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# Caring during crisis: the experiences of ethnic minority communities in Scotland during COVID-19

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- A Research and Knowledge Exchange linking UWS academics, Oxfam Scotland and community organisations in collaborative projects;
- The UWS-Oxfam Policy Forum, which brings all of these partners together with a broad range of external organisations from across all sectors of Scottish society, to discuss key questions and to inform understanding and engagement with both existing and emergent issues;
- A series of Collaborative Research Reports, available from the Partnership's website
   <u>www.uwsoxfampartnership.org.uk</u>.

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## **Executive summary**

#### The project

This report explores the experiences of ethnic minority carers in Scotland. It is the first such study since Gina Netto's 1996 report. It presents results from a research project undertaken between November 2021 and January 2022 which aimed to:

- Understand how unpaid care is arranged and experienced differently amongst ethnic minority carers along intersectional lines of immigration status and gender;
- Explore the impact of the COVID-19 pandemic on how members of ethnic minority groups have arranged their caring responsibilities;
- Scrutinise the different assets that ethnic minority carers have drawn from to cope with and manage pandemic-related risks in order to maintain their caring arrangements.

The primary data analysed in this report is drawn from qualitative semi-structured interviews with ten carers from ethnic minority backgrounds and living in Scotland. Some of them were asylum seekers or refugees. Due to the small number of interviews, the data are not generalisable. Nevertheless, the interviews have provided a deep insight into the experiences of some ethnic minority carers during the COVID-19 pandemic. In particular, the inclusion of asylum seekers and refugees has generated valuable insights into a group which is not often considered within the academic literature on unpaid care.

#### The findings

The analysis of the interview transcripts brought up four key themes which were of relevance to the research participants.

#### Theme 1: Reluctance to use the social security system and support services

Even when experiencing financial hardship, unpaid carers are often reluctant to turn to the welfare state and use the social security support they are entitled to. The same seems true regarding support services that could help carers in their role. Interview data suggests that this is due to – with regards to ethnic minority carers – the stigma associated with benefits, specific cultural expectations around 'self-sufficiency', and the notion that 'the family' should provide the necessary support rather than the state.

#### **Theme 2: Limited social connections**

Research participants relied heavily on existing social connections, in particular to family members, for support in their caring roles. Such support was not, however, available to all interviewees because of, for example, the geographical distance to their families. This problem was particularly severe for asylum seekers and refugees.

#### Theme 3: Barriers to paid employment

Due to the gendered distribution of care work, but also because of language barriers and restrictions around the right to work for those interviewees who were subject to immigration controls, engaging with paid work for some of our participants was difficult or impossible. This exacerbated their financial difficulties and also contributed to social isolation.

#### Theme 4: COVID-19 deepened existing inequalities

COVID-19 and its lockdowns and other restrictions deepened existing inequalities in Scotland in relation to gender, ethnicity, and immigration status. Interviewees spoke of experiences of poverty and poor physical and mental health, often compounded by limited access to social security and support services, limited access to paid work, and limited social connections. These problems became deeper because of the pandemic.

#### Key learning points for policy and practice

Protecting ethnic minority unpaid carers from poverty and valuing their contribution must be at the heart of a just, caring and green recovery from the crises since 2020. We provide a number of key learning points which should be taken into account by policy makers and others when discussing the policy area of unpaid care. Such discussion should also consider the Scottish Government's National Performance Framework and how it, in a future revised version, could explicitly acknowledge care, in its unpaid and paid forms, through the addition of a dedicated new National Outcome on care (see Maclean et al 2021).

#### 1. The need to tackle poverty amongst ethnic minority carers

- · Increase Universal Credit provision to reflect the growing cost of living;
- · Improve take-up of social security entitlements;
- Remove eligibility restrictions to the new Scottish Carer's Assistance for asylum seekers and those in fulltime education;
- Support carers' labour market access.

#### 2. The need to support the mental health of ethnic minority carers

- · Enhance digital mental health support;
- · Provide culturally sensitive mental health support that safeguards women against violence;
- Increase investment in carer organisations' mental health programmes.

#### 3. The need to support social networks among ethnic minority carers and to develop new social connections

- · Facilitate access to networks of social support;
- · Facilitate access to a transnational familial system of support;
- Provide flexible English language classes.

## **1. Introduction**

Unpaid carers serve a vital role in providing medical, domestic and emotional support. In 2019, Carers UK estimated that about 8.8 million adults in the UK were unpaid carers, providing support to family members living with a disability, addiction or long-term health condition (Carers UK 2019). The number of unpaid carers in the UK is set to increase against a backdrop of an ageing population and a staffing crisis in social care (Carers UK 2021).

Research has established a good general understanding of the personal and financial costs of caring to the unpaid carer. For example, carers report that they often struggle to balance work and caring. As a result, many unpaid carers say they face significant financial hardship (e.g. Pautz (ed) 2020), with 33% of unpaid carers in Scotland reporting to struggle financially, 21% reporting being in debt due to their caring role, and 7% saying they struggle to pay their utility bills (Carers UK 2021).

