

## An Exploration of The Lived Experience of Informal Student Carers During Covid-19

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### Abstract

Informal Student Carers (ISC) are students across the UK who provide unpaid care to a friend or family member needing support. We explored the lived experiences of ISCs and the challenges they faced throughout the Covid-19 pandemic. A scoping review, questionnaire-based survey and volunteer interviews were undertaken to identify the themes which predicate ISC's experience during the Covid-19 pandemic. Our research showed that a combination of financial concerns, time constraints, and the lack of visibility of student caregivers all contributed to this student group's poor mental health during the Covid-19 pandemic. Educational institutions have an obligation to be informed and support the unique and varied needs of ISCs.

### Introduction

The COVID-19 pandemic has brought about

unprecedented changes in the way we live our lives. For informal student carers (ISCs), the pandemic has made an already challenging situation even more difficult. ISCs are students who take care of a sick, vulnerable, or elderly friend or relative, but are not formally recognised for their role. This group is often marginalised and lacks the support they need (Carers Trust, 2015), and this is exacerbated during uncertain times such as during the pandemic and the subsequent cost-of living crisis. In this research study, we aim to explore the lived experiences of ISCs during COVID-19. The study is important as it sheds light on an under-represented group and highlights the unique challenges they face while studying and caregiving. We hope the findings will encourage universities to recognise the diversity of their student body and make necessary adjustments to provide support to ISCs.

Category	Source of papers: Pubmed, Web of Science and grey literature	
	Inclusion criteria	Exclusion criteria
Type of carer	<ul style="list-style-type: none"><li>Carers or young adult carers (YAC) at university</li><li>Covid and informal student caregivers</li></ul>	<ul style="list-style-type: none"><li>Paid carers</li><li>Young/child carers (as opposed to young adult carers)</li></ul>
Date	2010 - 2021	Before 2010
Country	UK	Non-UK studies
Content	<ul style="list-style-type: none"><li>Mental health and caring</li><li>COVID-19 and caring</li></ul>	

**Table 1** Inclusion / exclusion criteria of scoping review on informal student carers.

## Objectives

- Understand the specific challenges that ISCs face balancing student life with caring, and the impact the Covid-19 has had on this.
- Based on our findings, suggest recommendations for universities to make reasonable adjustments to support ISCs.

## Background

Currently there is limited research on ISCs as a specific group, and no research on this specific group was carried out during the pandemic. To identify what relevant research is available, a scoping review was conducted using PubMed, Web of Science and grey literature from 2010 to 2021 (Table 1.0). The findings have been organised into themes and have informed this paper's discussion (Table 2.0).

## Methods

**Questionnaire creation:** A questionnaire for the survey was created based on the findings of the scoping review. These included a variety of question types: demographics, multiple choice, rating scales and open-ended questions using survey administration software Google forms.

**Recruitment:** Questionnaires were distributed to carer charities listed on carers.org. This enabled ISC's from across the country to respond. Local recruitment was achieved by posters distributed around the KCL university campus and through student network across UK. The research received research ethical clearance (see MRA-20/21-20951).

**Responses:** Over three months, 55 responses were obtained. 9 were excluded due to not meeting the inclusion criteria (non-UK responses).

**Follow up:** Survey participants were followed up in a telephone interview. Two respondents, Respondent 1 and Respondent 2 agreed to

take part in interview. Responses from the interview were transcribed, and these gave a personal, in-depth narrative to the discussion.

**Analysis:** Responses from the survey and the interviews were coded and organized into the themes identified in the scoping review (Braun et al., 2018). The findings have been compared with those from previous studies and this has provided the basis for recommendations as to how to improve support for ISCs.

## Results, Discussion and Recommendations

### Carer mental wellbeing

The Carers Trust (2015) and Sempick and Becker (2014) have reported that ISC's are a group who have low self-reported mental health. Our study findings reflect this: 53.3% of respondents said that being a carer as well as a student has a negative impact on their mental health. When asked to elaborate on why, answers included reasons such as: 'lack of energy,' 'anxiousness,' 'constant stress,' 'emotional burden,' 'irritability,' 'depression,' 'lack of focus' and 'time constraints and deadlines.' The following quote from Respondent 2 illustrates this further: "My distress is very high and then I don't sleep, so I have to drag myself through weeks and weeks. I make plans and then never accomplish what I plan to."

