

R

Caring for family members with impairments and chronic illnesses

Young carers and young adult carers in asylum seeking and refugee families in the UK

Guðbjörg Ottósdóttir

Abstract

Research on disability and family care practices in families of refugee and asylum seekers are rare but suggest that due to poor support contexts, children and young adults may be drawn into providing significant care which negatively impacts on their lives (Evans 2011). This article discusses experiences of children and young adults in providing care to disabled parents who participated in a qualitative PhD study in the UK on experiences of disabled asylum seekers and refugees with disability and care. Children and young adults were found to face significant challenges in combining caring with their own needs, including their education, friendships and making transitions to adulthood. However, they held onto their aspirations despite the obstacles of caring, poverty and legal status. They 'navigated their social becoming' within their constraining socio-economic and legal contexts, both because of their caring responsibilities and prolonged periods of their families' lack of entitlements and rights. The findings highlight the importance that research and policy engage with specific needs of children and young adults in caring roles in families of asylum seeking and refugee background living with impairments and chronic illness.

Introduction

Research on disability and care in families of black and minority ethnic (BME) background highlights a multiple nature of support barriers due to issues such as: poverty and isolation, language and information barriers, families not identifying significant caring roles and carers' needs along with a lack of engagement from professionals and services with families' specific needs (Chambra et al. 1999; Trotter 2012). Families of refugee and asylum seeking backgrounds face same support barriers as BME families in addition to difficulties accessing welfare

support because of their limited legal entitlements to support (Roberts and Harris 2002). Lack of entitlements creates complex caring situations and family members, including children and young adults, are then likely to take on significant caring responsibilities in that context (The Children's Society 2012b). Research highlights the importance of disability and carers policy to target diverse needs of disabled people and family carers in diverse communities in society in order to address diverse socio-cultural needs for support (see Trotter 2012).

Since the 1980's there has been a growing policy and research interest in adult carers and the implications that carrying significant caring roles has for their wellbeing. From the 1990's that interest has extended to children and more recently to young adults aged 18 and 24 who provide significant care to family members with impairments and chronic illnesses. Children become drawn into providing significant amount of care, as part of supporting other adults in caring roles or become main carers in the absence of available adults in households and communities. Significant caring roles for extended periods in their lives have been shown to harm children and young adults emotionally, physically, mentally and socially (Becker 2000; Evans and Becker 2009). Only recently has attention been brought to children and young adults in refugee and asylum seeking households. This group has been shown to carry significantly more caring responsibilities than their peers due to adults' difficult access to welfare support and poverty for prolonged periods (The Children's Society 2012a).

- Children and young adults however consider caring to be part of their loving relationship with parents but also as part of the intergenerational role of duty.

This article specifically explores experiences of five children under 18 and adults between 18 and 25 who provided significant care to their disabled parents living with impairments and chronic illnesses who were asylum seekers or had in the past been in the asylum system. The article is based on a larger study which explored the experiences of disabled asylum seekers and refugees and their adult and children kin and non-kin carers with disability and care. The article

refers to *caring* as involving a diverse range of emotional, physical and mental activities of daily living (ADL) involving intimate and personal care and instrumental activities of daily living (IADL) meant to assist disabled people carry out daily responsibilities in and outside of households (MedicineNet Inc. 1996–2015).

The article provides an overview of policy and research context surrounding young carers and young adult carers in the UK. The article then discusses the research methods underpinning the findings. This is followed with a description of findings related to children's and young adult's experiences of becoming carers, tasks and responsibilities they performed, the impact caring had on their lives and their experiences of accessing formal support. Finally, I discuss the findings and their implications for research, policy and practice.

Children and young adults with caring responsibilities

Family carers include adults and children. In UK policy, they are referred to as individuals who provide unpaid care to another relative with care needs deriving from age, impairment and chronic illness or have other types of care need (Becker 2008). They are entitled to support which may include carers allowance depending on outcomes of carers assessment conducted by social services in local authorities in the UK. This includes children aged 16 to 18 depending on the outcome of carer assessment.

Young carers are in policy defined as children under 18 who provide care support to another family member doing diverse IADL and ADL activities as part of his or her responsibilities which may usually be expected of adults (Becker 2000). Their roles of care include ADL and IADL activities and

tasks in families and households and emerge out of their personal, cultural and social dispositions towards care as well as gendered and intergenerational expectations within families. A key reason for a policy interest and attention paid to support needs of children in caring roles is the fact that caring responsibilities over and above children's developmental abilities can affect their emotional and social development (Bowlby, McKie et al. 2010). Children's education, abilities to form and maintain friendships and participate in social activities may become negatively affected when children hold significant caring responsibilities and at the same time struggle to meet their own needs (The Children's Society 2012b).