It is clear that the care role is heavily gendered, with both paid and unpaid care work being disproportionately provided by women and girls (e.g. Coffey et al 2020). This can be partially explained by long-standing social norms which view care as 'women's work'. The unequal distribution of unpaid care responsibilities means that women have less time to pursue paid work or undertake efforts at career progression and, as a result, are more likely to be in part-time or precarious work with lower incomes. The provision of care is physically and mentally demanding, and carers often experience poor mental and physical health (e.g. Ploeg et al 2017; Treasure et al 2001; Lobban et al 2010 and 2013). A meta-analysis of 84 academic studies demonstrated that most researchers see carers as more likely to present with significantly higher levels of stress and depression and lower levels of subjective wellbeing than non-carers (Pinquart and Sörensen 2003).

However, there is a more limited understanding of unpaid care when it comes to ethnic minorities. This is true for the UK and for Scotland. Usually, research about unpaid care and carers does not generate or report on carers' ethnicity (Greenwood 2018). This knowledge gap is becoming increasingly problematic as the ethnic minority population in the UK is growing. Between the census of 2001 and that of 2011, the ethnic minority population of unpaid carers in Scotland doubled to just over 12,000 (Simpson 2014; Scottish Government 2015). Some consider this to be an underestimate (MECOPP 2017). While data from the 2011 census suggests that members of ethnic minority groups were less likely to provide care due to their younger age profile than their white British and Scottish counterparts (Scottish Government, 2014), others suggest that caring roles start at a younger age within ethnic minority groups (MECOPP 2017), possibly due to poorer health in these groups compared to the general population (Carers UK 2010; Germain and Yong 2020). Most research agrees that ethnic minority carers provide more unpaid care than the overall population and that they are more likely to experience poverty and difficulties associated with accessing information about social security entitlements (Institute for Social and Economic Research 2022; Carers UK 2010).

Further, but dated, evidence suggests that 76% of ethnic minority unpaid carers in Scotland are female and that most carers undertake the majority of their caring responsibilities between the age of 21 and 40 (Netto 1996; 1997). Netto also found that 48% of ethnic minority female carers in Scotland were unable to speak English and 49% of all ethnic minority carers' employment was adversely affected by their caring role. More recent research found that the lack of proficiency in the English language, and an inability to engage with the labour market due to the high demands of caring roles, contribute to material hardship so that ethnic minority carers experience higher levels of material deprivation (Moore et al 2019).

Existing evidence suggests that for some individuals from ethnic minority backgrounds, material hardships are exacerbated by access restrictions to social security benefits when they are subject to immigration control (Lindsay et al 2010). Non-UK citizens are a distinct group with respect to service and benefit provision. For example, immigration policy in the UK gives asylum seekers no entitlement to 'normal' social security benefits (Home Office 2021). If they are supported under the government's immigration policy, they received (in autumn 2020) £39.63 per week. Asylum seeker carers are not eligible for Carer's Allowance benefit. As asylum seekers generally do not have the right to work in the UK, they cannot improve their situation through paid work. These conditions have intensified differences among

immigrants, widening gaps between those deemed 'deserving' of support and those for who access to social security entitlement support is limited (Sales 2002).

Amid the context of existing gender and ethnic inequalities in Scotland, the COVID-19 pandemic has highlighted the importance of care while at the same time placing more pressure on unpaid carers, particularly women who provide most care. Many of these unpaid carers were already living in poverty prior to the pandemic (Oxfam Scotland 2020). Research by Carers UK (2020) found that during the COVID-19 pandemic, carers were often distressed and worried about what would happen to the person they cared for if they became ill. The closure of day services and respite care was especially problematic for those providing care for individuals with autism or dementia as the care-recipient often struggled to understand the changes to their routine (Giebel et al 2020; Carers UK 2020). Overall, in considering the implications of the COVID-19-related lockdowns in the UK, research by Whitley et al (2021) suggest that unpaid carers' mental health deteriorated more during the lockdown than for non-carers. The detrimental outcomes of the pandemic were also experienced differently along intersectional lines of class, gender, ethnicity and age (Bhala et al 2020; Eshareturi et al 2021). There is evidence showing that ethnic minorities in Scotland have been at greater risk of serious illness and death due to COVID-19 so that the pandemic deepened existing inequalities and added to the various pressures on ethnic minority households (Fixsen et al 2022; Qureshi et al 2020).

Set against this background, this report discusses the diversity of caring arrangements, and the impact of care provision on ethnic minority carers in Scotland. The key objectives of undertaking this research were to:

- Understand how unpaid care is arranged and experienced differently amongst ethnic minority carers along intersectional lines of immigration status and gender;
- Explore the impact of the COVID-19 pandemic on how members of ethnic minority groups have arranged their caring responsibilities;
- Scrutinise the different assets that ethnic minority carers have drawn from to cope with and manage pandemic-related risks in order to maintain their caring arrangements.

A short description of the research methodology underlying the report and some detail on the interviewee characteristics will be followed by the main section which presents the findings and their analysis. Following this section, the conclusion discusses four themes as they emerged from the interviews. These themes inform a set of 'key learning points for policy and practice'.

