

CARING ABOUT STUDENT CARERS

ABSTRACT

This project aims to better understand and support students who are carers. Recognising that student carers often face multiple challenges, this project investigated student experience of distance learning. Framing experience of study as emerging out of the affordances for learning offered by an institution and student subjectivities, the project foregrounded how students negotiated their learning trajectory through their modules. The project had two aims:

1. To explore how students who are carers experience and manage Open University (OU) study
2. To provide a sound foundation for further University-wide research in this area

20 telephone interviews were conducted with HWSC students with caring responsibilities. These were transcribed and analysed using a combination of Framework analysis and Thematic analysis. Student-carers faced similar challenges to carers elsewhere – financial and time limitations, along with challenging, exhausting and unpredictable demands. While the OU was chosen for its flexibility and affordability, caring could be incompatible with the time demands and routines of successful study. Carers actively managed their time, boundaries and others to maintain their study. Study was enjoyable, confidence building, potentially career enhancing and offered the potential to improve care. Student-carers were ambivalent about OU support with some keeping their caring responsibilities private. Some tutors were very supportive and others less so. Student tutor groups were not a priority.

For carers, caring responsibilities represented continuities in their sense of self. The layering on of university commitments potentially created tensions but did not disrupt the primacy of their caring role. Rather, study reinforced carer sense of personal integrity. Increased university flexibility would enhance affordances for carer learning. Follow-up interviews with the same students are planned for a year's time.

1. INTRODUCTION

1.1. Global demographic change means that more and more people will be a carer at some point in their lives and more and more people are likely to care more than once or be a 'sandwich carer' for both younger and older generations (Brown, Dodgeon, and Goodman, 2014; Carers UK, 2015; International Labour Organisation, 2018). That carers are often disadvantaged by caring (especially over the longer term) in relation to their health and wellbeing, finances, education, employment, and social life is well-documented. Policy changes and economic austerity mean that these disadvantages are likely to increase (Cronin *et al.* 2014; Carers UK, 2018; Larkin, Henwood and Milne, 2018).

1.2. Such evidence has led to carers being one of the priority groups within HE widening participation sector guidance across the OU's four nations. Organisations such as Carers Trust, Carers UK and National Union of Students (NUS) have been lobbying across the UK and undertaken research to raise the profile and needs of this group of students. In its report on the experience of student carers in the UK, the NUS highlights some of the many challenges facing student carers e.g. in addition to time

and financial pressures they often experience various personal difficulties which impact on their mental health and wellbeing (National Union of Students, 2013).

1.3. In theory, the flexibility and open access offered by the OU suggests that it has the potential to be experienced more positively than other forms of HE study by student carers. However, apart from a recent pilot project carried out by OU Wales, there is a distinct dearth of knowledge about supporting student carers in HE generally (National Union of Students, 2013; Larkin 2018) and the OU specifically. Indeed, a key limitation in understanding student carers is that they tend not to identify as carers. One of the recommendations of the OU Wales pilot project was that “the University should carry out further research and analysis of student carers’ circumstances their needs and aspirations, including those with multiple barriers” (Hudson, 2018, p8).

1.4. Student carers are more likely than their peers to consider leaving study due to their caring responsibilities (National Union of Students, 2013), The OU’s (2013) Equality Scheme emphasises that there is a need to better understand and support those experiencing such disadvantage. This project is the first of two projects which build on the Wales pilot project in order to develop an understanding of how students who are carers shape a learning trajectory within the context of the other commitments in their lives. It will form part of a cluster of associated HWSC scholarship projects investigating how specific personal challenges affect student study, persistence and retention. The research aims were:

- To explore how students who are carers experience and manage OU study
- To provide a sound foundation for further University-wide research in this area

The sub-questions were:

- what are the personal and study goals held by student carers?
- how does caring impact both positively and negatively on them as students and their student journey?
- what do they think are the outcomes (to date) of the positive impacts on them as carers and students?
- how do student carers respond to the negative impacts on them as carers and students?
- do they experience any other barriers to their study?
- what personal and organisational support do they find helpful that enables them to achieve and progress?
- what further organisational support do they require to enable them to achieve and progress?

2. CONTEXT

2.1. Following Billett’s (2008) concept of co-participation, building an understanding of the student-carer experience and management of study involves comprehending the transactional relationship between the affordances for learning offered by the institution and the individuals’ particular subjectivities. It is certainly the case that the OU affords particular types of educational experience (for example, the capacity to study at the time of one’s own choosing or the inflexibility of assignment deadlines) but these are not passively experienced by student-carers. Student engagement is shaped by their occupational, domestic, personal and social commitments (Woodley, 2004). Moss and Pittaway (2013) frame these commitments as ‘layers of involvement’ and responsibility which are intrinsically implicated in an individual’s identity as a parent, a carer for a disabled sibling, an employee or a student. A students’ sense of

what specifically is of most importance right now reflects the demands of these layers at any particular moment and as such, reflect an expression of identity. However, the demands of these layers potentially compete and as such, create tensions which the student-carer- must try to manage and reconcile in order to maintain their personal integrity (Adamson and Donovan 2005).

2.2. Consequently, the demands of these layers do not simply exist as a 'brute facts.' They are interpreted and managed by students as they make decisions about their continued engagement in study. This negotiation may involve aligning aspects of their lives with the demands of their modules (for example, asking that a family member take over responsibilities for care in order to meet a deadline). In contrast, it may involve ignoring other opportunities which appear essential to successful study. For example, it has been found that mature student-carers report that they do not have the time to participate in virtual or physical support groups (National Union of Students, 2013).

2.3. In Davidson and Wilson's (2013) compelling critique of Tinto's (1975) model of Social and Academic Integration, they highlight the limitations of standard models of student retention. While traditional students are more likely to embrace social opportunities which are considered to enhance student retention and satisfaction, non-traditional students may have a different response. However, those with caring responsibilities, may view these social opportunities as an unnecessary demands and might render opportunities for social involvements irrelevant. They focus on commitments and supports outside the university such as involvements with their families are more important (Woodley 2004).