Around 229,318 young adults between the age of 18–24 in the UK hold significant caring responsibilities, which accounts for 5.3% of all people in that age group. This group is referred to in policy as *young adult carers* and are at a stage in their lives where they are expected to be making transitions into adulthood and have aspirations for higher education, employment, independent lives and starting their own families. Significant caring responsibilities may impact negatively on this group's progression into adulthood, including their transitions into higher education, employment, friendships and social lives (Becker and Becker 2008).

Throughout the world, the family is a key source of care regardless of existing policies and available resources and women tend to take on primary roles in families although research over the last decade suggests that men and children also participate in family care (Williams 2004, Bowlby, McKie et al. 2010). In the UK, 58% of 6.5 million family carers are women and 42% are men (Carers UK 2014). The 2011 UK census revealed that 166,363 children aged 18 and younger provide a range of care for family members af-

ected with impairment, illnesses or have other types of care needs (The Children's Society 2013).

Family caring roles have great social impacts for those providing care if carers struggle to negotiate their needs and responsibilities with their caring role. Caring may affect carers emotionally and physically, and while carers may reap benefits from caring such as raised self-esteem, gained skills and closer relationships with the disabled person they support, caring can lead to worsening emotional and physical health if they themselves do not get support and support for the disabled person is limited from other sources (Becker 2008). Children and young adults are likely to experience great challenges in balancing their needs and interests with care responsibilities in comparison to older adult carers, because of their unequal position of power in relation to the adults in the family (Evans and Becker 2009). Fear of judgement, stigma of caring, impairment and poverty have been identified as barriers for young carers and young adult carers to seek formal support (Levine 2005).

Children may become drawn into significant caring roles in the adult's poor support context and become a main carer or as part of a supporting role to an adult carer. A parent's or relative's need for care may arise at a crucial stage in the child's life and their role as a young carer certainly challenges notions of 'normal' childhood patterns (Evans and Becker 2009). Children and young adults however consider caring to be part of their loving relationship with parents but also as part of the intergenerational role of duty. As such they seem to understand that they care for family members because they have 'no choice' in fact as there are no other alternatives available (Evans and Becker 2009; Evans and Atim 2011). How-

ever, research has also shown that parents strive to balance chores between their children and in this way attempt to mitigate the negative impact that caring responsibilities may have on their children (Evans 2011).

Young carers and adult young carers experience many positive benefits from caring. They form closer emotional attachments with their parents and other family members overall (Becker 2008). Thus, the impact of caring on children and young adults who provide care is not one way but rather shaped by a range of factors in various contexts in their lives and this includes their resilience to cope with difficult caring situations (Bowlby, McKie et al. 2010). Children negotiate stressful aspects in their environments by drawing on their skills and personal attributes, spiritual beliefs, hopes and aspirations and the supporting relationships formed with parents, friends and people in communities (Castro and Murray 2010; Zautra, Hall et al. 2010). The interdependent nature of family caring relationships, the levels of reciprocity involved and the aspirations held by many children and young adults for their future despite prolonged periods of caring have been identified as protective factors helping families to reduce some of the negative impacts of caring (Levine 2005).

Policy has sought to support young carers and their families and to mitigate some of the negative outcomes of caring for children. Many agencies employ a family based approach when working with disabled adults and young carers, supporting young carers in their role *as a carer* while also attending to their other needs *as children* and activities in their lives while also providing disabled people with support (Becker 2008). Local authorities mandate that agencies work together to support young carers (The Children's Society 2012b). However, research

suggests that professionals in social care often fail to identify and respond to needs of young carers above the age of 12 and their substantial caring roles in the home or fail to give them advice and provide them with support (Becker 2008).

Professional engagement has been shown to be significantly hindered by the legal status of disabled adult asylum seekers and those with limited migrant entitlements to support, due to high thresholds to social care and strict criteria for having 'care needs' for asylum seekers and those without access to public funds such as failed asylum seekers. Professionals, including social workers in local authority adult social services experience financial and policy pressures which affect their roles of care and cause ethical tensions in their roles (Ottosdottir and Evans 2014). Professionals identify a *hidden nature* of asylum seekers and refugees with impairment and those who support them in households, as families may be reluctant to come forward due to fear of immigration, stigma of impairment and refugee organisations not applying holistic approaches and thus failing to target people with impairments and their carers (Ottosdottir and Evans 2014).