The effect that Covid-19 has had on young adult carers in Scotland has been documented in two reports by the Carers Trust (2020a and 2020b). In these reports, young adult carers shared that there had been an increase in their caring responsibilities since the pandemic. This has had a negative impact on mental health as pressure and stress of caring has intensified (Carers Trust Scotland, 2020a; King, 2021). Studies by Wilner et al (2021), Alexander et al (2020) and King (2021) also detail how Covid-19 has had a negative impact on the mental health of informal caregivers.

Theme	Key papers
Mental health and emotional support	Sempick and Becker (2014) Carers Trust (2020a and 2020b) King (2021) Wilner et al (2021) Alexander et al (2020) Carers Trust Scotland (2020c) Kettell (2018)
Finances and financial support	NUS (2013) Carers Trust (2015) King (2021) Sempick and Becker's (2014)
Time constraints and flexible working	Sempick and Becker (2014) NUS (2013) Kettell (2018) Onwumere et al. (2021)
Carer visibility	Carers UK (2017) Kettell (2018)

**Table 2** Themes identified from the scoping review on informal student carers.

These reports are not explicit about whether the respondents are enrolled at university or not. However, the findings are consistent with the findings from the study which showed that 95.6% of survey respondents said that the pandemic has left them feeling anxious or stressed. It is significant that the pandemic has exacerbated the mental health of this group, especially as they already had poor mental health prior to the pandemic. This reinforces the need to identify and support ISC's during Covid-19.

The survey respondents reported multiple reasons for an increase in stress and angst during the pandemic. 86.8% of respondents are worried that the person they care for will catch Covid-19. This is consistent with findings from King's (2021) report on young adult carers and mental health. Furthermore, 69.8% of respondents said that the increased caring hours mean that their education is suffering. Worryingly, 85% said Covid-19 had caused them to seriously consider dropping out of university. These findings are congruent with the Carers Trust (2020c) report, which called for increased support in these areas for young adult carers in Scotland. Building on this, another Carers Trust (2020b) report has explicitly laid out ways in which young adult carers would like to be supported. This includes support for their emotional wellbeing and mental health; help to stay connected to friends and their communities; breaks from their caring role and the support of specialist services for young adult carers; more help to balance caring, education and employment and support to stay fit and healthy. Addressing these support needs would be beneficial for the respondents to our survey who reported the following reasons as to how

their support needs have changed since the pandemic: being busier than before, increase in financial strain, increase in psychological distress, feeling overworked and decrease in energy levels. It is imperative that these issues are addressed so not to further exacerbate mental health of ISC's and to prevent these students from dropping out.

Kettell (2018) suggests that one way that student carers could be supported whilst at university could be through a 'student carer society' and fresher's fair presence. When asked specifically, 69.2% of respondents said that knowing other student carers who they can relate to is or would be helpful. In their interview, Respondent 2 was firm in their view that connecting with others who they can relate to is extremely helpful as this helps to normalise their own experience: "You need to be in this house day-to-day, live here, and understand the challenges dealing with different mood swings and irrational challenges that really go on. And that really eats at your own self-worth, attacking your memory. So having other people who are in the same circumstances to share those stories and experiences ... this normalises yours". Respondent 1, on the other hand, has found other student carers difficult to relate to as their experience is so different from that of the other student carers whom they have met. Respondent 1 thinks that these groups can only work if they are facilitated "Because needs are disparate, and people are going through a lot - those groups need to be facilitated. In the same way with mental health groups - you would not just stick 10 people in a room with depression and expect them to make friends with each other - you would have a facilitator. Facilitated discussions can

be helpful and you can learn things.” These findings, echoing Kettell (2018), indicate that it would be worth universities setting up societies where students could connect. However, we must pay heed to Respondent 1’s comment and explore further the idea of facilitated group sessions as it may be a factor that could contribute to successful outcomes from these groups.

The mental health challenges that Covid-19 has brought to students has been recognised in government documentation and advice on how to act on this has been issued: Universities have a duty of care over their students and have a responsibility to support students with mental health conditions. It is up to individual institutions as to what welfare and counselling services should be provided to offer that support (Department of Education, 2020). Students who have caring responsibilities are an important group who should be at the receiving end of this duty of care. With view on acting on the above, the following two interventions could be considered by universities: 1) Facilitated student groups where student carers can connect and relate to each other; 2) specific support or counselling for student carers and pandemic related stress.

