Narratives from a participatory photodiary study with university student carers

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All [the university] has to realise, and it is true of any university in the UK, would be that students who are going into tertiary education, who have grown up with disabled parents or parents that they care for at the very least, universities that would help you get through financially because it’s so expensive now, that would be an enormous great PR point for any university.

[Student carer, participatory workshop]
“A carer is defined as anyone who cares, unpaid, for a family member who, due to illness, disability, a mental health problem or an addiction, cannot cope without their support”.
BACKGROUND

- According to the 2011 Census, 10.3% of the UK population (6.5 million people) provide unpaid care (Adcock & Roberts, 2016: 4).

- 375,000 young adult carers in the UK aged 14–25 (Sempik & Becker, 2014).

- Between 3% and 6% of the UK student population are caregivers (National Union of Students, 2013).

Photograph credits: all images in this presentation belong to the ‘Students who Bounce Back’ project.
BACKGROUND

- Student carers have been found to feel “not a proper student”, and to present issues of exhaustion and lateness when submitting assignments (Kirton, Richardson, Jack, & Jinks, 2012: 644).

- 29% of the young adult carers survey respondents who had been to college or university dropped out due to their caring responsibilities (Sempik & Becker, 2014: 3).
**BACKGROUND**

- Carers Allowance recipients “must not be in full-time education, and must not have an income of more than £110 per week after deductions” (Adcock & Roberts, 2016: 4).

- ‘Student carer’: an oxymoron?

- OFFA’s remit of under-represented and disadvantaged groups → support is encouraged.
RESEARCH OBJECTIVES

- To explore the life experience of student carers and the impact of caring in their learning experiences.
- To determine, in co-production with students, the main motivations and expectations of their university experience, and their contact with the different support mechanisms.
- To contribute to wider debates and developments about the learning experience of student carers in the HE sector.
METHODS

- Focus on dialogue: visual and verbal narratives that captured multi-voicedness (Marková, 2007).
- Purposive sampling: heterogeneity.

- Triangulation of elicitation methods:
  - Photodiaries over a month
  - Photo-elicited biographical narrative interviews.
  - Participatory workshop.
## Sample Characteristics

<table>
<thead>
<tr>
<th>Gender</th>
<th>Age group</th>
<th>Person cared for</th>
<th>Condition cared for</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>21 – 30 (PG)</td>
<td>Father</td>
<td>Multiple sclerosis</td>
</tr>
<tr>
<td>Male</td>
<td>31 – 40 (UG*)</td>
<td>Father (mainly) Mother</td>
<td>Dementia Chronic fatigue syndrome (unconfirmed)</td>
</tr>
<tr>
<td>Female</td>
<td>31 – 40 (UG*)</td>
<td>Grandmother</td>
<td>Dementia (Alzheimer’s)</td>
</tr>
<tr>
<td>Female</td>
<td>31 – 40 (UG*)</td>
<td>Father Son</td>
<td>Leukaemia, multiple myeloma Autism</td>
</tr>
<tr>
<td>Female</td>
<td>21 – 30 (UG)</td>
<td>Mother</td>
<td>Bipolar disorder</td>
</tr>
<tr>
<td>Female</td>
<td>21 – 30 (UG)</td>
<td>Grandmother Mother</td>
<td>Cancer, double incontinence Carpal tunnel syndrome</td>
</tr>
<tr>
<td>Female</td>
<td>17 – 20 (UG)</td>
<td>Mother</td>
<td>Auto-immune hepatitis</td>
</tr>
</tbody>
</table>

*Mature student, defined as those aged 21 or over at the start of their course.*
…I took part in this because I don’t want people to be as unsupported as I have been, if they are not as strong as I am or less determined… [Student carer, interview]

…my department…have really supported me for my extracurricular caring responsibilities and I've never really heard of a department just going that extra mile and giving me multiple deadlines and just trying to make things easier, trying to think of alternative assessments. It's been really really comforting so I'd like to, part of the reason I've done this, is to give something back…[Student carer, interview]
I think the stress of applying to university was perhaps the worst thing, not knowing what was going to happen, not knowing if you were going to be accepted and actually not knowing if you were going to have to organise extra help for the people that you care for because you don’t know if you are going to be going to university you know, it takes a while to find out if you are going to be accepted, if you’re going to be on the course and that was quite stressful for me being unsure about what’s going to happen over the next few years and I think that stress did have a knock on effect because you are always thinking about what’s going to happen? What am I going to do? What if it goes this way? What if I don’t get in? What am I going to do then?...[Student carer, interview]
I think I have been [open] with all the staff, and I think again my classmates know because I did do a project as well, where I took [relative cared for] portrait, so that comes up in conversation…[Student carer, interview]

…I didn’t want to divulge to anyone. Basically my [relative cared for] had tried to commit suicide and I didn’t want to tell anyone that who I worked with because I didn’t want them to work with me and be different. So I couldn’t tell [workplace] and I don’t really want to tell everyone at Uni and I finally got hold of my academic advisor and she was fine and I just had to go to my doctor and he signed me off but I didn’t get any support…[Student carer, interview]
JUGGLING RESPONSIBILITIES