Young carers in black and minority ethnic minority (BME) communities often have additional caring responsibilities to those held by their peers in non-BME communities that may include translating for adults, filling out forms and liaising with other adults and professionals in the community on the adult's behalf (The Children's Society 2013). Organisations working with young carers observe high levels of caring amongst young carers in asylum seeking families and refugee families with other kind of legal restrictions to support (The Children's Society 2013). This group is at high risk of their caring resulting in negative social outcomes because of car-

ing in a poor support context for prolonged periods. Young adult carers are reported to experience challenges in making transitions to adulthood, as those with citizenships in countries outside the EU struggle to pay for required university fees and thus, postpone higher education till they gain UK Citizenships (The Children's Society 2013).

Research methods

This article focuses on findings related to experiences of 5 children and young adults caring for their disabled parents of asylum seeking and refugee background and is part of a larger PhD study conducted in 2010–2015 where the aim was to explore experiences of families of refugee and asylum seeking background with disability and care. Qualitative semi-structured interviews were conducted with 15 adults with diverse impairments and national backgrounds who had lived in the UK between 1 to 12 years (8 females and 7 males aged 25 to 84), with diverse statuses as asylum seekers or refugees with limited entitlements attached to their residence permits of *leave to remain*, 13 kin and non-kin carers (7 females and 6 males aged 13 to 78). Interviews were held with 17 professionals in social care (4 males and 13 females, 11 from statutory (4 social workers) and 6 from third sector services) who supported asylum seekers and refugees, disabled people and/or family carers. Participants were recruited by a purposive sampling method and refugee and ethnic organisations helped identify potential participants. English was spoken in interviews except five where interpreters were used.

The data was analysed by using an inductive coding technique that analyses further themes and subthemes and was structured by summarising each interview to assist in reading across the data. Interviews were

summarised under the themes reflected in the interview schedules, themes drawn on from concepts and ideas in the literature. Pseudonyms related to the children's and young adults' identities are used throughout the article.

The five children and young adult kin carers all lived in single mother households and included: The siblings John aged 16 and Charlotte aged 21 from a country in Sub-Saharan Africa caring for their mother Faith living with HIV, Susan aged 25 from a country in Sub-Saharan Africa caring for her mother Isabella living with HIV and helping to care for two younger siblings, Filad aged 20 from a country in Eastern Africa who cared for her physically disabled mother Lana and her own few months old baby and Mohsin, aged 13 from a country in the Middle East who cared for his physically disabled mother Rameen. John, Charlotte and Filad had been asylum seekers in the past but now held permanent residence permits. Susan was on a limited residence permit which required her to reapply for a residence permit over the course of ten years and Mohsin was an asylum seeker.

Findings

Commencement of caring roles

The analysis of interviews revealed that children's and young adults' roles of providing significant care to their parents were influenced by a range of factors, including their parents' impairment related needs, available informal and formal support, changes in family structure and households due to migration and settlement processes, gendered and intergenerational roles and expectations, stigma of impairment and their personal motivations. All of the young adults described started to care when their mothers became impaired and needed support

with ADL and IADL. As the children and young adults explained, they “had to” take on a significant caring role “because there was no one else available” (Filad).

John, Charlotte, Filad and Mohsin had started to care at a young age (10 to 13) and Susan at the age of 20. Filad described starting to care when she was aged 10 after her mother’s arm was amputated during war conflict. She had shared caring responsibilities with her older sister and was assisted by female relatives, but following her and her mothers’ migration to the UK where she and her mother applied for asylum and the consequent separation from family, she became her mother’s main carer.

John, Susan and Charlotte caring for mothers Isabella and Faith stated that their caring commenced when their mothers became acutely ill with HIV in the UK while seeking asylum. They explained that nearby relatives had been unwilling to help them due to the stigma of HIV, having withdrawn their support upon finding out about their mothers’ illnesses. They described the progression of their mothers’ illnesses as an abrupt event in their lives at a time when they were asylum seekers with limited social and financial support which they felt had affected them greatly along with the social stigma their mother’s illness brought with it in their ethnic communities.

