'All of us put other people first': Narratives from a participatory photodiary study with university student carers

Background

The number of people providing unpaid care in the UK is growing, with the 2011 census identifying 10.3% of the population (6.5 million people) as carers[1]. In the higher education context, students with caring responsibilities are under-represented[2]. Student carers are also hidden: there are no official figures, although it is estimated that they constitute between 3% and 6% of the student population[3].

Combining university studies and caring responsibilities is complex. Student carers have been found to feel "not a proper student" and to present issues of exhaustion when submitting university assignments[4]. A recent survey found that 29% of the young adult carers respondents who had been to college or university dropped out due to their caring responsibilities[5]. However, the scant literature concentrates on mature students, student parents with dependants, and student carers in 'caring' professions [4, 6, 7, 8].

Research framework

This study contributes with an in-depth exploration of the life and learning experiences of student carers with heterogeneous characteristics (enrolled in various programmes, young and mature, at different stages in their university studies). It draws on Paulo Freire's[9] work on education for critical consciousness, pursuing the full engagement of students and work *with* them (and not on them). It is driven by a focus on dialogue and the generation of visual and verbal narratives that capture the multi-voicedness[10] of caring responsibilities. It has a twofold aim:

- To explore the life experience of student carers and the impact of caring on 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 at university.

Methods

A purposive sampling strategy was followed, seeking to maximise heterogeneity. Seven student carers were recruited from the same UK University. The research triangulated data from three sources:

Photodiaries over a month. Participants took "a picture a day" that represented their quotidian experiences.

Photo-elicited biographical narrative interviews, focused on biographical elicitation (past), present (photo-elicited) and future.

Participatory workshop, seeking to tap into participants' experiences with support at [University's name] and elsewhere, and to enable initial participatory analysis of their printed photographs.

More than 300 photographs and 150,000 words comprise the data corpus. Interviews were read line by line, related to their corresponding images, and annotated, seeking to identify common themes that addressed the research objectives. A further narrative analysis[11] is being conducted using the software MAXQDA.

Preliminary results

All participating student carers reported having some kind of caring role during childhood or adolescence. Transition into adulthood caring varied: the majority of participants had caring responsibilities when applying to university, while one of them acquired these responsibilities during their undergraduate studies.

Table 1. Sample composition.

Participant pseudonym	Gender	Age group	Person cared for	Condition cared for
Martin	Male	$21-30$ (PG)	Father	Multiple sclerosis
Joseph	Male	$31-40$ (UG*)	Father (mainly). Mother	Dementia. Chronic fatigue syndrome
Trisha	Female	$31-40$ (UG*)	Grandmother	Dementia
Amelia	Female	$31-40$ (UG*)	Father. Son	Leukaemia, multiple myeloma. Autism
Jennifer	Female	$21-30$ (UG)	Mother	Bipolar disorder
Sydney	Female	$21-30$ (UG)	Grandmother. Mother	Cancer, double incontinence. Carpal tunnel syndrome
Ruth	Female	$17-20$ (UG)	Mother	Auto-immune hepatitis

*Mature student: those aged 21 or over at the start of their course.

The process of choosing University reveals the duality of the condition of being a student carer. On the one hand, they assess options as any other typical student. On the other hand, they must consider the implications for their caring duties. They do not present themselves as an 'alien' category, but as 'mainstream' students with added responsibilities. In addition, their narratives point to the need to have appropriate mechanisms in place for students to disclose their caring role should they wish to do so.
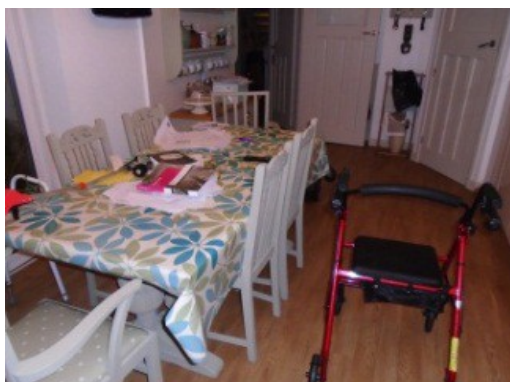
"A chaotic time working for exams. I was putting myself first, but my Dad is still there in the background".