### **Finances**

Financial struggles are well-reported amongst studies on student carers (NUS,2013; Carers Trust, 2015). According to NUS (2013) there is a significant relationship between financial issues and drop-out rate. This has been reflected in the questionnaire responses. When asked what type of support ISC’s would benefit from, financial support was the most popular option. Finances were also frequently mentioned in the free-text survey questions. For example: “Honestly, it is pretty depressing seeing all the young people around me whose parents can work full time and help fund their studies. Even with full government loans it’s difficult and then I must consider setting some aside in case my family need it back home”. Respondent 1’s words in interview also made apparent the types of struggles ISC’s might face: “If, for some reason, something happens, and you must arrange for emergency care [...] then that can be very expensive - so funds to cover this would be very good. [...] If there was an option for the

university to help with the cost of the activities that they expect you to do for your course - like a drinks mixer - then that would really make a difference for people who don’t have the funds to pay for respite”. Respondent 1’s words are helpful in highlighting an area of the lived experience of ISC’s that could easily be overlooked when thinking about allocations of reasonable hardship funds. The provision of off-hand grants for respite care is something that universities could consider with view of facilitating inclusion of student carers, especially when it comes to course- related activities.

When asked explicitly how they could benefit from extra help from the university during the pandemic, ‘financial’ was again the most popular option (33.3%). The frequent mention of financial struggles in this study corroborates the need for means-tested, targeted financial support for ISC’s. To some extent, this financial need has been addressed in the form of Institutional Hardship Funds (Carers Trust, 2015). The UCAS website outlines the financial support that some universities can provide and who is eligible for them. However, there is no recognition that financial circumstances have changed throughout Covid-19. The need for financial support increases in these circumstances, as suggested by our study. This is further corroborated by King’s (2021) report, which details that young carers’ financial concerns and worry around their own health and wellbeing has increased during Covid-19. The cost-of-living crisis is another more current adverse circumstance that will be disproportionately detrimental to ISC’s, who do not earn much or any income but cannot cut costs without affecting the safety of the person that they care for (Carers UK, 2022; gov.uk, 2022). Indeed, Carers UK (2022) report that 63% of unpaid carers are ‘extremely’ worried about how they will manage their monthly costs during the crisis. Understanding of eligibility for bursaries is particularly relevant for new students as UK carers lose their right to claim carers allowance once their course commences (gov.uk, 2021). Echoing Sempick and Becker’s (2014) recommendations, there needs to be clear guidance for student carers to navigate financial aid that may be available to them, detailing how this might have

changed since the pandemic.

### **Time constraints**

Flexibility of study and remote options are important for student carers. Previous studies have shown that students who have caring responsibilities feel less able to balance their commitments and are more likely to drop out of university than students who do not have caring responsibilities (Sempick and Becker, 2014; NUS, 2013; Kettell, 2018). Onwumere *et al.* (2021) discuss how the role of informal caregivers has become more challenging because of the pandemic. For example, with health checks becoming remote appointments, healthcare providers have become more reliant on the involvement of informal carers to support care recipients with physical health checks (*ibid*). This was reflected in our study where 'time constraints' or 'time management' were repeatedly mentioned when describing the struggles involved in caring alongside studying. Respondent 1 further illustrated this in her interview: "It is just easier just be at home. If one of the carers calls in sick, I would be able to schedule the times that I go in and care for Tom. Whereas if that happened and I had class to go to in person, I would have to choose and realistically there is one choice...I don't have a choice". This concept of 'not having a choice' aligns with what Onwumere *et al.* (2021) acknowledge - that carers are unlikely to have any other option than to continue being a carer. The pandemic has not changed this fact. Rather, it has highlighted the hidden key worker status of informal carers (*ibid*).

A difficult aspect of caring for somebody is that it can be unpredictable. This difficulty is present to a varying degree and depends on the level of care one is expected to provide. For some this means being unable to concentrate in class due to always being on call. For others, such as Respondent 2 who cares for her partner with depression and bipolar, this could mean waking up on a difficult day and having to tend to all the basic needs of the person she cares for, giving Respondent 2 no other choice than to drop all other planned commitments. Respondent 1, who cares for an extremely clinically vulnerable individual, who normally has a 24/7 paid-for care package, explained that Covid-

19 makes everything unpredictable: "With Covid as soon somebody has a symptom they can't come in until they have done a PCR, that knocks people out for days. So, I cover when nobody else can. This is very variable. It is 0 hours on a good week but 48 on a bad week". Kettell's (2018) pre-pandemic study argued for flexibility regarding attendance of ISC for compulsory educational activities. With Covid-19, online learning tools and remote attendance have become widely accepted as the norm. It is now easier than ever for courses to supply fully online material to facilitate remote and flexible learning for those who are not able to attend in person. The worry of passing Covid to a vulnerable individual should be sufficient reason for a student carer's physical absence in what would have otherwise been a class that mandated in-person attendance. For the vulnerable people in our society, the idea of going 'back to normal' post-Covid rings a lot less true than it does for others. The thousands of people who were previously shielding will continue to take specific measures that the rest of the public will do less of - such as social distancing, wearing masks and continual testing. Their carers also must follow these measures. Therefore, carers should, by association, be supported to do so. One method of such support could come from universities assuring the long-term provision of remote learning for those who need it, for as long as they need it.