The analysis of interviews revealed that mothers of Susan and Charlotte trusted them as their oldest children and daughters with their diagnosis because they feared the emotional and social impact that the stigma of HIV would have on their younger children. Susan and Charlotte described being drawn into significant caring roles because of their mother’s request that they keep their mothers’ diagnosis a secret from relatives and people in their communities and their own fear of how people may react should they find out.

Mohsin explained beginning to care for his mother Rameen after he and his mother moved to another area far from where his aunts lived who had been his mother’s main carers. He spoke of his reason for caring. “Because I am the only one in the family who lives with her” (Mohsin). As described by the children and young adults the experience of ‘caring’ was a process requiring them to, “learn everything very quickly” (Filad) and “mature quickly” (John), which suggests that they experienced significant shifts in their roles and relationships with parents. The disruptive effect that caring roles had on intergenerational norms of care and the influence of migration and settlement in this regard was observed in all the accounts given by children and young adults whose caring had commenced at a young age in a context where adults were not available and access to formal support limited.

Caring roles were further shaped by existing gendered and intergenerational norms of care as in Susan’s and Charlotte’s situation whose main caring responsibility towards their mothers’ personal needs and domestic chores in the household had been influenced by families’ gendered preferences, as explained by them. Mothers of children and young adults recognised that their children had taken on different caring responsibilities than they had held previously in the families and at an earlier stage in their lives than would usually be expected in their communities and explained that typically women and girls would provide most of the personal and domestic care. In instances when boys became involved in personal care as was the case with Isabella’s youngest child and son, this seemed to be influenced by a crisis or the urgency of the situation in which parents found themselves as explained by Isabella: “You just have to get on with it. You don’t think about the fact that he is a boy or that they are

of certain age because you are so helpless and have no choice!” (Isabella).

Love and emotional attachments were also factors shaping caring roles as the children and young adults referred to their love and emotional attachments when explaining their motivation to care whilst also referring to obligations as part of being daughters and sons. A reference given to emotional attachment was seen in Filad’s explanation: “I like caring for my mother because that is my role as her daughter” (Filad).

Caring tasks and responsibilities

The findings revealed that children and young adults assisted their mothers with a range of diverse activities in their daily lives, including ADL such as assisting them to use the bathroom, bathing, dressing and cutting hair and assisting their mothers to carry out IADL, including domestic work such as cooking, cleaning, washing, shopping and helping them to use public transport. They also reported accompanying their mothers to places in the community including hospitals, doctors’ offices, social services and refugee and ethnic organisations and translating and explaining to their mothers’ information about entitlements and available services. Thus, children and young adults were assisting their mothers with quite a wide range of diverse activities in their lives that were complex in nature due to care needs based on the nature of mothers’ impairments, lack of financial resources, language barriers, information needs as well as their mothers’ difficulties in accessing health and social support. Their mothers’ unmet needs for language support and barriers to social and health care services appeared also to influence why children and young people became drawn into providing such diverse kinds of social support to their mothers.

Some of the children and young adults reported providing regular support over periods when their mothers were physically or mentally unwell and some described doing more ADL support than others. All of them described being involved in assisting with a range of instrumental activities and providing regular physical, emotional and mental support to their mothers although the intensity and time of caring changed in line with their mother’s health. Caring was described by children and young adults as taking time and being intensive, requiring them sometimes to be present throughout the day and to carry out tasks. Mohsin, described his care for his mother Rameen as involving personal care, domestic chores and emotional and moral support: She is mostly in bed but she goes to the toilet on her own. She can walk a little but not if too far because then she has a lot of pain. She needs someone to be with her all the time. She is afraid if she is left alone and she needs someone to give her drinks and food” (Mohsin).

Susan, John and Charlotte, caring for their mothers living with HIV described their caring routines as less demanding at times but as intensive when their mothers were unwell as that required them to attend to their mother at all times and help them perform ADL. They however considered their caring roles as ongoing in their lives as part of their caring involved emotionally support, helping mothers to cope with the fluctuating nature of their impairments and the impact it was having on their abilities and health. Emotional support was in fact a persistent part of all the children’s and young adults’ ongoing caring responsibilities while other responsibilities tended to be alleviated when mothers gained full legal status and access to formal support. Caring hence had a continual nature in all the children and young adults’ lives while it changed in terms of activities required.

