of this article, where Omar needs help to understand decisions made by, in that case, the social services. After receiving a rejection on their application, they want to apply for help from the Swedish social insurance system, and they ask us to help them navigate that process as well.

The disharmony between their immigration status and their roles as carers is also evident in the persistent demands on Fatemeh to finish Swedish-language education for adult immigrants (SFI):

Fatemeh studies Swedish during the day but doesn’t talk that much Swedish with me anymore. She finds it harder and harder, but today she brings her books and tries to speak Swedish with me. I ask her about the food bank, where we first met — how she finds it and what it means to her. The food is sometimes old, she says, and the bread stale. She goes on to explain that money
is tight and that a bag of food might cost around 500 Swedish kronor (approx. EUR 50), which they can use for something else. (Observational note)

The family lacks social security and is in constant need of financial support. We first met Fatemeh at a food bank, where she regularly obtains food for the family. At the same time, she is studying full-time to satisfy the conditions placed on her by the social services to receive any financial support. As immigration applicants, they are thus forced to live up to the demands put on them by the authorities in order to avoid being sanctioned or, worse, deported. As a result, the family is caught between complying with the rules and expectations placed on them by the authorities, on the one hand, and providing the best possible care for their youngest daughter, on the other. Therefore, the Khalil family must both navigate the rules and guidelines imposed on them as immigration applicants in Sweden, and find the best possible solution for their daughter’s care, while providing informal care themselves.

This need to chart a course between competing demands is particularly noticeable when people receive no support from the authorities or the healthcare system because of their immigration status. Daniel exemplifies this. He is Armenian and was 17 years old when he fled from Russia to Sweden with his mother, father and older brother. Initially, the family fled because of persecution and due to the mother’s poor health. They had heard that Sweden “helps people and provides good care”. However, as asylum-seekers, they could not get the support that Daniel’s mother needed. Instead, the family were left to take care of the mother, who was suffering severe depression and epileptic seizures, by themselves. Daniel’s family thus had to provide informal care to the mother. The care included providing her with medication and emotional support, and talking to her about her suicidal thoughts, even though they felt they lacked sufficient knowledge to support her when she was suicidal. As the mother had tried to commit suicide on several occasions, they also felt obliged to never leave her alone. In Sweden, formal care for those suffering from depression, suicidal thoughts and epilepsy is usually available, but this help was never offered to Daniel’s family because they are asylum-seekers. Thus, Daniel’s case exemplifies how the need for care intersects with how people are framed within the welfare system as sufficiently grievable or not.

In this section, we have provided examples of how informal care is performed and may manifest itself among the participants. Their informal care practices are intertwined with their life predicaments as asylum-seekers. The participants are primarily framed as less grievable than full Swedish citizens and given fewer legal rights. For some, this means not being granted access to any formal care at all, while for others, it means having some access to formal care. All, however, must balance their level of access with demands put on them as asylum-seekers to find housing and a secure job, or to learn Swedish within a specific time frame determined by the authorities’ different decisions. Should they fail to comply, it could result in deportation. This interrelatedness of what level of care can be obtained and provided, and the participants’ position as asylum-seekers, is further developed in the next section. We also discuss how their situation impacts social relationships.

Navigating the migration context and informal care

Informal care can be provided in many ways, such as parents providing extra support to their children due to medical issues or children providing additional support to
parents who are older or suffer from medical conditions. In our data, however, it is evident that the asylum context appears to ‘push’ the participants into an increased need for informal care, as the formal care system is either only partially accessible or not accessible at all because of how they are framed as asylum-seekers. It is also evident how contagious/transferable deportability and becoming ungrievable is among family members when looking at the issue of informal care.