2.4. Students do not just *experience* a course of study. They negotiate a trajectory through it, managing the layers of involvements in their lives in order to maintain personal integrity. Developing such an appreciation of how student-carers manage this trajectory, challenges the deficit model sometimes used in understanding students who are vulnerable to drop out. Instead, it is hoped that this project will encourage the OU to consider an alternative framing of student-carers as dedicated students who can be accommodated in a more appropriate way.

3. RESEARCH METHODS

3.1. This was a qualitative study that ran from January - September 2019 (nine months) with a sample of 20 HWSC students across modules, levels and programmes with caring responsibilities. It was conducted by the following members of the Carer research group:

| Name | School/research cluster |
|-----------------------|-------------------------|
| Mary LARKIN (PI) | HWSC |
| Manik DEEPAK-GOPINATH | HWSC |
| Chris KUBIAK | HWSC |
| Julie MESSENGER | HWSC |
| Jitka VSETECKOVA | HWSC |

3.2. Ethical approval was obtained from the relevant committees; Human Research Ethics Committee (HREC) approval was given on 29th January 2019 and Student Research Project Panel (SRPP) approval on 15th February 2019.

3.3. Using information available from the WELS Student Support Team, HWSC students with caring responsibilities were invited by email to participate in the project. Despite sending out 2 CAMEL surveys, the original sample size was 3 short of the target of 25. As it then transpired that 2 of the 22 students who offered to be interviewed were not carers, the actual sample size was 20 students – 16 females and 4 males. An attempt to address the discrepancy between the numbers of females and males was made by including a reminder email in the second CAMEL survey to emphasise that we particularly wanted to hear from male carers as their voices are often underrepresented in research studies. In addition, although the intention was to use purposive sampling (e.g. by module, degree, age, gender, SES, disability, ethnicity) this proved to be impossible logistically. The sample was structured in terms of gender only with a view to adopting a more systematic approach to sampling for the next study.

3.4. The caring situations of the participants were diverse; they cared for people of various ages who have long-term disabilities, health conditions or frailties: 12 were caring for one person; 5 had caring responsibilities for a child with complex needs, 4 for a parent, 2 for a partner and 1 for a brother. The remaining 8 participants had (or had in the past) multiple caring responsibilities. These included caring for at least two children or older parents, or an adult (older parent, partner or sibling) and a child. There were 11 in the sample who were combining care, study and full or part time work. Duration of caring responsibilities ranged from 2 to 23 years, suggesting that some of the participants had long caring careers. Their caring circumstances were also both dynamic and evolving with a few reporting transitioning in and out of caring (e.g. those caring primarily for aged parents) while others were experiencing ever-increasing caring demands and shifts in the type of care required.

3.5. A HWSC PhD student was appointed on a five-day consultancy contract to carry out semi-structured telephone (Skype for Business) interviews with these 20 students between March and June 2019. The interviews were supported with a topic guide based on the subquestions above (see Appendix 1). Interviews lasted an hour and were transcribed by a professional transcription service. Participating students were sent a handwritten note of thanks and a £10 Lovers to shop voucher.

4. ANALYSIS

The data was analysed using an approach based on a combination of Framework analysis and Thematic analysis (Boyzatis, 1998; Braun and Clarke, 2006; Parkinson et al., 2015; Ainley et al, 2018). During the first stage each of the project team members familiarized themselves and thematically coded 4 scripts. This involved labelling anything they considered important and noting recurring themes. The project team then met and using their notes taken during the familiarization stage, developed a thematic framework (see Appendix 2) based on the key issues, concepts and themes that had been expressed by the participants. In order to filter and classify all the data, the thematic framework was transferred onto an SharePoint excel sheet on which team members inserted summary points and quotes from their 4 transcripts that corresponded to the codes. A frequency analysis of the codes was undertaken to identify the most commonly occurring (plus exceptions).

5. THE THEMES AND SUBTHEMES

The three main themes were 'About caring', 'About studying' and 'Support from the University and other students'. For the purposes of creating a narrative, the key issues within these themes are discussed under the following heading in Sections 6 to 11 respectively:

- Caring and studying
- Benefits of studying
- Studying with the OU
- Coping with OU study
- OU support
- Suggestions for improving institutional support for students with caring responsibilities.

6. CARING AND STUDYING

6.1. Many talked about the positive aspects of caring, reflecting on how caring had supported their acquisition of specific skills and qualities. These included: 'patience and understanding', becoming 'focused', 'organised and planned', 'being able to manage', and the ability to function with high levels of stress and anxiety.

'I think it's [CARING] taught me to manage my time a lot more effectively, because I have to. If you'd have asked me that even a few years ago, my time management skills were not great...'

Some focused on how rewarding and emotionally satisfying caring could be in terms of making the person for whom they care 'happy and contented' and 'well'.

'...I mean it's nice when they're happy and contented. But it's, that's the best of it'.

6.2. The satisfaction they derived from the way they could now provide a better quality of care for the cared-for person because of the understanding of his/her needs and expectations they had developed over time was also mentioned.

'...I think being a carer you learn what the person needs, if you like, over time[...] As opposed to a carer coming in and having short periods of time in and out I think you can make their life so much better because you find out what works for them and, you know, how you can improve their quality of life.'

6.3. Caring had inspired career choices in care. Others felt their caring experiences (especially, constantly negotiating support with service providers) had developed skills and understanding that they used in their workplace roles. One participant, who was a shop floor assistant at a supermarket, described how she used her experience and knowledge of her son's health condition to help parents and the local community.

'I felt that it's [Caring] encouraged me to really be proactive, and I've actually helped a lot So with my job role I come into contact with complete strangers, and they look baffled. A lot of children are now coming in with illnesses or allergies to milk, gluten and wheat, and parents don't know where to start [I say] well try this, here's an example of a product you can try first. And I've found that with my job role they've actually, I've protested to get the free from ranges that bigger [Supermarkets] have into my store... they've got it in, and it's stayed in..And the local community has benefited.'