Children and young adults were asked about how they negotiated caring responsibilities with their own needs and responsibilities. They described attempting to organise their chores, getting support from neighbours and relatives or sharing their responsibilities with siblings if they were living with them. This usually involved a joint decision making process as evident in Filad's account:

I organise caring if I am going out with my friends and I take my baby along with me and I cook meals that my mum can eat and I tell her: "I have prepared meals and everything for you and before I go let me know if I have to do something. If she is like, "Oh I want this and I want that" then I prepare everything before I go out and tell her that if she needs anything she can just phone me (Filad).

The mothers stated that they tried to organise their children's care responsibilities by giving their older children chores they felt required greater maturity, such as personal care, accompanying them to appointments in the community and taking care of house bills. They involved their younger children in lighter housework. Hence mothers and children tended to strive at reaching a balance between needs and responsibilities based on an implicit understanding between family members.

The children and young adults described their caring relationships with their mothers as reciprocal. For example, Filad described her mother advising and encouraging her to attend university of which Filad was very appreciative. All the mothers described having emotional and financial caring relationships with children living abroad. Hence caring relationships between mothers and children appeared to be based on mutual reciprocal care exchanges and relationships embed-

ded in both local and transnational contexts. Yet mothers also described difficulties fulfilling their caring roles as parents and fulfilling their financial and emotional responsibilities because of prolonged periods of poverty, travel restrictions attached to their legal permits and not knowing when they would be reunited with their children.

Impact of caring roles on children and young adults

Children and young adults described their caring roles as impacting on them emotionally, physically and socially. They described struggling when caring was intensive and required much time, feeling physically and emotionally tired and sometimes unable to attend school or spend time with friends because their responsibilities conflicted with their needs. This required them to try to balance caring with their own needs. Filad who at the time was unemployed felt for instance that she would be unable to care for her mother and her baby if she was working, thus describing a social impact of caring. Susan, John and Charlotte described the stigma surrounding HIV as having impacted on them emotionally and socially. This was coupled with their mother's fear of people finding out about their HIV status, which meant that they used coping strategies such as not inviting friends to their homes, disclosing to one selected friend about their caring and pretending that they had other obligations when asked out by friends. Being unable to talk to anyone about their caring responsibilities was difficult as described by Susan, who explained that caring was, "Emotionally difficult because I didn't have anyone else to talk to. The way we [the family] dealt with it was by not talking about it [HIV]" (Susan).

The findings suggest that caring impacted on the children's and young adults'

identities and family relationships. Charlotte explained that keeping family secrets about her mother's HIV status and their status as asylum seekers had meant that she, "had to make up things, I had to run away from people because I wanted to say it [talk about her caring responsibilities and her mother's illness] but I couldn't" (Charlotte). Others similarly struggled with friendships because of the stigma related to impairments, but their struggles were also related to the stigma of migrant status as in the case of Mohsin who stated, "I don't want my friends to know we are asylum seekers" (Mohsin). Similarly, the stigma of mental health impairment meant that Filad kept secrets from her friends as she, "didn't want my friends to think negatively about my mum. I find it to difficult. I want to keep how she behaves to myself [her mother's behaviour linked to her mental health impairment]" (Filad). So did the stigma of poverty: "When I go to school I become a different person. No one knows that when I am at home I have to care for my mother and so I have got freedom in school because no one knows me really. They think I am cool and I live in this nice house and have this and that" (Filad).

The findings thus suggest that caring intersected with stigma of impairment, migrant status and poverty. Children and young adults in fact developed ways to be 'normal' and develop friendships, which meant that they had to be dishonest about their circumstance and the reasons for not being able to socialise, reasons due to stigma, but also the lack of financial resources.

Children and young adults referred to negative feelings in regards to their caring relationship, referring to feeling a lack of freedom in their lives, feeling constrained by their mothers' dependency on their care. The findings hence suggest that intensive caring in a poor support context increased

stress for families and had an effect on their wellbeing. Children and young adults referred however to having developed closer relationships with their mothers and siblings as a result of their caring and that caring had helped them cope with adversity and prepared them for challenges they might encounter later in their lives. The findings also suggest that despite mothers' dependencies on their children they continued to provide their children with emotional guidance and support. As discussed earlier, Filad described how her mother provided her with parental guidance and support, encouraging her throughout her life to achieve her goals and attend higher education, giving her space to do homework and attend school by drawing on support from neighbours and distant relatives when she needed to attend school: "My mum always encouraged me a lot. Studying was never affected by her condition" (Filad).