## 2. Research methodology

Participant 10

Female

35-44

The data presented in this report is drawn from qualitative semi-structured interviews with ten ethnic minority carers (see Table 1). Interviewee recruitment was facilitated by multiple organisations working with ethnic minority communities in Scotland by sharing information about the project with their members. In addition, the snowballing technique was used whereby participants helped to recruit additional participants for the study. To take part, the interviewees had to live in Scotland, have a caring responsibility and self-identify as belonging to an ethnic minority community. As an incentive to take part in an interview and in recognition of the demands on respondents' time, potential interviewees were offered a £10 e-shopping voucher. The interviews were conducted using Zoom video-conferencing software to both mitigate the risks around COVID-19 and to make it easier for interviewees to take part by removing travel time and costs. Interviews lasted around 60 minutes and took place at a time determined by the research participant in order to work around their caring responsibilities.

The interview schedule contained 16 questions. These questions were split into four themes: 'The care situation'; 'COVID-19 and caring arrangements'; 'The support networks'; and 'Financial support'. In this report, all interviewees are given numbers to protect their identity. The interview transcripts were analysed using thematic analysis techniques (Braun and Clarke 2006).

Table 1 below describes those who participated in the interviews with regards to their ethnic identity, gender, age range and annual household income. In this project, following Bhopal (2004), ethnicity is understood as a self-defined category. As such, the ethnic identities in Table 1 present each participant's self-identification. The income level of participants is also self-reported.

Table 1: Profile of interviewees						
Participant	Gender	Age range	Ethnicity / Nationality	Household income		
Participant 1	Female	45-54	Pakistani	£400 to £499 per week / £20,800 to £25,999 per year		
Participant 2	Female	25-34	Pakistani Scottish	£200 to £299 per week / £10,400 to £15,599 per year		
Participant 3	Male	25-34	Pakistani	£100 to £199 per week / £5,200 to £10,399 per year		
Participant 4	Female	35-44	Scottish African	£500 to £699 per week / £26,000 to £36,399 per year		
Participant 5	Female	35-44	Kurdish	Less than £100 per week / Less than £5,200 per year		
Participant 6	Female	25-34	Pakistani	£1000 to £1,499 per week / £52,000 to £77, 999		
Participant 7	Female	45-54	Yemenite	Less than £100 per week / Less than £5,200 per year		
Participant 8	Female	45-54	Pakistani Scottish	£100 to £199 per week / £5,200 to £10,399 per year		
Participant 9	Female	35-44	Iranian	Less than £100 per week / Less than £5,200 per year		
Participant 10	Female	35-44	Polish	£200 to £299 per week /		

Polish

£10,400 to £15,599 per year

## 3. Findings and analysis

The ethnic minority carers interviewed for this project provide a diversity of care for both children and adult family members, including parents and extended family members. This is discussed in more detail in Section 3.1. Participants told us that the often intense nature of caring makes it difficult for them to engage with paid employment. As a result, some reported experiencing financial hardship – discussed further in Section 3.2 – and health challenges, explored in Section 3.3. To meet the requirements of their roles as carers, participants spoke about how they relied on diverse social connections further discussed in Section 3.4, but also how they used a range of coping mechanisms. These are illustrated in Section 3.5. Throughout the following discussion, interview data is used to show the profound impact of COVID-19 on our participants' experience of caring.

Perhaps unsurprisingly, ethnic minority unpaid carers' experiences, as identified in this study, are not dissimilar to those reported by their white British and Scottish counterparts in other studies. However, differences were clear with regards to the need for culturally appropriate support services and awareness of individual's rights and entitlements to benefits and services. The need for culturally appropriate services – and for awareness-raising – is borne out of the apparent reluctance often described by ethnic minority carers to access social security entitlements and instead to opt for self-sufficiency and to rely on family or ethnic community networks.

### 3.1 The care arrangements

The forms of care which the ethnic minority carers interviewed reported undertaking, and the amount of time they devoted to caring, mirrored the caring arrangements found within the population of carers in the UK and Scotland (e.g. Carers UK 2019; Carers Trust Scotland 2021). Each of the ten participants reported that they had a wide range of caring responsibilities, including childcare (Participants 2, 4, 5, 6 and 9), looking after adult family members (Participants 1 and 3), or both (Participant 7, 8 and 10). The number of individuals that participants cared for varied from one (Participant 1) to six (Participant 7).

able 2: Care resp	oonsibilities of participants	
Participant	Number of people cared for by the participant	Detail on those cared for
Participant 1	1	Adult brother
Participant 2	1	Child
Participant 3	1	Adult brother
Participant 4	3	Children
Participant 5	1	Child
Participant 6	3	Children, one with additiona support needs
Participant 7	6	Five children and one mothe
Participant 8	2	Mother and aunt
Participant 9	2	Children
Participant 10	4	Three children and one moth

## 3.2 The experience of poverty

Based on 2019-20 figures, a family in Scotland is considered as living in poverty if, after housing costs, they live on less than £333 a week (or £17,400 a year) for a single person with two children aged between five and 14. For a couple with children aged between five and 14, the threshold sits at £450 per week (or £23,400 a year) (Scottish Government 2021a).