6.4. However, many were coping with intense and challenging levels of caring.

'I care for both of my children. The one is classified as disabled, the other one isn't, but obviously being adopted he comes with attachment difficulties and his own set of special sort

of specific needs shall we say. Then my oldest son he has attachment disorder and dyspraxia and suffers with anxiety a lot. He needs that constant reassurance. For my eldest son, it can be just even fastening some of the buttons on his clothes, different things like that. I also care for mum as well. I do have to help her get dressed, get undressed, get to bed, get out of bed. Personally, you know, washing and certain things’.

6.5. Even those who were in less demanding caring situations described everyday life as a ‘balancing act’ and talked about how they had to ‘juggle’ to ‘keep all airplanes in air’. They felt the demands of care constantly competed and conflicted with family, leisure, work and study commitments. For example, some reported feelings of guilt about not being able to fully participate in family life and the lack of opportunities ‘to relax or enjoy a social life’.

‘...would have given more time to children if I had not been a carer ...’

and

‘... when I hear, sometimes when I hear other people talk about they’ve got to look after their kids or take their kids to the park and I’m thinking my God, I’d love to just take kids to the park today kind of thing. Sit out in the garden or something.’

Others talked about how caring responsibilities not only led to changed roles and responsibilities (such as becoming the breadwinner or giving up work) but also influenced their decisions about the pattern, timing and type of paid work – decisions taken so that they could ‘care around the times’ they work. Some remarked that caring was impacting their future plans about pursuing paid work too.

6.6. Many participants referred to the unpredictable nature of care. The way it can vary over the course of a day or from week to week meant being a carer often prevented them from meeting study commitments; they talked about how this unpredictability ‘ate away’ the time they had planned to dedicate to their studies.

‘...when it comes to [caree son’s] needs, [He] can’t, I can’t say the same to him and him just accept it because if he needs me at the drop of hat to save world war three and ...harming himself I have to do it there and then [...]people they’re working shifts and they know what they’re working that week and they know how to work around it and what hours they have but as a carer you never do. You can plan something but it’s not necessarily going to go to plan. And you could end up, you might think well I’ve got five hours to do this work today and not end up with that five hours due to whoever you’re caring for. And then that puts you back [for study].

and

‘...one of the most difficult things is if you have a sudden doctor’s appointment or if somebody isn’t very well and then you have to push something to one side, usually study goes to one side and your caring has to take over...’

6.7. A linked point was made about the pressures on their time - either not having enough time to study or uninterrupted study time. These could be exacerbated by financial pressures they faced:

‘I have to stop [studying] to go and do stuff, because I can’t pay for taxis to pick [son] up, for example, because then I know that if something, god forbid happened, then at least he would be with somebody in a vehicle, against on a bus or on a train’.

6.8. Such constraints led to them getting behind on reading; being unable to digest or enjoy what they were reading; not being able to attend live tutorials and be part of a collective; feeling stressed because they could not submit their assignments on time.

In addition, limited or interrupted study time combined with feeling 'drained', 'tired', "beyond tired" 'knackered' and 'exhausted' because of their caring responsibilities affected their ability to 'concentrate', 'sit down to study' and have the 'headspace' to study. A few said they had come close to giving up on studying or had failed a module previously.

'I had a particular bad week a couple of modules back and I missed a week, and it took forever to catch up. I was really concerned about it[...] as a carer I don't really have that time to catch up.And that becomes very difficult and more tiring, really tiring...I've had a couple of assignments in this module as well that has fell during school holidays and that has been particularly stressful.'

and

'I do get very low sometimes and do have down days. I wanted, in my last assignment, I actually sent an email to my tutor and said I can't do this, I'm just going to do hand in my notice, I can't do it anymore, I can't carry on. Because I was having such a hard time with everything ...I don't do my studying when I feel really low. I can't do it.'

7. BENEFITS OF STUDYING

7.1. Studying was referred to as 'me time' and although some experienced guilt, it was seen as being enjoyable and as a substitute for social or leisure activities.

'And this [studying] is something for me This is something that I enjoy doing. While my friends like to enjoy nights out on a Friday night I like sitting here and I've got my uni work to do. I've got my laptop and I've got my books and I enjoy it... it's refreshing really...'

and

'... (studying) does help me concentrate that this is my time, it's important, it's valuable...'

7.2. There were also comments about the way studying had increased their confidence.

'I've found it quite, it's been good for me in my confidence in finding something that's not anything to do with the kids additional needs, it's refreshing really.'

and

'...it's also given me more confidence So I can stand up in front of a group of seven children who are 16-17 years old with autism, and I can actually talk to them about health and social care and know what I'm talking about... and I've got the confidence to do it, which I wouldn't have had before I started doing all my studying' .

Participants who were parents often talked about their pride in being a role model for their children:

'...my kids can both see me studying and, hopefully, and I'm hoping that it will encourage them to do their studying'.

7.3. Most participants reported studying enabled them to gain a better understanding of care and caring (including relevant legislation) and that this understanding improved the caring experience for the person for whom they care.

'I wanted something that was going to help me with my looking after my mother. Because the course is all about caring ..., good care, bad care, you know, sort of all sorts, there's all sorts of aspects of social care really... the course is varied and I've really enjoyed it. It's bolstered me a bit against some, just feeling sort of a bit exposed to misery really...'

Others mentioned the value of sharing the information with those who need it, either professionally or in their unpaid caring roles.....

'...So the information that I get through the coursework goes quite far, because there's lots of people looking for information'.

7.4. Studying was also seen as beneficial to their career and employment; many had chosen courses that were relevant to a future career and improving their employment prospects. Although some expressed their desire to 'earn money' and 'to be rich', most of them wanted to work in the Nursing and Social Work field. However, they reported losing their identity in the process of studying; their life goals became blurred during their education journey.