...the booklet is one that I got because I had to go on a speed awareness course because I got caught speeding and actually I felt it was relevant because I was speeding coming back from university because my [relative cared for] pressed [the] button, [the] alarm button, and [they] needed help straight away. I didn’t know what the problem was and I was caught going 36 mph in a 30 mph zone, so, yeah I had to go on a course, a speed awareness course...[...]...I just got the letter through the thing, and it listed my options, you know I’ve been caught speeding and it listed my options, and my only options were to take the course or to accept the fine and take 3 points on my licence... [Student carer, interview]
JUGGLING RESPONSIBILITIES

…this is all my alarms that I have for getting up early, just as, yeah…[…]…I just need them. They just have to keep going off because I have to get up so early, I’m just so tired, but once I’m up I’m up….[…]…I have to make sure everything is done before I go to work….[…]…like the dishwasher’s empty, the cat’s got food, that we’ve got some sort of food in, which I usually do before I go to bed but sometimes I’ll just make my own lunch for work…[Student carer, interview]
JUGGLING RESPONSIBILITIES

“A chaotic time working for exams. I was putting myself first, but my Dad is still there in the background”. [Caption from exhibition]
Support: External to University
...I felt it was very dangerous, but the council wouldn’t change their mind even after I told them this so I had to make an application to the HM court and tribunal service so that we could get it changed and that meant I would have to go up in front of a panel of people and I can have like 3 witnesses, and I’d have to go against the council and they’d have their witnesses... it was very stressful because I wasn’t able to sleep very well because I was worried about what would happen if we didn’t get the result that we wanted, this could change [relative cared for]’s future and things, so that, this picture actually represents the battle we had...[Student carer, interview]
**SUPPORT: EXTERNAL TO UNIVERSITY**

...do you know where I got most of the information from? About everything the paperwork, the house deferred payment scheme? The Alzheimer’s Society website and AGE UK website because they are charities and they are more up on it than the government are. I rang the government and they couldn’t answer my questions ‘Oh we’re not really sure, the Care Act has just changed’. I was like ‘but surely you guys are the ones that made this Care Act?’ and they couldn’t answer my questions so I went to charities to get help...[Student carer, workshop]
...I happened to be in my GP’s surgery so I thought I want kind of evidence, I...saw that carer’s board and I thought, that’s really good to highlight it. I’ve never noticed that before but you know I was in that mind set with the camera, I thought OK, I mean it’s a bit hidden in the surgery, in the main area. I thought ‘it’s good that it’s getting better, it’s a work in progress, carers are getting that recognition’. There is help out there. You need to know where to go, kind of thing, [Hmm] but I thought it was just marvellous there’s stuff there. [Student carer, interview]
Student carer A: It’s weird loopholes because for me with the benefit stuff, even though I was a student I had to apply for personal independence payment first before I could apply for employment support allowance but if I’d applied for employment support allowance before I’d have got rejected because I hadn’t applied for personal independence payment

[Student carer B: Oh my god] it’s confusing [Student carer B: Yeah] and maybe [Student Union] needs to have people [Student carer B: Who can advise us] advise us directly, because I know [Student Union] have an advice service but they are more like a general service and they need someone more specialised. [Workshop]
...I have a hard time articulating things when I’m stressed, I don’t know I find the programme administrators aren’t too understanding because they need to like get the evidence, get that in...[...]...I know it gets stressful on their side but for me they need to be a bit more flexible and then especially with the caring stuff as well now...[...]...[Social services] came in the beginning mostly because my academic advisor wrote some letter to my MP before I left...[...]...Because when I left it was clearly because I wasn’t coping cause there was so much to do at home...[...]...I think it was nice because they knew there was so much they could do as members of the university so they knew they were sending me back here they wanted me to have some sort of support...[Student carer, interview]
**RECOMMENDATIONS**

1. Consider disseminating information regarding university-based support for student carers through the admissions section of the institutional website.

2. Maintaining a tick box in the enrolment forms, which would prompt student carers to self-identify, should be contemplated. Through these data, it could be possible to compile a list of carers at the University in any given year and so attain a greater understanding of the level of potential support required. Consider conducting a consultation regarding the uses of such list.

3. Promote dialogue with the voluntary and non-for profit sector in the region, and ensure that the information about their services is readily available to both student carers and staff who are in close contact with them.
RECOMMENDATIONS

4. Consider avenues to improve institutional communication channels, as well as referring academic staff to colleagues knowledgeable on specific issues (student caring in this case).

5. The expansion of social support for student carers is highly recommended.

6. It is advisable to perform continuous checks regarding the inclusivity and relevance of the definitions of student carer, unpaid caring and eligibility criteria for financial support.
THANK YOU

References available on request

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