Based on what participants told us (see Table 1), eight out of the ten participants could be deemed to live in poverty. It is generally the case that unpaid carers are more likely than the general population to live in poverty and material deprivation as 'care and poverty are deeply connected' (Ferrer and Butt 2020, 5). However, ethnic minority carers are more likely to struggle financially than the overall carer population (Greenwood 2018). However, ethnic minority carers are not a homogenous group and there are differences in the financial circumstances amongst them. This is also reflected in what the interviewees told us. It is likely that it is asylum seekers without recourse to public funds (including access to Carer's Allowance) and without the right to work who experience the greatest financial difficulties. It is important to note here that care is rarely considered through the lens of asylum status, making comparisons difficult and thorough insights into asylum seekers' situations rare.

For many of our interviewees, their care responsibilities seemed like a 'full time job' so that they were unable to pursue paid employment that would help them to improve their financial circumstances. One interviewee explained how his mother and himself found it hard to find employment due to the care needs of his brother:

## We are not employed. I am trying to find something now. It's difficult to find something given the demands of caring, so I need something where I can work from home to make it easier for all my different roles (Participant 3).

The interview data supports existing (pre-pandemic) evidence which showed that 38% of all carers reported they had given up work to undertake care, while 21% had reduced their working hours (Carers Scotland 2019). The problematic incompatibility of wide-ranging caring responsibilities with paid work is aggravated, according to Participant 8, by rules that reduce income through benefits as soon as there is earned income:

#### I am a single parent on benefits, and I try to work and volunteer, but I couldn't do any extra work to help my benefit [Universal Credit], it would make things worse. The price of gas and heating everything has gone up. I couldn't do any extra work like cleaning or home help, so I couldn't get any extra money (Participant 8).

As Universal Credit is a 'dynamic' benefit system, payments respond to changes in recipients' net earned incomes. As Participant 8 explained, if she started to earn, her Universal Credit would reduce in ways that suggest to her that 'work does not pay'. For Participant 8, this arrangement seemed to make it impossible to address increases in the cost of living by – in this case – low-paid part-time work. Such an experience is, of course, hardly limited to ethnic minority carers. Some of the evidence presented to the House of Commons' Welfare Policy in Scotland inquiry suggested that the 'payment award for claimants of Universal Credit is not enough to tackle poverty in Scotland and provide claimants with a stable support from which they can access the job market' (Scottish Affairs Committee 2021, 43).

While Universal Credit seemed not to offer a sufficient barrier against poverty for many of our interviewees, some of our participants experienced a number of further obstacles that made it harder for them to reduce their risk of experiencing poverty. Again, it is asylum seekers with their limited social security entitlements – the support rate was £39.63 per week in autumn 2020, constituting only 53% of Jobseeker's Allowance – and the restricted right to work who were struggling the most (Gower 2021). Participant 7 spoke about her experiences as an asylum seeker as follows:

They give the refugee money weekly but, you know, for us in a week it's £39. Five Pound or so daily, per person. Everything is expensive, and we eat Halal and it's not available in our shops. It's so expensive, the chickens, three small chicken pieces are so expensive, I cook it one time because we are a big family. We are not allowed to work because we are asylum seekers. We don't have enough money (Participant 7). Such testimony supports existing evidence that asylum seekers often cannot afford sufficient food and, as a result, suffer poor physical and mental health (Quinn and Strang 2014; Dempsey and Pautz 2021; Pautz and Dempsey 2022), a situation which further cements their experience of poverty (Asylum Matters 2020). The relationship between low-income and poor diet is certainly not limited to asylum seekers or people from ethnic minority communities. Research by French et al (2019) has shown that, generally speaking, lower household income is consistently associated with a poor diet and thus poorer health outcomes.

Some of our participants told us how they felt reluctant about accessing social security entitlements and about using support services:

In our culture you just get on with it. You don't want to have to rely on outside agencies too much. You don't wanna tell your business to too many people. I think relying on outside agencies who are not able to give the same kind of care eventually things are gonna... if you put all your trust and hope in paid workers eventually its gonna break down at some point. We need to be more self-reliant (Participant 1).

Such reluctance appears to be related to culturally embedded notions around obligations of family members to look after each other (Greenwood 2018), but also to a perception of 'outside agencies' not providing the same quality of care as family members. In addition, and as explained by Participant 1, the reluctance to engage with carer support services is also related to the stigma around not being self-sufficient and being in need of benefit support (Baumberg et al 2012). Here, it might be important to note Netto's comment that while the family may be an important element of the support network, there is a 'myth' around it. She argued this by reference to the 47% of carers from ethnic minority groups who reported a complete lack of time off from caring and on the basis of data suggesting that the proportion of sole carers in ethnic minority groups groups was larger than in the general population (Netto 1998, 224).

Out of the ten interviewees, only two reported having applied for care-related social security entitlement support, including Carer's Allowance and Employment and Support Allowance, while only one participant was claiming Universal Credit. Some participants in receipt of Carer's Allowance indicated that the current eligibility criteria were a barrier with regards to their own career aspirations:

You can't be studying full time and get your Carer's Allowance. I feel that should be changed. Most people don't just want to be a carer, they want to do other stuff and it's a hindrance, so they should change that, so you have the opportunity to study full time (Participant 3).