'My career is.., I'm not a carer, I'm not a nurse, I'm not a nursing assistant, I'm not a maternity nurse, I'm not a teacher...I don't think I've got a career path anymore'.

8. STUDYING WITH THE OU

8.1. The OU's flexibility and affordability were two key factors that influenced these students' choice of university. For example, there were comments about how OU study met carers needs in terms of being able to work and study around caring responsibilities and enabling them to work online from home rather than travel into university for tuition. Some students speculated that without caring responsibilities they would probably have gone to a

'.....a proper bricks and mortar university, because I wouldn't have that responsibility of having to be at home, and making sure that he's all right for the evening and stuff like that, and up in the morning and all that kind of stuff..'

8.2. Students implicitly acknowledged the OU's open access policy and saw the OU as pivotal in meeting their personal expectations for growth and development.

'And it just, I got stuck in the rut of being a mum for quite a while when I thought I need to do something that's for me, because I wasn't actually doing anything that was for me as a person. It was more this is what I need to do for xxx today. I've got to do this for xxx today. And there was absolutely nothing that I was doing for myself so I thought I need to do something that would be beneficial to me and the kids in the end'.

8.3. Some students said engaging in OU studies had built their confidence and resilience.

'I like the online aspect of the course; the videos, the audios, the video clips. I like the organisation of the course to show your progress as you're going along. That's all good'.

In terms of OU learning design, there were comments about the helpfulness of being able to plan and schedule work, using the study calendar to keep on track.

8.4. Where students were more negative it was about the loneliness of OU study.

'I had an examination the end of year three and I met two students there. There was only three of us. But I did meet other people, that was quite nice, but other than that I've never met a tutor or a student face-to-face. I think the hardest thing is thinking that you're on your own. Thinking that you're the only person that is in this position. And it can be very isolating'.

They were also critical of learning materials that failed to feed into student's preferred learning styles. Although they did not appear find online tuition or access to online forums problematic, some felt that learning within groups did not suit their preferred learning style; because of the unpredictability of their caring responsibilities, they saw themselves more as independent learners and could not commit to set times for group learning was within groups. A further issue was the timing of assignments, especially if assignment submission fell in school holidays as this impacted significantly on carers. Carers commented that at such times their caring responsibilities increased and the home environment was both noisier and less conducive to study and writing.

9. COPING WITH OU STUDY

9.1. Despite making positive comments about their experiences of OU study, those interviewed repeatedly said that studying was harder than they had expected. Many admitted that managing the pressures of caring and studying alongside commitments is tough, and on occasions overwhelming. Interestingly a degree of pragmatism prevailed; many accepted caring comes first and is not something from which they cannot take a break. They adopted the view that 'you just get on with it', and all was not lost if they did not achieve their goals.

'I am not expecting anyone to do it for me, it has to be done and it has to be me who does it, no one can do it for you.'

and

'it's like I think I took it upon myself that nobody pushed me into the course.And I pushed myself to do this course. I said if everything comes to it I know it's the money I will lose but then nobody is going to hang me for not finishing it...'

For some too, particularly long-term carers (i.e. at least 6 years and more), coping with these pressures had become a part of daily life and they had become acclimatised to operating in difficult caring situations and under high levels of stress and anxiety.

9.2. Nonetheless, there was evidence of a range of coping strategies being used. Some emphasised the importance of learning to 'go with the flow' and replanning when opportunities for study time dissipated.

'...it's just trying to work round the situation that happens at that particular day or time. Whatever there is....'

Other coping strategies were based on careful time management and self-discipline in order to make the most of the time available. Participants talked about being 'a bit ahead of the game.... because you're just playing catch up all the time'. They also described how they carefully fitted in their study around the needs of the person for who they were caring.

'I work and provide the care around the times that I work. And then I do my study on the evening when everybody's gone to bed.'

and

'When the children have gone to school I go and help my mum. And then mum's OK. And then I go to work, come back from work and study. I study in the afternoon until half past three when the children come home and then start again with the caring, children, then my mum.... one of the most difficult things is if you have a sudden doctor's appointment or if somebody isn't very well and then you have to push something to one side, usually study goes to one side and your caring has to take over... So if I'm two days behind then I would probably study on the Saturday and the Sunday where I'd normally have my freetime to catch up...'

and

'...I've got to manage my time so that I'm working when my mother's resting. Either before she gets up or when she's having a rest. That's the main thing....'

Those who were in employment often mentioned strategically planning and taking time off work to manage their study.

9.3. Central to these coping strategies was setting clear boundaries wherever possible and managing other people's (mostly those who were being cared for) expectations.

'...you've just got to make it very clear before you start with all your co-dependents'

and

'as long as she knows that I've got to get something done, she's happy to let me get on with it, as long as I spend time with her and keep her amused...have to be selfish now...'

It is important to note that irrespective of the success of these more decisive strategies, participants invariably experienced guilt when taking time away from caring.

9.4. Many highlighted the role of immediate and wider family, friends and community in their lives as sources of emotional and practical support (e.g. with childcare, managing household and sharing of caring tasks).

'I had a good cry to one of my girlfriends this morning because I got stuck on something, and I said, oh I don't want to do this anymore... she sat there and we talked through it and it made it a lot clearer in my head what I was trying to write so I would carry on with it'.

Sharing the experience of studying could be a two-way process and have unexpected benefits; as one participant explained, sharing her experiences with her daughter had helped them both

'...she's [DAUGHTER] been very difficult at some points of my studies. But then she's actually taken an interest in what I'm doing, so it's become a bonding thing between me and her... we've had a conversation, and I was showing her the maths on here, and the English there and I said if I can try a little bit harder, so can you. And that seems to have given her a little bit more confidence too.'

9.5. Securing support from these sources could involve advance planning and organisation

'...my husband is very good. He does work full-time, but he is very good. My husband and I have an evening off each month where we both go out and we have people to look after everybody else so that I get a break away from the house. [..]I'm very lucky I've got a good family network. And my auntie came to stay for the last week, for the last assignment that I had and she took care of the children. She took the children out every day for me..'