One push into informal care can be brought to the fore when new family members arrive. One such case is Mahnaz. Mahnaz, who had been living in Sweden with a residence permit for years, was suddenly pushed into caring for her adult daughter, Afrah, and her two granddaughters, Mahtab and Sepideh. Afrah was abused by her husband and managed to flee to Sweden. She applied for a residence permit but was denied. Together with her two daughters, she is now hiding from the Swedish authorities to avoid deportation. Mahnaz talks about the situation:

Mahnaz: ‘She can’t return. The Migration Agency doesn’t believe her. They ask her, “Why can’t you return?” “It’s not the country; it’s my husband”, she tells them. “If so, why did he let you come here?”, they say.’

Interviewer: ‘They don’t listen?’

Mahnaz: ‘She couldn’t even get a passport without him signing for it. She got him to do it, but he took it and gave it to their neighbours. They helped her one day when he was away. We had to get her smuggled out. It’s not [the country]; it’s her husband. She doesn’t do anything anymore. If only she could get a job to get out of the apartment.’

Afrah’s situation as deportable has led to her isolation. She only stays in bed, refuses to go outside and does not take care of herself anymore. She is afraid that she will be suddenly picked up and taken into custody to await deportation. She has given up. This is why we meet Mahnaz in the first place because, in addition to holding down a paid job, she also takes care of Afrah and the two children. She provides them with food, care and support, manages her contacts with lawyers, and tries to motivate Afrah to do something and interact with people to survive socially. Afrah is an example of how contagious deportability can be (see Sager and Öberg, 2017). Deportability reproduces a vulnerability within the entire family. Afrah’s legal and social status, affected by the asylum process, creates a need for informal care by her mother. Afrah can no longer manage the situation herself and depends on her mother to provide her with the necessities she needs to handle her situation and status as deportable. Seemingly, in the eyes of the Swedish authorities, Afrah and her two daughters are framed as ungrievable. They lack the right to access support and are forced to care for themselves or rely on the goodwill of others. Their status as deportable not only creates a need for informal care, but also puts extra pressure on that informal care and support to be enough. They cannot expect help from anyone else. The pressure on Mahnaz to provide the proper care and support is intense, as there is always the risk of revealing the status of her daughter and granddaughters, which could lead to their deportation. Other participants describe similar experiences.

Tekie has a temporary permit to stay in Sweden, is 17 years old and comes from Eritrea. His family could not afford to flee together, so he went in advance.
plan was that Tekie’s father, mother and younger brother would follow him as soon as possible. The family needed enough money to pay the people supposed to help organise the journey. As it turned out, however, Tekie’s father was murdered only a few weeks after Tekie left Eritrea, resulting in his mother and younger brother needing to flee alone. Currently, they are stuck in Sudan, with seemingly no hope of continuing the journey and reconnecting with Tekie in Sweden. Tekie has, however, been able to maintain sporadic contact with his mother by phone:

‘I don’t know. What can I say? I feel sad because I can’t bring them here, and they aren’t allowed to come here…. I mean, I feel safe here. I have a future here. At the same time, you think about your family, your brother. I don’t think about myself. I feel safe, but when my family’s in a terrible place, it becomes hard to think about them. I know they’re struggling. She doesn’t know anyone there; they have no money. It’s hard. They thought they could come here but got rejected. They got angry with me; told me to help them. I tried, but it’s not easy. I don’t understand why my family cannot come.’

Tekie has tried hard to understand the Swedish migration system and do what he can to give his family advice on coming to Sweden. Tekie is trying to navigate this new role and responsibility. To him, the family is grievable, but the Swedish authorities consider them ungrievable, pushing Tekie into informal care practices. He sends them money when he can and gives them information on how to get to Sweden, obtain a residence permit and generally improve their situation. What Tekie does is often discussed in terms of transnational caregiving (Näre, 2020). Tekie takes extensive responsibility for his family, providing them with care and support beyond what he did before they fled.