The impact of increased caring responsibilities as a result of COVID-10 lockdowns and other restrictions between March 2020 and May 2021 disproportionally impacted the female interviewees who reported that they were responsible for most of the caring duties within their household. The key impact was on their experiences of poverty. For example, Participant 6 explained that she had to resign from work to take on increased childcare duties because of the closure of her children's nursery:

## The income my husband brings in covers the whole house, and my income covers the childcare and anything they need. But I couldn't cover what the kids would need because they would need me at the same time (Participant 6).

The closure of childcare services because of the pandemic also meant that the families spent more time at home. As explained by Participant 1, this contributed to higher gas and electricity bills and higher expenditure on food because, for example, provision of free meals at schools ended:

Financially, they [COVID-19 restrictions] impacted because we were spending more time in the house with electricity, gas and food bills going up (Participant 1).

## 3.3 The physical and mental health of carers

Unpaid carers often cite experiencing intrinsic rewards related to caregiving (Zarzycki and Morrison 2021; Stansfeld et al 2017). But the act of caring can often bring with it personal costs, including negative impacts on employment and relationships and on the availability of time for self-care. This can result in increased emotional labour for the carer, reduced income, and poorer physical and mental health (Hirst 2005; Pinquart and Sorensen 2003; Schulz 2020). Within the carer population female cares have been identified as a higher risk group for worsening mental health (Schulz 2020), while evidence suggests that, for example, British Indian carers experience greater levels of anxiety and depression (Manning et al 2014).

With regards to the COVID-19 pandemic, research exploring the physical and psychological impact that self-isolation measures and lockdown had on unpaid carers (e.g. Pavlopoulou et al 2020; Carers UK 2020) indicates that the pandemic significantly worsened unpaid carers' mental health. Restricted access to healthcare during the lockdowns and beyond also contributed to worse physical and mental health amongst carers and those needing care (Whitley et al 2021). Our interview data supports such insights as all research participants reported experiencing poor mental health as a consequence of their carer status. They also reported that the pandemic and lockdowns had a negative impact not only on their mental and physical health but also on that of those they were caring for.

Participants' perceived duty to care sometimes negatively impacted on their own physical and mental health as they reported little time for attending to their own needs. Participant 3 spoke of the health challenges associated with being a long-term carer and voiced a desire to have a break from his caring responsibilities whilst feeling guilty about it:

I would like to be able to go on holiday or a break without him. But I don't know if this is selfish. If someone could look after him, so we can get a holiday, so we can rest (Participant 3).

A feeling of guilt with regards to the tension between caring responsibilities and the desire to pursue or develop personal interests and aspirations is reflected in what Participant 10 told us:

I'm sorry, this may sound very selfish, but my life now is about everybody else, not me. I miss myself. I even feel ashamed talking about it out loud, but I don't feel happy. My days, weeks, months, years are all about looking after someone. I don't think I have time or energy to think what I would like. I feel bad even saying it out loud. Looking after your family, including your kids and parents, is your responsibility and you should do it (Participant 10).

This situation was common among participants as they spoke about being overwhelmed and affected by stress and anxiety. Such experience was described by Participant 7 who, because of her caring responsibilities, barely considered her own needs:

Sometimes at 8pm I am shaking – why am I feeling angry, why is it like that? I remember I have not eaten anything at all since I woke up. Even water, I am not drinking (Participant 7).

While all ten participants reported physical and mental struggles related to maintaining their caring for those participants whose immigration status was uncertain, these challenges were exacerbated. Participant 7, an asylum seeker, said:

If they don't accept me as a refugee, I don't know what will happen. [...]. Sometimes I am crying, crying, crying. I couldn't sleep. Too much... I feel this depressing inside. I am so angry. There are many problems here in my home. Me and my husband – he is feeling stressed because he can't work because we are asylum seekers. Sometimes they [the family] saw me crying, sometimes I try to hold myself because they can't do anything for me (Participant 7).

Statements such as these illustrate how the wait for, and worry about, the asylum decision, the experience of being in poverty and the restrictions on work have a combined impact upon individuals' mental health. According to Quinn and Strang (2014), many asylum seekers describe waiting for a decision on their claim as a state of perpetual limbo. However, despite reporting mental health problems, Participant 7 told us she did not want professional help. In this, the interview data supports existing evidence which suggests that ethnic minority women are less likely to demonstrate help-seeking behaviours due to language difficulties, lack of familiarity with the health and social security system, and practical barriers such as transport costs (Byrow et al 2020).

Interviewees told us of how the pandemic worsened their physical and mental health. The suspension of routine healthcare checks and treatments beyond intensive and critical care during the pandemic resulted in a disruption of health care. For example, Participant 1 talked about having limited access to GP and mental health support:

## If you had to make an appointment with the GP or mental health team, they weren't around. It was really hard to make appointments (Participant 1).

Others, such as Participant 6, described how her children struggled with accessing healthcare, in particular diagnostic screening due the pandemic. She explained:

## The five year old, we are still waiting for an assessment, a diagnosis, she might have ADHD [Attention Deficit Hyperactivity Disorder], and I think she might have autism. So, we are waiting for that. We battled to get a screening (Participant 6).