9.6. Some of these coping strategies point to the importance of student carers' social and financial contexts. This point was reinforced by the fact that those participants who were sole carers operating with minimal or no support were more likely to experience poorer wellbeing generally and struggle with module deadlines.

10. OU SUPPORT

10.1. Another dimension to 'coping' with studying and caring was accessing the support provided by the OU. Many students said that the university provides 'good support' with students reflecting positively on the important role provided by most of their tutors in supporting them as carers. The best tutors were those who had been proactive in their contact with students; clarifying their role and accessibility; and establishing clear expectations for students. Where students had openly spoken to tutors about their caring responsibilities these tutors had responded appropriately and supported and encouraged students when they experienced challenges associated with study and their role as carers. Some students went as far as describing tutors as 'helpful', 'brilliant' and 'fantastic'. Students found tutors particularly responsive to their needs should they ask for extensions on their assignment submission dates.

'They (the tutor) knows your situation. You come to them and if you need an extension for submission of an assignment, they are more understanding in giving you every opportunity to succeed, so yes...I'm blessed to have the tutors of the OU yes, they are great'.

10.2. However not all students chose to disclose their caring responsibilities to the OU. Those who did not said it was because they did not see themselves as a carer.....

'...sometimes you just tend to think that you just do it (caring tasks), you don't really sort of see yourself as a carer do you?...'

Those that did were quick to point out that that did they want to be seen as using it to their advantage and not an excuse from doing the work and finishing the course:

'I didn't want that (caring role) to be used as an excuse I just mentioned it once to my tutor that's all...'

Furthermore, there seemed to be a general reluctance to ask for support even when they knew it was available and an emphasis on being self-reliant.

'So, I sort a few things out myself really without asking for any help. But like I said I've always been lucky that I know that help would be there'.

10.3. In many cases, participants justified remaining silent because of the unpredictable needs of the person for who they cared and uncertainly of the caring situation. For example, they had little confidence that an extension would buy extra time when there was a reduction in their caring responsibilities.

'You can't go telling the tutors last minute or anything like that if you're having any difficulties. Because the nature of the illness that my daughter has, you just don't know when she's going to be worse and when she's going to be, you know, she's got good days and bad days, so you just don't know when it's going to be worse for her than other days.'

10.4 Surprisingly few talked about attendance at tutorials which are known to be problematic for many students due to timing and geographical location. Where tutorials were mentioned, one student who was carer for their partner with ongoing mental health needs stated that:

'I've never been to any tutorials or met up with anyone or anything like that.....I can't be bothered.....a lot of them they're a bit far away from where I am and I couldn't leave the kids'.

10.5. What did emerge from the findings were criticisms of the 'university limitations' for meeting the needs of student carers; there was concern about being eligible for support if a formal diagnosis had still to be reached on the person receiving care and how carers evidenced their caring role. When the following student talked about requesting an assignment extension she said that ...

...they tend to need proof, and how can you prove that. I don't know how to prove that.....I don't know how to prove my daily life. It's just how it is. It's not documented or anything like that, it's just life for me'.

10.6. Where mental health was the focus of the caring role, students felt that this was often misunderstood by the university with little direct support available to carers supporting others with these needs. This is an interesting perception for students to draw and highly relevant when so much attention is around student support relating to mental health making it a very topical area for discussion across the university sector currently.

11.SUGGESTIONS FOR IMPROVING INSTITUTIONAL SUPPORT FOR STUDENTS WITH CARING RESPONSIBILITIES.

11.1. A few students spoke about a need to return to some elements of face-to-face tuition to increase the visibility of their peer community. However others commented that access to day schools etc. was often prohibited due to geographical distance and ongoing caring responsibilities.

11.2. They suggested that peer support facilitated through learning design was a way forward in combating the loneliness of OU study. Although some participants thought there ought to be Student carers forums, they did not have any ideas as to what these would provide over and above support that was available. In addition, even if such a group existed, the extent to which it would be beneficial was questionable as students

seemed to attach stigma to their roles as carers and/or wanted to keep this part of their life separate to their studies.

'Being a carer has been very private to me.....I don't even know I've even spoke to anybody else on the course about being a carer'.

11.3. One student spoke about the need to have specialist advisors available to support students who are carers. This was linked to students' need for sources of advice on possible grants to help them continue their studies should they be experiencing financial difficulties.

11.4. The value of financial support to help them cope with studying whilst caring was also mentioned....

...[Financial support] It would just allow me to maybe get some help in order to study. So when it does come to exam times etc, I know that I can pay somebody to come and take over caring responsibilities for a few hours a week...'

11.5. There were two suggestions about assignment management. The first was, the need for consideration of timing of submission; specifically, not to occur in school holidays where many carers of children will hold additional caring responsibilities. Secondly, the University rule about no extensions on End of Module assignment/examination submissions should be waived for student carers should their caring commitments become unstable or escalate at this point in a module.

'If the OU could have just understood a little bit more what I was going through, I was literally caring for a child who couldn't get out of bed for five days.... But that's the way goes. It clearly says that no extensions on EMA shall be given under any circumstances. But actually, think of the person that really does need it'.

12. DISCUSSION

12.1. This project set out to explore how student-carers experience and manage OU study. The student-carers interviewed in this study described caring as personally rewarding but a challenging, exhausting and unpredictable role which left them with limited time and finance. In terms of Moss and Pittaway's (2013) 'layers of involvement', caring responsibilities were not easily compatible with the time demands and routines involved in successful study – carers actively managed their time, boundaries and the expectations of those around them to keep up with their modules. Choosing the OU for its flexibility and affordability reflects on such active management of demands. However, student-carers were much more ambivalent about the support offered by the OU – they had mixed experiences of tuition and the potential personal value of support offered by tutorials and forum discussions with students. Some preferred to keep their caring responsibilities private while other indicated that they might benefit from communing with others with similar concerns. Despite the challenges of study, carers also found it enjoyable, confidence building, potentially career enhancing and offering the potential to improve their care.