Making transitions to adulthood

The findings revealed that caring affected children's and young adults' education. Legal status was also found to intersect with this process. Charlotte, aged 21, felt that her legal status and caring role had negatively affected her transition into higher education as she couldn't afford the higher fees required for students from countries outside of EEA: "I couldn't go to school for two years because I did not have *leave to remain* and so I couldn't afford to go and so I was just working and also working at home" (Charlotte).

The findings suggest that the two young adult carers to whom this situation applied (Susan and Charlotte) faced great barriers when making their transitions into university education. Like Charlotte, Susan experienced a barrier to higher education because of her limited legal status and limited entitlements as she would not qualify

for lower university fees until she had gained a residence permit after having applied for consequent limited permits over the course of ten years. Susan explained: "I will probably be near 30 years old then you know. I mean I want to do my education now! Unfortunately, it is not going to work for me so I am hoping to get a good job that pays me well so that I can put myself through school" (Susan).

This comment explains the legal barriers she faced but also demonstrates that she had made plans despite such hindrances to make it possible for her to achieve her goal of entering higher education. Charlotte felt that that her caring responsibilities had changed now that she was attending university, living by herself and working part time to support herself and to supply income to the family: "Now that I started studying I don't have a lot of time and I work as well. So, I get there when I can. Once every ten days I drive her that is what I do. I am appointed driver for her" (Charlotte).

Charlotte considered thus that her caring had continued in her life, providing distant caring in the form of emotional care, and as demonstrated in the example above, by driving and doing other activities.

The analysis of interviews with Charlotte, Susan and Filad revealed that their caring had continued in their adulthood and that despite their difficult circumstances they continued to hold onto their aspirations to attend university, enter employment and start families; events that are important to most young adults. These findings suggest that they in fact negotiated the challenges they faced by drawing on available resources, such as making plans as evident in Susan's account above. They also made plans that included a continued care for their mothers into adulthood. For example, Filad explained that she planned to attend

university in another city and planned to find accommodation where she could live with her baby and her mother while attending university. The findings demonstrate hence that the children and young adults were resilient in the face of difficult family situations and held onto their aspirations for their future for prolonged periods.

Access to formal support

The analysis of interviews revealed that the children and young adults were not supported by local authorities' social services as 'young carers' and 'young adult carers' despite UK's policy emphasis on supporting children and young adults who provide significant care to adults in households. Mohsin, Susan and Filad were all unaware of their roles as 'carers' and had not been engaged by neither social services or third sector services working with young carers as explained by them. At the time of the study and based on the analysis of the interviews it was apparent that they were unaware of the services or entitlements they may have as a 'family carer'. Charlotte and John described having been through carers' assessment but having not qualified as young carers with *significant* caring responsibilities and thus qualifying for carers allowances. Charlotte and John had instead been referred by a social worker from the local authority social services to a third sector organisation supporting people living with HIV and family carers in African communities along with their mother Faith. John described his experiences of accessing formal support back when his mother became ill with HIV when he was aged 10: "Eh well I did to a certain extent get support. I was supported by someone talking to me, about telling me about my mum's diagnosis. But then after that they just sort of disappeared" (John).

Inconsistent engagement with children and young adults in this study as ‘carers’ was confirmed by accounts of the third sector professionals who stated that they felt that local authority social services were often reluctant to take on support for asylum seekers because, “asylum seekers are not high on their list of priorities” (Alexandra, an executive director in a BME organisation) and needs of children, were thus likely to be neglected. Alexandra, observed that local authorities did not usually support older children caring for adults, but more attention was focused on young children. She stated, “It is enough for them to see that the family is coping with the care” (Alexandra) in households involving young carers older than 14. In asylum policy, local authorities do not in fact have a duty to support adult carers, but they do however have a duty to children in caring roles under the legislation of *children in need* as confirmed by the professionals. In households where children are present, the social workers participating in the study reported that children would be referred to children’s services. In cases where there were no child welfare concerns, disabled adults would only receive support with parenting. Marge, a social worker in local authority explained: “Usually there are no concerns about children, it’s just that the dad or the mum has got a disability and we need to help them with just that” (Marge).