Prioritisation of COVID-19 patients, alongside the suspension of routine healthcare checks and treatments resulted in the reduction of access to healthcare services for all, including ethnic minority carers. COVID-19 restrictions, the closure and reduction of public services as well as the limited support available from family members also led to an increase in caring duties that disproportionally impacted unpaid carers (Carers Trust 2021). Participant 3 explained her experiences as follow:

## Yeah, I had to take on more caring responsibilities. We didn't have as much respite because activities and support workers weren't able to come in and take him out. The places he would go to for art were also shut, so they were long days (Participant 3).

Similarly, Participant 10 talked about an increase in caring responsibilities for her three children and the need to juggle multiple caring roles while also experiencing poor physical health due to post-birth recovery:

First it was lockdown. So, my kids were not able to go to school or nursery. Our son was new-born at this point, and I needed some time to recover, but instead I had my two oldest kids at home with little support. My husband was on furlough for a little while but needed to return to work after six months. It was difficult as the kids wanted to go out, play and I had a small baby at home. Being locked down with young children, I was devastated at some point and really needed some difference. It was terrible mentally, but also physically.... COVID made it worse and it isolated me even more. I'm on my own, my husband works, my mum needs me, my kids need me and this is what I do (Participant 10).

While the demands for caring intensified due to COVID-19 restrictions, participants indicated that the resources that they had relied on – for example, family networks, access to public spaces, and support by public services – had become very limited. This left them further isolated. The severe experience of social isolation during the pandemic was also reported by participants who were subject to immigration controls. For example, Participant 7 described her experiences as follows:

Lockdown was hard because we didn't know the people or the area. We didn't know anything here like where we can buy halal food. Now, two years on, and I don't know anybody here. It's just 'hi, hi'. I also can't understand the Scottish... I couldn't sleep. Too much (Participant 7). The interview data suggests that all research participants experienced poor mental health outcomes as a consequence of their carer status, regardless of ethnicity or their gender identity. This echoes similar findings across the general carer population (Manning et al 2014; Schulz 2020). The findings about the impacts of the COVID-19 pandemic on research participants' mental and physical health are consistent with existing research about how unpaid carers, regardless of ethnicity, have reported barriers to healthcare access and support services for care recipients and their carers (Whitley et al 2021). Similarly, what interviewees have told us about having to deal with challenging behaviours from those they care for due to frustrations associated with lockdown is comparable to what research suggests about the general population of carers (Carers UK 2020). A key difference between ethnic minority carers and unpaid carers generally may lie in how refugees and asylum seekers find it more difficult to draw from familial and community support. This subgroup of ethnic minority carers is more affected by limited social connections and the isolation that this brings. This is discussed in the next section.

### 3.4 The role and limitations of social connections

Interviewees emphasised how important links to family members, local friends and local services were for their sustained ability to address responsibilities associated with their caring roles. The social connections which our participants spoke about can be categorised threefold: social bonds (with family or co-ethnic, co-national, co-religious groups), social bridges (to other communities), and social links (with the structures of the state) (Putnam 2000; Ager and Strang 2008; Strang and Quinn 2019).

Family relations often play an important part in providing informal care, both for adults and children. This is true for carers generally, as it is true for our interviewees. Participant 1 emphasised the crucial role of family members for maintaining caring responsibilities as opposed to relying on outside agencies or paid carers:

We need to be more self-reliant. It depends on your family, but you are not going to have the same relationship with a stranger. With my grandmother, when she was living with us, my mum did a lot for her because we didn't want to get anybody in [to provide care]. It wasn't a cultural or language thing, we just didn't feel we wanted outside support. If we could do it ourselves, we would (Participant 1).

However, the family as a source of support is only available to those whose family members live nearby. Such residential proximity was not a reality for all participants, especially for those whose family members were born outside the UK and did not have British citizenship. Participant 7, who at the point of the interview was an asylum seeker and thus did not hold the right to family reunion, outlined her struggles with her care responsibilities as follows:

#### I don't have anyone here in this country. My mother and family are not here. I wish I had come with mother and sister. I am very busy with children and cooking and shopping and have no free time. I have WhatsApp contact with them, but they can't come here. It's very hard (Participant 7).

As explained by Participant 7, holding asylum-seeking status often correlates with experiences of social isolation due to broken family and community networks as a result of forced migration. Social relationships provide a sense of belonging, promote integration into the host country and support wellbeing. Little is known about how these social connections function to support mental health and wellbeing amongst refugees and asylum seekers, but Strang and Quinn (2019) found patterns of extreme social isolation and limited social connections with family and a tendency for increased reliance on support services and on other refugees from the same country of origin.

Having little or no family support, as explained by the interviewees, makes fulfilling caring responsibilities difficult. Some participants who could not rely on family members to support them tended to seek support from carer organisations and professional care services. This was illustrated by Participant 3:

We don't have any connection to family for help or support. But we do get support from caring organisations and support workers (Participant 3).

With regards to the role and significance of social connections, the experiences of ethnic minority carers in this study are not too dissimilar from carers in general. Carers report a broad range of experiences related to familial systems of support; for example, Davies et al (2019) show that some carers will be supported by family and friends, while others may be in a period of their life where this familial support is unavailable due to ageing, poor health or the cessation of networks due to increased caring responsibilities.