12.2. This section frames the accounts of student-carers within Billett's (2008) concept of co-participation. It attempts to connect the experiences of student-carers to other carers before providing a critical account of the affordances for learning offered by he OU. It also explores how student-carers negotiate their studies. Recommendations and directions for future research are presented.

Affordances for study

12.3. The interviews outlined the way in which caring had shaped the contours of the participants' life. Adamson and Johnson's (2005) observation about the similarity between the experiences of South Asian and African-Caribbean carers and other groups of carers is apposite here. The challenges experienced by student-carers are similar to those carers in other groups. A student-carer's life is demanding as are the lives of other carers – employment choices are shaped by the demands of the caring role, finances are limited and time is short (Carers UK, 2019). However, student-carers highlighted the unpredictable demands of caring as the caree may have a fluctuating condition. The opportunity to plan in the short to long term with any certainty is limited. Even so, given the understood expectations of successful study – security, the need to maintain a routine, the capacity to plan several months ahead and to meet deadlines – caring appears antithetical to successful study. Yet in the participants' accounts, they continued in their studies. Given the demands of caring work, it is significant that student-carers are, as observed by the National Union of Students (2013) dedicated to their studies.

12.4. Certainly, student-carers make educational choices which fit their caring responsibilities (Sempik and Becker, 2014). As such, distance learning offered student-carers certain affordances which are more compatible with the demands of caring than conventional education. The OU's open access policy allows access to those who may not have limited educational opportunities. Given the financial disadvantages typically experienced by carers (National Union of Students, 2013), distance learning fees were seen as more affordable. The flexibility in terms of time and place to study accommodated both the need for carers to remain at home as well as the unpredictable demands of the role itself. Tutors were often, but not always, praised for their supportiveness whether the carer declared their status or not. As significant is that many carers framed the demands of caring as preparing them well for the demands of studying – their sense of their own resilience, taking what life throws at you, just keeping going, managing others and their expectations were all presented as the characteristics of successful student-carers.

'Me-time': the construction and negotiation of student-carer identities

12.5. Student learning emerges out of the intersection of the affordances of an educational setting and how the individual perceives and negotiates a learning trajectory through those affordances (Billett, 2008). With reference to Moss and Pittaway's (2013) concept of layers of involvement, the interviews suggest that understanding how student-carers negotiate their trajectory through their studies need to be set within the context of how they make sense of their caring role and their own sense of who they are and what they value. Barkin (2014) draws on Corbin and Straus's (1987) work to explain how individual's act on and interpret their circumstances to sustain and develop valued aspects of the self. Reflecting on Bury's (1991) seminal work on biographical disruption to speculate whether carers too will experience profound ruptures in their sense of self, Adamson and Donovan (2005) found that caring offered a degree of continuity in personal identity. Certainly, caring work was demanding, challenging and exhausting but it did not necessarily represent a rupture in their sense of self. The caring role presented carers with some degree of coherence in that they were acting in a way consistent with their roles as parents, partners or siblings. In this light, it is unsurprising that that carers in this study, like carers more generally (see Molyneaux et al., 2011) were reluctant to declare their caring status.

12.6. For the participants in this study, they presented caring as sitting consistently with what they value – knowing someone well, caring for them better than anyone else and more broadly, having a good understanding of a particular condition. Carers are motivated to maintain personal integrity or coherence in their activities. Barkin (2014) refers to the way that people with long term conditions incorporate the illness trajectory into personal biography as ‘contextualising’. In the same way, carer-students also contextualised their study by incorporating it into their sense of caring well. Despite the demands of study, caring always came first. However, while studying represented ‘me time’ to some – a personally sustaining leisure and recreational activity – it could sit uneasily with their sense of personal integrity. Some student-carers felt guilty about prioritising their own needs over their caring responsibilities.

12.7. For other participants, their interpretation of studying while caring can be viewed of ‘biographical recasting’ – reinterpreting their present actions in the light of a particular imagined future (see Barkin 2014). Presenting as a role model to one’s children, becoming a more knowledgeable carer and using the combined experience of caring and training to pursue a career in health and social care all present as important aspects of maintaining personal integrity and a vision of the future which is optimistic and positive. While it has been noted elsewhere that studying enables student-carers to expand their identity beyond that of carer (National Union of Students 2013), this overlooks a significant nuance around how carers integrate the two identities to achieve personal integrity.

Future directions

12.8. This small-scale study highlights potential directions to develop both in terms of university support for carers and further research. In terms of university support for carers, students-carers present an ambiguous figure for universities because they do not always appear to seek full immersion in the university community. Reluctance to declare caring status, refer to their caring responsibilities when talking to tutors or to fully engage in student communities are three such examples of ambivalence. While it may certainly be the case that some carers may find that study provides access to a supportive community of others (National Union of Students, 2013), for others this will be a distraction from their caring responsibilities. Consequently, in conceptualising support for students or methods to improve retention, assumptions that group-based student support is *sine non qua* cannot be held unreflectively simply because for student-carers, personal support can be found elsewhere.

12.9. This is not to say that universities should not take student-carer support needs into account. The ‘standard’ university model of group support may need to be supplemented with individual support. Carers can respond well to and benefit from individual tutor support from an individual member of staff (such as a personal tutor), rather group tutorials (Carers Trust, 2018). The growth in individual tutorials on Health, Wellbeing and Social Care modules is one such model which stresses individual-focused support offered at a time responsive to individual student-carer need.

12.10. Similarly, insight into carer needs should underpin support. The way in which some carers encountered requests for documentary evidence to support requests for extensions reflects a misunderstanding of the unpredictable nature of caring for someone with a long-term disability, for example. That student-carers may feel guilt in prioritising study or conversely will not take a needed extension for fear of falling behind suggests the need for sensitive and insightful individual support. The

appointment of student-carer specialist advisor in the Nottingham Student Support Team reflects a positive development in providing skilled support.