The pandemic has put caregivers under increased strain as anxieties and practical difficulties associated with caregiving have been exacerbated (Onwumere *et al.*,2021). This has made time management more difficult, making deadlines more stressful, as indicated by several of our survey respondents. UCL offer an adjustment for students with disabilities whereby they are entitled to take an extension on all their assignments, should they need it (UCL,2021). This is something that ISC's nation-wide could really benefit from and should be considered as a reasonable adjustment that all universities could offer to support student carers. It could help them deal with balancing their studies alongside the unpredictability of their caring role.

For appropriate support to be provided, the

infrastructure needs to be there, which in turn comes with awareness of what student carers do and an increase in their visibility. Some universities have better infrastructure for this than others. Respondent 2 explained that her experience with the Open University, which works on a model of flexible and distance learning (Open University, 2021), was always positive as applying for last minute extensions or making a case for flexible learning felt very accessible. Now a student at King's College London, Respondent 2 feels that if she required extenuating circumstances then she would have to meet a strict set of criteria to qualify, which she would "not even have the time to apply for". With remote study being the norm in universities across the country, the model used by the Open University, where flexible working is part of their blueprint, could be followed to increase ease of accessing extensions or applying for extenuating circumstances.

### **Carer visibility**

Kettell (2018) recommended the use of Carer's Passports (Carers UK, 2017). This would be a wallet-card that will "signify to all staff that a student is also a carer, alleviating the need to explain their circumstances multiple times" (Carers UK, 2017; Kettell, 2018). "This may be useful when the impact of caring is difficult to negotiate" (Kettell, 2018). When asked about whether she would find the Carers Passport useful, Respondent 2 said: "I love this concept- I would love to have it on my head and walk around with it. We need to bring visibility to carers because it is difficult. If we look at the number of people who have depression in the world and who must hide it... Having to explain it repeatedly is also very unsettling for me." A student carer's distinct support needs should be recognised from the outset. Their needs ought to be formally assessed and quantified at the beginning of their university journey. This could be in the form of a 'carers need assessment', like a 'disability needs assessment' which is standard practice for new students with disabilities across most universities. Universities ought to reach out to students who have disclosed their carer status and offer them an assessment appointment in which they provide evidence of their caring role and the university makes reasonable adjustments to respond to their needs. Part of

this could include setting them up with a carer's passport. This could and should then be re-assessed and updated annually or when times are challenging. The pandemic and the aftermath are present examples of such challenging times where the lives of so many have been so transformed. The above suggested support systems would go a long way for ISCs who continue to struggle with ongoing difficulties caused by long-Covid and the current cost-of-living crisis.

### **Conclusion**

This research has explored the lived experience of ISC's and the challenges they have faced throughout Covid-19. The combination of financial worries, time constraints and the lack of visibility of student carers has a large part to play in the poor mental health of this student group. These issues have helped inform recommendations which universities would do well to consider in order to support the unique and varied needs of their students who are also caring for somebody. Universities need to reach out to student carers. They have a duty of care to the students, and they are accountable for drop-outs. They should therefore design effective retention strategies, based on the recommendations made throughout this discussion, which are informed by the lived experience of ISCs. The pandemic and the stages after its peak, including the cost-of-living crisis, continue to be difficult for student carers. Just as with other aspects of student life, the pandemic and cost of living crisis has been more difficult for student carers that it has been for their non-caring peers. Universities must not let Covid-19 nor the cost-of-living crisis be further reasons for student carers to go unseen and unheard.

### **Personal reflection**

As clinicians-in-training, this project has been useful to reflect on. As doctors, we will often be one of the first points of call to services for a patient and those involved in their care. Therefore, it is important that we are educated on the topic. Now that we know the unique challenges that ISCs face, we are better equipped to advocate for them. To be an advocate, we will ensure we take appropriate steps to recognize their involvement in patient care. We will be mindful of the individuality of

their situations and signpost them to appropriate support and make sure to follow up with them to ensure that they access support where necessary. We will also start conversations amongst our colleagues, highlighting the role of informal carers, the valuable role that they play and what we, as doctors, can do to help them.

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