Professionals in both sectors stated that despite the recognition of the needs and rights of young carers, and young adult carers in UK social policy, engagement with young and young adult carers of disabled people seeking asylum was difficult because of funding pressures and high thresholds to social care when it came to asylum seekers. The division between adult and children’s services in social care services was in fact identified as a key barrier by Marge, to en-

gage with the *whole family*. The social workers observed they rarely worked with young carers from an asylum seeking background and inferred that may also be because, “there are a lot out there that are really, really hidden” (Marge). Families would try to hide their caring needs by encouraging their children not to disclose information about their caring role due to fears they might be reported to the authorities and be deported. This situation had in fact applied to Charlotte’s situation who explained:

My mum always used to tell me stories about her friends that had been, been sleeping at their house and immigration came and just took them, you know because they did not have leave to remain. Not that they were illegal but they did not have the confirmed status. So, she always used to worry about that they would suddenly appear...My mum used to say: “listen you are not like any of these children. If your friends are going wherever and start to have fun you should think that for you that is not normal because for one you don’t have leave to remain (LR) and you don’t have the money”, so always those two things (Charlotte).

Discussion and conclusion

The findings suggest that children and young people’s caring roles were shaped by an intersection of diverse factors in their lives, including migration and settlement processes which changed family forms and household structures, impairment, lack of formal and informal support, gendered and intergenerational norms of care and values of impairment in families and communities. They held *significant* emotional, and physical caring responsibilities, doing a range of quite diverse activities in and outside their

homes. Caring was routine and sometimes less intensive linked to impairment of parents. Intensive caring affected children and young adults emotionally and socially, including their friendships, education and transitions into adulthood. The findings highlight the importance of recognising that caring intersects with different types of stigma in children's and young adults' lives, not merely poverty as suggested by previous research on young carers for instance, but also migrant status. The findings resonate with previous findings in regards to the diverse caring roles and responsibilities that children and young adults from a BME background take on in comparison with their non-BME peers (Evans and Becker 2009; The Children's Society 2013). Their caring responsibilities are above and beyond what their peers in non-BME communities may have and include translating and helping adults to navigate their pathways to health and social support and in this study this was in particular linked to the situation of their parents as migrant with diverse needs. Prior research has suggested that this group of young carers tends to take on significant levels of care in particular due to parents high and unmet needs (The Children's Society 2013)

The findings illustrate that despite difficult circumstances, young adult carers however continued to hold onto their aspirations to attend university, be employed and start families. Previous studies highlight how caring and poverty may hinder young adult carers in their transitions to adulthood because of lack of support (Evans and Becker 2009) but less attention has been paid to the impact that legal status has in this regard. To date, there is no research that specifically explores how legal status affects the lives of young adult carers between the ages of 18 and 24 and the impacts this has on their

transitions into adulthood. The findings of this study are thus an important contribution to the research field of family care as well as children and migration.

Caring relationships were described as not merely negative but positive, strengthening family relationships and children and young adults describing holding onto their aspirations of expected transitions into education and employment and parents providing them with mutual care. The findings thus suggest positive elements of caring as these contributed to the resilience of the children and young adults in the study. The findings confirm other research findings which highlight a positive nature of caring and suggest that caring responsibilities may promote children's resilience in coping with adversity in their lives (Levine 2005; Evans 2011; Hopkins and Hill 2010).

In conclusion, the findings have significant implications for research and policy in the field of family and young carers as well as migration and children. They underline the importance of recognising children's complex migration and settlement situations and diverse roles in families and asylum seeking and refugee households. The intersection of socio-cultural and ethical values of care, the identities of children and young adults and disabled adults within contexts of impairment, migration and settlement is complex. The findings of this study show that the welfare system particularly fails children and young adults of asylum seeking and refugee background in families living with impairment and chronic illness. There is a great need for policy and practice to engage with the specific support needs this group has as well as the needs of their families.