12.11. It is often observed in module team reviews that most students withdraw from their module because of 'personal' reasons. For student-carers who are constantly grappling with personal issues, such an analysis risks pathologizing students who drop out. Accommodating the 'personal issues' of student-carers in a more supportive and less deficit focused model involves recognising the unpredictable demands placed on student-carers as well as understanding that even though caring comes first for these students, it does not mean that they don't care about their studies. Developing more flexible modules shares the responsibility for the students-carers' personal issues:

- multiple options for tutorial sessions as provided under group tuition (rather than allowing provision to be dominated by the priority given to maintaining student group-single tutor relationship);
- removing examinations in modules that do not require that model of assessment to demonstrate the learning outcomes. Examinations are inflexibly scheduled and often require travel out of town to attend. For student-carers, financial limitations, the need to remain close to home and respond to the unpredictable can make exams untenable.
- building fallow periods into modules so students falling behind can catch up;
- providing 'fast track' reading routes through modules for student-carers needing to carefully manage their time or catch up after a difficult period;
- given that students in difficulty rarely ask for support, proactive student support may well be a sensible investment (Simpson 2010). There are Student Support projects which involve contacting students marked as carers on CIRCE, to discuss their studies, study intentions and ensure they are fully supported during their module and overall OU studies. This project is yet to report but appears promising.

12.12. Such approaches are a more positive and less deficit-focused approach to support student-carer retention in that they are sensitive to the choices made by this group.

12.13. As noted earlier, this report is the first in a two-part study designed to capture a view of student-carers over time. The current project hints at some of the nuanced understandings of student-carer agency in the management of their studies. Moving beyond the current study, fidelity to the concept of co-participation requires a method that is more attuned to individual difference. For example, the use of biographical methods are more suited to uncovering individual context and the agentic choices involved in learning (Biesta and Tedder 2007). The use of framework analysis may be a more suitable analytic technique. Finally, by focusing on Health and Social Care students only, we may have inadvertently privileged one particular discourse in use by student-carers. The study of health and social care is a natural companion to caring but may only reflect one particular orientation to one's studies. It would be intriguing to broaden the scope of the study to include students in the natural sciences or the arts to capture a potentially alternative framing of studying while caring

13. CONCLUSION

This project has successfully built on the Wales pilot project (see Introduction) and laid the foundations for developing further understanding of how OU students who are carers not only experience, but also and manage and negotiate competing demands. It has usefully confirmed that the OU offers students who are carers flexibility and affordability. Furthermore, there was positive reinforcement of what the OU is doing for these students in that they find their OU studies enjoyable, confidence building, and see them as potential routes to career enhancement and improving the care they provide.

The study revealed the coping strategies student carers adopt to actively manage their time, boundaries, and others in order to render the (often) unpredictable demands of caring as compatible as possible with study. Significantly throughout these processes, their focus was on not disrupting the primacy of their caring role and identity. There were also insights into the challenges they face during such management and how this can threaten their progression and retention.

Although the OU's existing support for carers clearly has many strengths, there was ambivalence about the extent to which it really meets carers' needs. Identifying ways of improving such support is further complicated by the fact that some carers choose not to reveal their caring status as carers. However, ways of enhancing affordances for carer learning emerged from the study. These were around investing in proactive support for student carers and developing more flexible modules (e.g. multiple options for tutorial sessions; removing examinations; building fallow periods into modules, providing 'fast track' reading routes).

Follow-up interviews with the same students are planned for a year's time in the second of this two-part study. These studies will contribute to HWSC scholarship about how personal challenges affect student study, persistence and retention. As caring become part of more and more people's lives, they can potentially improve the learning trajectories of the growing number of students who combine OU study with caring. This is particularly relevant in light of evidence about increased pressures on carers because of policy changes and reduced public spending.

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APPENDIX 1: STUDENT CARERS INTERVIEW SCHEDULE

You have been invited to participate in this interview, because you indicated that you have caring responsibilities. Before we start:

- Thank you for filling in the consent form.
- These questions can be quite personal. You don't have to answer all the questions. You can pass on anything;
- Just relax – I'm not looking for right answers, I just want to know what you think. I'm not looking for fully thought through answers - if you have a hunch about something being important, just say it and we can explore it together.

Instructions for interviewer

- Be sensitive to issues of finances and explore if necessary.
- Some questions might be difficult for participants to answer. Please be sensitive to any difficult emotions expressed by the participant and direct to support if necessary.

- Ensure you keep bringing students back to the link between study and caring responsibilities.

1. a) I would like to start by finding a little bit more about you.....

- *What are you currently studying?*
- *What do you like about your studies?*
- *What is it you enjoy the most?*
- *Qualification aim*
- *Time studying at the OU*

In addition to studying and caring, what are other commitments on your time do you have?

b) Tell me how you ended up enrolling with the Open University?

- *What were you doing before you enrolled?*
- *Motivations for wanting to go to university?*
- *What helped you make the decision?*
- *Anything holding you back?*
- *What have been your experiences of education before this?*
- *What made you decide to declare your caring status?*

2. Where would you like to be in the next 3-5 years?

- *Professionally and personally*
- *How are these studies helping you achieve these goals?*
- *Anything else helping you achieve these goals?*

3. Would you tell us more about you caring role?

- *Could you tell us more about the caregiving role?*
- *Who do you care for?*
- *Can you tell us more about the intensity and duration?*
- *Did you start your caring role before becoming a student? Could you tell us more?*
- *Could you tell us about positive & negative experiences?*
- *Can we explore together how your caring role marries with your life as a student, as a carer and as a person?*

4. One of the positive impacts you have mentioned was *(allow the student to choose two of the most significant aspects mentioned from Question 3) ...*