Not only can the push into informal care put stress on relationships, but it can also increase the burden on those providing informal care. Daniel explains:

‘But I feel worse when my mum got the care she needed from the Swedish care system. I’m not ungrateful for the help we got when she fell on the stove due to an epileptic attack and had to have an operation on her arm. They tried to help us, but they say they cannot do more as we lack the last four digits (in the social security number). So, we wait. They tell us we must leave, but there’s no country that will receive us…. My mother’s tried to kill herself more than once. She’s tired of this situation. Last time, she went to intensive care, it was close. But she’s promised not to try again. But you never know. Anything can happen. One little thing and she might think, “Now it went bad”. And my brother? What can I say? As he’s gotten older, his thoughts have been getting worse. He smokes cigarettes, foreign cigarettes, which are dangerous. He smokes and thinks, smokes and thinks. The family’s going crazy because of these thoughts. There’s nothing that makes us feel human anymore in our situation.’

The last four digits of the social security number become decisive for how the mother is framed. Without them, she is indeed framed as grievable enough to receive emergency care but not grievable enough to receive the support and care she needs. In this way, the migration system in Sweden affects how other Swedish authorities
frame people in need of care and support. This situation also illustrates how the precariousness of Daniel's mother's condition and the lack of support due to their status as deportable, stateless refugees create a situation where the whole family is left outside the formal care system. Indeed, Daniel’s mother’s ungrievability seemingly intensifies the precarity of the family as a whole when the formal care apparatus fails to provide sufficient support and care. Nowadays, it is not only the mother who needs care; rather, Daniel and his brother also need help due to financial difficulty, uncertainty about the future and providing informal care to their mother. To help them cope with their situation, Swedish friends have supported them. In this instance, then, in a way, others are filling a void left by the state.

This section has illustrated how the migration context and its conditions push people to take on responsibility for the care of family members and friends. This push also shows how contagious the deportable and ungrievable status is for migrants, as well as the potential ‘contagiousness’ of (the need for) informal care within the migration context.

Withholding information and fear

Since the immigration process puts people in an uncertain and often deportable position, they must find ways to cope and survive. As mentioned, this often includes providing information, personal care and help in meetings with authorities. One way of providing care and support, which is relatively common among the participants, is to spare family members from the pain, sadness or hopelessness resulting from them being stuck in the immigration system and apparatus. This emotional work (Hochschild, 2003) is done by dealing with practicalities without sharing details with the vulnerable family member and withholding information about what is happening in the asylum application process. Samih, for example, lives with his 81-year-old mother, Lila. They are stateless and are awaiting deportation. After receiving the third and final rejection of their application for permanent residence, we ask Samih how his mother is handling the situation. He answers:

‘Yes, believe me, I’ve received this kind of letter so many times. I try to avoid telling her about the new decision we received. Because for someone her age — and she has an illness and so on — it’s not good to hear more of those decisions. It makes her health worse…. She needs to follow up with the hospital, but without her card [proving her right to reside in Sweden], she cannot do it — she cannot follow up with her dentist, her clinics and all these things … for cholesterol and blood pressure; she has diabetes and pains. But everything will stop. After taking all our things, I don’t know where our lives will go. I have no idea, actually. I just wish this nightmare would end soon.’

Samih has decided not to tell his mother about the urgent threat of deportation. He cares for her well-being and, as a result, chooses to carry the anxiety for her. His motive for keeping information from his mother is related to his desire to save her from exacerbating her ill health. This strategy should also be understood in relation to the fact that they have no access to a formal care system when they are notified of imminent deportation. Put differently, seeking formal care could mean being detained and deported. Although keeping information from family members could
be interpreted as a lack of care, we would argue the opposite. When Samih chooses not to tell his mother, it is out of concern for her health, not out of spite. As such, keeping information from her could be interpreted as a type of informal care taking place in the asylum and deportation context. Samih himself is doing the work of carrying the anxiety over imminent deportation. A similar situation is evident with Rashed and his family:

Rashed: ‘We don’t wanna be in this situation. My father ended up in custody in [town]. But we haven’t told Mum yet. She thinks he’s at a friend’s place, helping him out. If we tell her, she’ll be really stressed.’