References

- Becker, F. and Becker, S. 2008. *Young Adult Carers in the UK: Experiences, Needs and Services for Carers Aged 16–24*. London: Princess Royal Trust for Carers.
- Becker, S. 2000. Young carers. In: M. Davies, ed. *The Blackwell Encyclopedia of Social Work*. Oxford: Blackwell.
- Becker, S. 2008. Informal family care givers. In: G. Wilson, G. Ruch, M. Lymberry and A. Cooper. *Social Work: An Introduction to Contemporary Practice*. London: Pearson Longman.
- Bowlby, S., McKie, L., Gregory, S. and MacPherson, I. 2010. *Interdependency and Care Over the Lifecourse*. London and New York: Routledge.
- Carers UK. 2014. *Facts About Carers: Policy Briefings*. Retrieved from <http://www.carersuk.org/for-professionals/policy/policy-library/facts-about-carers-2014>.
- Castro, F. G. and Murray, K. E. 2010. Cultural adaptation and resilience: controversies, issues, and emerging models. In: J. W. Reich, A. J. Zautra and J. S. Hall, eds. *Handbook of Adult Resilience*. New York: Guilford Press.
- Chambra, R., Ahmad, W., Hirst, M., Lawton, D. og Beresford, B. 1999. *On the Edge: Minority Ethnic Families Caring for a Severely Disabled Child*. Bristol: The Policy press.
- Evans, R. 2011. Young caregiving and HIV in the UK: caring relationships and mobilities in African migrant families. *Population, Space and Place* 17(4): 338–360.
- Evans, R. and Atim, A. 2011. Care, disability and HIV in Africa: Diverging or interconnected concepts and practices. *Third World Quarterly* 32(8): 1437–1454.
- Evans, R. and Becker, S. 2009. *Children Caring for Parents with HIV and AIDS : Global Issues and Policy Responses*. Bristol: Policy Press.
- Hopkins, P. and Hill, M. 2010. The needs and strengths of unaccompanied asylum Seeking young People in Scotland. *Child and Family Social Work* 15(4): 1–10.
- Levine, C. 2005. Young adult caregivers: A first look at an unstudied population. *American Journal of Public Health* 95(11): 2071–2005.
- MedicineNet Inc. 1996–2015. *Definition of ADL (activities of daily living)*. Retrieved 18 February 2015 from <http://www.medicinenet.com/script/main/art.asp?articlekey=2152>.
- Ottosdottir, G. and Evans, R. 2014. Ethics of care in supporting disabled forced migrants: Interactions with professionals and ethical dilemmas in health and social care in the south-east of England. *British Journal of Social Work* 44(1): 53–69.
- Roberts, K. and Harris, J. 2002. *Disabled People in Refugee and Asylum Seeking Communities*. Bristol, Joseph Rowntree Foundation/Policy Press.
- The Children's Society. 2012a. *I Don't Feel Human: The Experiences of Destitution Among Young Refugees and Migrants*. London: The Children's Society. Retrieved 1 October 2016 from http://www.childrenssociety.org.uk/sites/default/files/tcs/research_docs/thechildrenssociety_idontfeelhuman_final.pdf.
- The Children's Society. 2012b. *Working Together to Support Young Carers and Their Families*. London: The Children's Society. Retrieved 4 May 2014 from http://www.youngcarer.com/sites/default/files/imce_user_files/PTP/mou_young_carers_2012.pdf
- The Children's Society. 2013. *Hidden from View: The Experiences of Young Carers in England*. London: The Children's Society Retrieved 15 March 2014 from http://www.childrenssociety.org.uk/sites/default/files/tcs/report_hidden-from-view_young-carers_final.pdf.
- Trotter, R. 2012. *Over-looked Communities, Over-due Change: How Services Can Better Support BME Disabled People*. London: Scope. Retrieved 15 March 2014 from <http://www.scope.org.uk/Scope/media/Images/Publication%20Directory/Over-looked-communities-over-due-change.pdf?ext=.pdf>.

Williams, F. 2004. *Rethinking Families*. London: Calouste Gulbenkian Foundation.

Zautra, A. J., Hall, J. S. and Murray, K.E. 2010. Resilience: A new definition of health for people and communities. In: J. W. Reich, A. J. Zautra and J. S. Hall, eds. *Handbook of Adult Resilience*. New York: Guilford.

Guðbjörg Ottósdóttir is an assistant professor in Social Work, Faculty of Social Work, School of Social Sciences, University of Iceland where she has worked since 2013. Previously, Guðbjörg was a social worker in Iceland working with migrants and refugees. She completed her PhD in Human Geography in 2015 at the University of Reading. Her research focused on the experiences of disabled asylum seekers and refugees and those caring for them in the South East of England. Her main research interest lies in the area of migration, disability, care and social work. Her publications include "Disability and chronic illness" (with Ruth Evans, *Handbook of Migration and Health* 2016), „Disabled asylum seekers and refugees and access to social care in South-East England" (*Icelandic Journal of Social work* 2016)

Guðbjörg Ottósdóttir, Faculty of Social Work, Gimli v/Sæmundargata, University of Iceland, IS-101 Reykjavik, Iceland. E-mail: gudbjoro@hi.is