- *Related to your life as student – does the caring experience help when studying? Related to your life as carer – does studying give you an identity while caring?*
 - *Related to your life as a person – is it increasing your confidence, contributing to employment opportunities, increasing ability to prioritize?*
 - *Can we explore these more in detail?*
 - *From that perspective, if you weren't a carer, how would your life as a student be different?*

5. One of the negative impacts you have mentioned was *(allow the student to choose two of the most significant aspects mentioned from Question 3) ...*

- *Related to your life as student – pressure of caring could for example mean you have less time than you would like for studying and / unable to be as successful as you would like*
- *Related to your life as carer - eg feel guilty when studying and not caring*
- *Related to your life as a person - eg feel under pressure to meet demands of caring and studying*
- *How do you tackle and respond to the negative impact of caring as a student, a carer and a person...*
- *Did you anticipate any of the negative impacts that you have just mentioned on your studies?*
- *Can we explore these more in detail?*
- *From that perspective, if you weren't a carer, how would your life as a student be different?*

6. Have you sought help from your fellow students, your tutors or other areas of the university to support you in your studies?

- *If so, how?*
- *Fellow students?*
- *Tutors?*
- *Anyone else?*
- *What kind of help, could you please give some examples?*

7. Was the help offered sensitive to your needs as both a carer and a student and did you find it helpful?

- *Imagine that you were stuck with something in your course. Who would you go to first, second, third ... for help?.*

8. If you could ask for anything, what else could the university offer in terms of support to help you meet your goals? How would this help you?

- *What other support from anywhere else in your life would help you?*

9. Is there anything else you would like me to know about being a carer and an OU student we haven't discussed so far?

Please use the information below if you feel the interviewee needs referring to support following the interview:

- Caring related personal matters: Carers UK, Carers Trust or their local Carers Centre
- Caring-related academic matters or just academic matters; Student Support Team hsc-advice@open.ac.uk

APPENDIX 2: THEMATIC CODING FRAMEWORK

THEME 1 - About caring

1. Challenges and demands of caring

- 1.1.1. Imposed routine
- 1.1.2. Caree's emotional state and challenging – anxiety, tantrums
- 1.1.3. No routine/unpredictable requirements
- 1.1.4 Accompanying to appointments or other professional requirements
- 1.1.5 Caring without help from others
- 1.1.6 Limits participants' spare time/time to study
- 1.1.7 No opportunities for personal and leisure activities
- 1.1.8 Uncertainty about when caree will be more independent
- 1.1.9 Is tiring /draining
- 1.1.10 Changed paid work life to accommodate caring responsibilities
- 1.1.11 Financial implications

2. Caring responsibility- positive factors

- 1.2.1 Inspires career choices in care
- 1.2.2 The care I give is better than the care provided by someone else
- 1.2.3 Better understanding of the nature of disabilities and of those caring
- 1.2.4 Satisfying to provide care
- 1.2.5 Self-worth, sharing knowledge, advocacy
- 1.2.6 Enabling better quality of life for cared

3. Resilience

- 1.3.1 coping strategies
- 1.3.2 Family and community support
- 1.3.3 Personal outlook and beliefs
- 1.3.4 You Just do it

THEME 2 - About studying

1. Study aspirations and motivations

- 2.1.1 To work with people like caree
- 2.1.2 Nursing and social work
- 2.1.3 Return to work with CYP
- 2.1.4 To improve life in the future/easier to get a job
- 2.1.5 Chooses courses relevant to future or current career
- 2.1.6 Self worth
- 2.1.7 Understanding care

2. Declaring caring status because .../ideal consequences of/inadequacies of declaring

- 2.2.1 Declared and why
- 2.2.2 Not declared and why not
- 2.2.3 Ambivalence

3. Attitude to study/impact of study

- 2.3.2 Enjoyable substitute for social or leisure activities
- 2.3.2 Studying prioritised over commitments (outside of caring) e.g., Caree comes first, then study then family
- 2.3.3 Study makes participant happy/is 'me time'/Enjoys it
- 2.3.4 Empathy – studying helps me understand I'm not the only one to feel like this
- 2.3.5 Study creates guilt as not attending to other things
- 2.3.6 Studying is harder than expected
- 2.3.7 Relationships
- 2.3.8 Study informs paid work

4. Managing time/planning/organising space

- 2.4.1 Study and work must fit around care priorities
- 2.4.2 Rejects opportunities outside of core study tasks
- 2.4.3 Manages environment/schedule to create uninterrupted or dedicated study time/anticipate crises/manage guilt
- 2.4.4 Demands on time unpredictable/caring tasks intrude on study in anticipated fashion
- 2.4.5 Tired - too tired to study/used to being tired
- 2.4.6 Workplace supportive of study
- 2.4.7 Active strategisation

5. Caree as resourceful constraint (i.e. provides understanding or opportunities which support study)

- 2.5.1 Caree's routine creates routine for study
- 2.5.2 . Searches for info to inform study/helps with study

THEME 3 - Support from University and students

1. University support/student uptake of support/student holding out as a carer

- 3.1.1 University provides 'good support'
- 3.1.2 Proactive contact from tutor/university and conveying availability of support
- 3.1.3 Order of support when stuck
- 3.1.4 Student engagement with support
- 3.1.5 University flexibility
 - does not ask for extensions as will create problems
 - rejects extension as will delay workload
 - cannot provide proof needed to get extension
- 3.1.6 Students taking up support

2. Learning design

- 3.2.1 Course helps you plan/schedule work
- 3.2.2 OpenLearn builds your confidence with studying
- 3.2.3 Placements,
- 3.2.4 Assessments

3. Support from other students

- 3.3.1 Local support group for carers
- 3.3.2 No university support group for students – one is needed
- 3.3.3 Contact/support from other students-in-the-main via module

4. Choice of university/trajectory

3.4.1 OU chosen for flexibility

3.4.2 OU chosen for affordability

3.4.3 Credit transferred existing credit

3.4.4 Advice given on course choice

3.4.5 `Interweaving of caring and study trajectory

5. Suggestions to improve institutional support