A recurrent element in student carers' narratives concerns the time invested in the manifold tasks that caring entails. They report planning their daily activities on a regular basis as a means to attain some sense of control over their time.

Caring responsibilities, financial difficulties and mental health problems often present themselves together. Concerns regarding financial instability were present in all interviews and all participating student carers admitted high levels of stress.

"It can be easy for carers to neglect themselves. Me being a carer, it's given my children a bit more of a caring side".

Participants considered their interactions with statutory services as a constant struggle, sometimes described as a 'battle'. The narratives portrayed students as resourceful agents who would pursue the goods and services that the relatives they care for need, and would go to extensive lengths to achieve this.
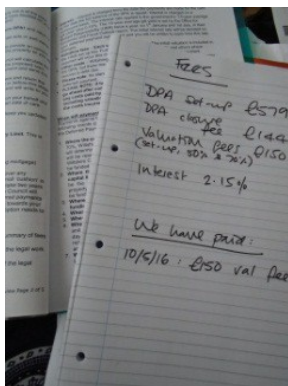
"My Nan worked until she was 81 and paid off the mortgage on her bungalow but the government will force the sale in a few years to pay her care home bill. The paperwork is never ending!"

The majority of these battles seem to be won by student carers, but battling against the statutory sector takes a vast toll on them. In contrast, student carers perceive the voluntary sector as a strong ally when battling against the statutory sector.

The boundaries between accessing academic help and obtaining pastoral (personal) support are not clear for all student carers. Accessing one-on-one support for specific circumstances and crises related

to caring is shaped by both the student's willingness to disclose and by the inclination of university staff to 'go the extra mile' in supporting students.

Student carers would value the enhancement of social support available at university, including peer-to-peer interaction.

Implications

Practical recommendations will be presented in terms of dissemination of information regarding university-based support, unobtrusive mechanisms to allow self-identification as a carer, promotion of dialogue between universities and the voluntary and non-for profit sector, and the maintenance and enhancement of social support for student carers within the university.

References

1. Adcock, A., & Roberts, N. (2016). *Carers. Briefing Paper Number 007756*. Retrieved from http://www.centreonconstitutionalchange.ac.uk/sites/default/files/papers/ifsbn_sept13.pdf

2. Office for Fair Access (last updated February 2017). Target groups. Retrieved December 2016 from https://www.offa.org.uk/universities-and-colleges/guidance/target-groups/#carers

3. National Union of Students. (2013). *Learning with care. Experiences of student carers in the UK*. London: National Union of Students. Retrieved from https://www.nus.org.uk/global/campaigns/learning%20with%20care%20-%20nus%20research%20report.pdf

4. Kirton, J. A., Richardson, K., Jack, B. A., & Jinks, A. M. (2012). A study identifying the difficulties healthcare students have in their role as a healthcare student when they are also an informal carer. *Nurse Education Today*, *32*(6), 641–646. https://doi.org/10.1016/j.nedt.2012.01.010

5. Sempik, J., & Becker, S. (2014). Young Adult Carers and Employment. *Young Carers International & The University of Nottingham*. Retrieved from https://professionals.carers.org/sites/default/files/young_adult_carers_and_employment.pdf

6. Alsop, R., Gonzalez-Arnal, S., & Kilkey, M. (2008). The widening participation agenda: the marginal place of care. *Gender and Education*, *20*(6), 623–637.

7. Day, C. (2015). Young adult carers: a literature review informing the re-conceptualisation of young adult caregiving in Australia. *Journal of Youth Studies*, *18*(7), 855–866. http://doi.org/10.1080/13676261.2014.1001826

8. Hussain, Z., Pickering, V., Percy, D., Crane, J., & Bogg, J. (2011). An analysis of the experiences of radiography and radiotherapy students who are carers at one UK university. *Radiography*, *17*(1), 49–54. http://doi.org/10.1016/j.radi.2010.08.006

9. Freire, P. (2008). *Education for critical consciousness* (n. e.). London: Continuum Publishing Group.

10. Marková, I. (2007). Dialogicality and Social Representations. Cambridge: Cambridge University Press.

11. Riessman, C. K. (2008). Narrative Methods for the Human Sciences. London: Sage.