For the research participants who did not have familial support in this study, either due to domestic violence, estrangement or bereavement, there was a strong need to rely on support services. However, they reported that not all support services provided adequate support. For example, while support provided by community-based organisations was reported to be crucial for some, for Participant 2 the support available from that source did not resonate with her:

Then there's the Muslim women's association, I did try use a lot of them, but I found it quite... too cultural. I think they are more for people originally from Asian countries like Pakistan or India or from an Arab country, whereas I am Scottish so I feel I couldn't click with them as much (Participant 2).

The experience of Participant 2 illustrates a complex range of relations within migrant and ethnicity-based community organisations that involve different levels of trust, reciprocity and need, depending on one's identity. For example, Participant 2 is of Pakistani heritage, she was born in Scotland and described herself as a secular Muslim. She therefore felt that her identity was at odds with the support that was on offer from organisations focussed on immigrants and refugees which, she said, placed a strong emphasis on religion. Our data therefore supports Evergeti and Zontini (2006) when they argue that a focus on the significance of 'ethnic solidarity' risks overlooking internal divisions along the lines of class, gender, age and belief.

The discussion demonstrates a varied pattern of social connections amongst carers, depending on individual familial circumstances and ranging from access to family support networks to a distinct lack of familial support. COVID-19 disrupted familial support for those carers who relied on kin networks and exacerbated loneliness and isolation.

### 3.5 The coping mechanisms

As discussed in Section 3.3, care responsibilities can cause significant stress to the carer. Many of our participants spoke about strategies to help them cope with the impact that caring had on their physical and mental well-being. These can be categorised into cognitive, behavioural, and emotional strategies (Huang et al 2007) and are similar to approaches found within the wider unpaid carer population (Fortune et al 2005; Gallagher et al 2015). In the following, examples of each category are discussed.

Participant 1 reported that she tried to acquire knowledge about the illness of those they care for and how to best care for them – an example of a cognitive coping strategy:

I have read a few books and watched things on YouTube, that's helped me. I watch a lot of Jordan Peterson [media personality and clinical psychologist] and I listen to him all the time. I hope my brother will listen to him but he never does (Participant 1).

Behavioural coping mechanisms were demonstrated by participants who turned to activities such as employment or volunteering to maintain their own wellbeing. As such, being in paid employment was not only a source of income for our research participants but it also provided them with a temporary 'escape' from caring:

For me, work is an escape. Being able to interact with other adults and not having to worry about 'is my child occupied' (Participant 2).

I need work for the sanity, mainly. But part-time, because I have that guilt with the kids, so it's about keeping that balance (Participant 6).

Beyond work, many of the interviewees emphasised the importance of hobbies to maintain their wellbeing and a sense of identity:

I attend workshops online; my husband and mother complain and shout 'you have meetings, you are busy all the time', but I am not listening because I do everything for them and I do the craft for me, this is my time (Participant 7).

Religion appears to be both a cognitive and behavioural action-oriented coping mechanism for some who participated in this study, including Participant 7:

Believe me, our God, because I have faith that's why I call myself a strong woman, because in this situation I am still strong. I have many problems in my home, but I am still strong because I have a faith (Participant 7).

Our findings on spirituality align with Fortune et al (2005) who suggest that carers often draw on spirituality and cognitive reframing as a coping mechanism for emotional distress. Cognitive reframing is the act of altering perceptions of negative, distorted or self-defeating beliefs into positive and supportive ideas in order to gain a sense of personal control and improve wellbeing (Robson and Troutman-Jordan 2014). Furthermore, our data supports findings by Gallagher et al (2015) and Masuku and Khoza-Shangase (2018) who discuss spirituality as a resource for coping.

Our research also shows that during the pandemic faith communities often provided material support for ethic minority carers through, for example, food parcels. Participants were asked if they had accessed foodbanks during the lockdown, and many said they received support from a local place of worship instead:

No, I didn't go to foodbanks. But some people did drop food off to me through a church. I didn't ask for it, but it just came through God's will to me and that worked out great just when it was needed (Participant 2).

While spiritual practices have been an important coping mechanism for the majority of the participants who took part in this research, it seems that the reliance on faith-based coping can be problematic. For example, Participant 2 entered a shelter with her daughter due to domestic violence. Prior to her decision to leave her home, she said she had approached a Muslim charity for extra support. However, she reported that she did not receive advice that helped her safety and recovery needs:

I wanted to go for counselling for trauma from the abuse I received, but they told me I just needed to pray (Participant 2).

Experiences outlined by Participant 2 suggest that while culturally sensitive support services are needed, priority must be given to the safety of, and support for women.

## 4. Conclusion

This report sought to explore how ethnic minority families organise their caring responsibilities and what kind of challenges and barriers they encounter in doing so. Interview data and existing research demonstrated how complex and mentally and physically challenging caring can be. Whilst there are many similarities between the experiences of ethnic minority unpaid carers in this study and unpaid carers more broadly, there are a number of specific issues that ethnic minority carers appear to experience. These differences can be summarised in four themes which inform our key learning points for policy and practice.