Interviewer: ‘You want to protect her from that?’

Rashed: ‘Yeah.’

Interviewer: ‘But what happened?’

Rashed: ‘He drove a car and got busted…. They asked for his LMA card [an ID card for asylum-seekers] and he didn’t have it. The Migration Office had taken it. So, they called the Migration Office, who said his case is closed. So, they took him into custody and from there to [town].’

Interviewer: ‘So, you have been informed that you will be deported.’

Rashed: ‘Yes, the decision’s final. But there’s no country to receive us. Even Interpol has told them that when the Swedish Migration Agency asked them. First, they were to send us to Latvia, then Azerbaijan, but they asked Armenia and Russia too. I’m not even from Armenia; I’m only ethnically Armenian. They only want to find somewhere to send us, so they don’t have to give us a residence permit, after nine years.’

Rashed, like Sami, chooses — out of care — not to tell his mother what has happened in order to spare her anxiety and distress. Their precarious situation and the age and health of the elderly mothers create a situation where the family members provide care by carrying the emotional burden of deportation. Consequently, the relationships within the families can become damaged by dishonesty. Although we argue that this dishonesty emanates from care and can be seen as emotion work (Hochschild, 2003), since Rashed and Sami manage to regulate their family members’ emotions, their narratives do not foretell how their mothers feel about being kept in oblivion. Particularly when taking gender and age into consideration, this strategy could be interpreted as paternalistic informal care and emotion work (Larios, 2019), changing the power balance and equality between family members (Lynch et al, 2009). It can also be noted that it emerges as a direct consequence of the formal care system from which the asylum-seekers are excluded. Thus, as illustrated, this type of informal care comes at a potentially high price, not only for our participants’ health, but also for how it may damage family relationships and trust.
Discussion and conclusion

In the scholarly debate, informal care is usually discussed with formal care and the welfare state, focusing on the supplementary, often unpaid, care provided by family members and friends. In migration research, however, asylum-seekers and the informal care provided by them and aimed at them have not been a central focus (De Tavernier and Draulans, 2019; Larios, 2019; Chaouni et al, 2020). This is surprising since asylum-seekers’ access to formal care is often limited and may exacerbate the need for informal care.

This study illustrates how asylum-seekers simultaneously navigate the asylum process and the necessity of informal care resulting from this process. When the participants are framed as ungrievable by the authorities and the formal care systems, the need for informal care increases. This is the case even in a country like Sweden, where the responsibility for care ultimately lies within the formal care system on a municipal level. As a result, the need to provide informal care can collide with the civic integration demands put on asylum-seekers as conditions of them being granted asylum or a residence permit. Fatemeh, for example, is required to study Swedish in order to receive financial support but must also provide informal care for her daughter. This precarious situation puts pressure on the family from two angles: obtaining a residence permit and providing their daughter with care. Furthermore, regardless of whether deportation occurs or not, this study shows how the precariousness of our participants living under the threat of deportation shapes their social bonds and informal care practices.

In the study, we have argued for including the emotional distress that accompanies asylum-seekers’ precarious lives in the conceptual discussion of informal care, deportability and the effects of living under social structures that frame individuals as grievable or ungrievable. Rasheed and Samih both exemplify how decisions from Swedish authorities are weighed against sparing family members from pain, worry and deteriorating mental health. As shown, carrying the burden of being framed as deportable and ungrievable can be interpreted as a form of informal care, where the participants try to keep their families safe and healthy by keeping them in ignorance of their actual situation.

Although this article rests on the narratives of a few, it highlights the importance of including care provided informally by immigrants and asylum-seekers in the ongoing debate on informal care and its impact on families. Furthermore, we argue for further analysis of how asylum-seekers are framed by authorities and, generally, in society, of the impact on and of their informal care practices. In addition, further research is needed on how immigration and asylum legislation can contribute to a need for informal care by disqualifying people from accessing the formal care system.

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