#### Theme 1: Reluctance to use the social security system and support services

Even when experiencing financial hardship, unpaid carers are often reluctant to turn to the welfare state and access the social security they are entitled to. The same seems true regarding support services that could help carers in their role. Interview data suggests that this is due to – with regards to ethnic minority carers – the stigma associated with benefits, specific cultural expectations around 'self-sufficiency', and the notion that 'the family' should provide the necessary support rather than the state.

#### **Theme 2: Limited social connections**

Research participants relied heavily on existing social connections, in particular to family members, for support in their caring roles. Such support was not, however, available to all interviewees because of, for example, the geographical distance to their families. This problem was particularly severe for asylum seekers and refugees.

#### **Theme 3: Barriers to paid employment**

Due to the gendered distribution of care work, but also because of language barriers and restrictions around the right to work for those interviewees who were subject to immigration controls, engaging with paid work for some of our participants was difficult or impossible. This led to further financial difficulties and also contributed to social isolation.

#### Theme 4: COVID-19 deepened existing inequalities

COVID-19 and its lockdowns and other restrictions exacerbated existing inequalities in Scotland in relation to gender, ethnicity, and immigration status. Interviewees spoke of experiences of poverty and poor physical and mental health, often compounded by limited access to social security and support services, limited access to paid work, and limited social connections. These problems became deeper because of the pandemic.

#### Key learning points for policy and practice

Protecting carers from poverty and valuing their contribution must be at the heart of a just, caring and green recovery from the crises since 2020. To meet these expectations, we provide the following policy key learnings which we believe should be taken into account by policymakers and other actors seeking to support ethnic minority unpaid carers. Such discussion should also consider the Scottish Government's National Performance Framework and how it, in a future revised version, could explicitly acknowledge care, in its unpaid and paid forms, through the addition of a dedicated new National Outcome on care (see Maclean et al 2021 for a 'blueprint' of a new National Outcome on care).

#### 1. The need to tackle poverty amongst ethnic minority carers

- Increase Universal Credit provision to reflect the growing cost of living: our research supports existing
  evidence that the support provided through Universal Credit is not sufficient, in particular in the face of
  rising food prices and fuel poverty, to avoid poverty (Turner 2022).
- Improve uptake of social security entitlements: unpaid carers need to be made aware of their rights and entitlements. To this end, a culturally sensitive outreach programme would benefit ethnic minority carers. To increase the success of the outreach programme, the stigmatisation of social security services users in general needs to be tackled.

- Ensure wider access to the new Scottish Carer's Assistance: restrictions to the receipt of Scottish Carer's
  Assistance by those in full-time education should be removed to support carers in their development of
  their career aspirations. Also, the new Carer's Assistance should be opened to asylum seekers, and we
  welcome the Scottish Government's exploration into whether this is possible.
- Support carers' labour market access: more efforts, by all stakeholders, need to be invested into allowing carers to pursue paid work that is compatible with their caring responsibilities. The Scottish Government's Fair Work Action plan (Scottish Government 2021b) needs to go further in promoting decent jobs for carers. While the Carer Positive employer accreditation scheme is a positive step, take-up of this scheme is low, and evidence suggests that some of the more positive elements of the devolved approach are not being implemented (One Parent Families Scotland 2021). Further work is required by employers to develop and provide greater opportunities for flexible working patterns for those who have caring responsibilities. We welcome the framework set out by One Parent Families Scotland (2021) proposing that person-centred services should be underpinned by co-creation and based on parents' and carers' needs. Such a framework requires consistent funding for support being provided effectively. We propose that access to paid work should be improved for carers by increasing the earning limit for Scottish Carer's Assistance. Finally, it is vital that restrictions and barriers surrounding asylum seekers' right to work are removed.

#### 2. The need to support the mental health of ethnic minority carers

- Enhance digital mental health support provision: because carers often have little time and opportunity to look after their own mental health and wellbeing, mental health support delivered via online platforms may be a suitable approach if it takes account of language barriers and cultural practices.
- Provide culturally sensitive mental health support that safeguards women against violence: organisations providing mental health support to survivors of domestic abuse should support ethnic minority women in culturally sensitive ways. However, the safeguarding of ethnic minority women and girls must be at the forefront of all mental health support provision.
- Increase investment in carer organisations: further funding is required to increase the provision of mental health outreach programmes within carer organisations.

## **3.** The need to support social networks among ethnic minority carers and to develop new social connections

- Facilitate access to networks of social support: The absence of transnational familial systems of support often felt by our interviewees highlights the need for access to culturally sensitive support groups, peer mentoring, learning, and social and leisure opportunities to reduce loneliness and isolation. These services must also consider the barriers faced by those people who do not speak English.
- Facilitate access to transnational familial system of support: access to family networks is key in supporting and maintaining caring obligations for ethnic minority communities. The extent and form of support ethnic minority carers are able to draw upon is often dependant on their immigration status. In these situations, the opportunity to apply for a family visitor visa allowing for a long stay of their family members is crucial, especially in periods of intensive care requirements.
- Provide flexible ESOL classes: proficiency in English is, generally speaking, key to successful integration
  as well as to ensuring the well-being of ethnic minority carers. Access to social support networks and to
  social security entitlements is often hindered by language barriers.

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