

‘More than just saving the government care costs’: re-presenting UK student carers’ narratives

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‘Most people going into uni with disabled parents aren’t just low income households but they’re low income households with no savings or very little to their name, so every little help is not just appreciated but it goes towards getting these people back into the economy more than just saving the government care costs’ (Research participant, workshop discussion)

The research reported in this chapter draws on narratives of care from university students, generated through biographic and photography-based methods. These narratives give us insights into the lives of student carers, an under-researched, often resource-challenged and marginalised population. The opening quote exemplifies how articulate and acutely aware student carers can be about their position within the interlocking structural systems of inequality in which they are embedded. This chapter documents their resourcefulness, while analysing their stories through the conceptual lenses of intersectionality and transitions.

Care and student carers in the UK context

In the UK, the rights of carers were recognised for the first time in the law, alongside provisions for those they care for, through the Care Act 2014. This piece of legislation promotes the wellbeing of carers, including ‘participation in work, education, training or recreation’. However, as a matter of statutory policy, Carer’s Allowance recipients ‘must not be in full-time education, and must not have an income of more than £123 per week after deductions’ (Powell *et al.*, 2019, pp.4-5). This restriction renders the phrase ‘student carer’ a contradiction, as officially students are not recognised as carers (or at least not recognised to the point of being entitled to Carer’s Allowance). Furthermore, while there are means-tested financial support allowances that student carers could potentially access (e.g. Adult Dependents’ Grant of £3,094 in the 2020/21 academic year), these are not aimed to carers specifically but to undergraduates in general.

The UK’s Department of Health and Social Care considers that a carer is ‘anyone who spends time looking after or helping a friend, family member or neighbour who, because of their health and care needs, would find it difficult to cope without this help regardless of age or whether they identify as a

carer' (2018, p.7). Despite this established definition, data regarding care are variable, complicating policy development and implementation. While the 2011 Census found that 5.8 million people (10.3% of the population) in England and Wales provide unpaid care (Office for National Statistics, 2013), the Family Resources Survey reported 5.4 and 4.5 million of informal carers in the UK in 2016/17 and 2017/18, respectively (Department for Work and Pensions, 2019). Data are patchier for student carers, with the National Union of Students (2013) estimating that they account for between 3% and 6% of the student population in the UK, and the Family Resources Survey finding that they constituted around 3% of the total of carers in 2017/18 (Department for Work and Pensions, 2019).

More than a decade ago, Alsop *et al.* noted the minor role of care in the widening participation policy agenda, calling for a 'higher education "care culture"' (2008, p.623). In recognition of the growing evidence regarding student carers' struggles, from spring 2020 the UK's Universities and Colleges Admissions Service (UCAS) includes new questions in the university application process, allowing student candidates to self-identify as carers. UCAS also offers information to prospective university students with caring responsibilities, highlighting that 'many universities and colleges have initiatives or support programmes in place to help students with care responsibilities' (UCAS, n.d.). In the UK, however, there are no official policy provisions in terms of caring responsibility needs of university students: academic, financial and emotional support for student carers remain at the discretion of individual higher education institutions.

Research involving participants in their dual role as students and carers is scant. Early studies included healthcare students in caring roles, focusing mainly on the manifold challenges, concerns and negative impact on their studies, underscoring the need for targeted support (Hussain *et al.*, 2011; Kirton *et al.*, 2012). Recent research with student samples mirrors this focus on the adverse effects of caring, with one study revealing that frequency of face-to-face contact with a cared for friend, housemate or partner with mental health issues predicted negative consequences of caregiving for university students in caring roles (Byrom, 2017). On these grounds, it is hardly surprising that 29% of the young adult carers survey respondents who had been to college or university reported dropping out due to their caring responsibilities, in a study commissioned by the Carers Trust (Sempik and Becker, 2014, p.3).

More recent, fine-textured studies with student carers and a focus on meaning-making are also considering negotiation of barriers (Kettell, 2020) and student carers' resilience and ability to cope (Jones, 2018). It is to this emerging body of literature that this chapter seeks to contribute,

challenging the deficit model in care research whereby care is tacitly presented as a burden and services as assistance (Milne and Larkin, 2015, p. 9), and following trends in international young carers research that problematizes straightforward associations between caring and negative outcomes (Skovdal, 2011).

Theoretical underpinnings

Intersectionality

Quantitative research has offered evidence of the detrimental effects of multiple disadvantages on adults' mental and physical health, and functional limitations (Grollman, 2014). This research has also shown that a focus on a single disadvantage (in this case, that of carer status while in higher education), misses potential concomitant disadvantages that are interlocked and in fluid relationship with care—social divisions including gender, age, race/ethnicity, social class, (dis)ability and political orientation both shape and are shaped by the experience of caring. For instance, feminist researchers have discussed the gendered dimension of care, underscoring the reproduction of structural gender-based expectations (Barnes, 2012; Tronto, 2013). While gender is central as a social division, a number of multifaceted salient identities of carers, only one of which is gender, intertwine and unfold through caring interactions. Another important example of these salient identities for caring is age. Care researchers (Larkin *et al.*, 2019, p.62) highlight that, taken as a single salient characteristic, a sizable amount of research has been conducted including young carers, despite the fact that they account for only 3% of all carers in the UK. Instead of an exclusive focus on age, the importance of a 'life-course' approach to care is now acknowledged, suggesting that age interacts with other (potentially disadvantaging) characteristics such as gender to provide a different care experience and wellbeing consequences (Hamilton and Cass, 2017, p.80) and that care evolves over time (Bowlby *et al.*, 2010, p.46, cited in Milne and Larkin, 2015, p.8).

Against this backdrop, recent care research has called for the use of an intersectionality lens to analyse particular groups of carers, to account for the complexity of caring and of these groups (Hankivsky, 2014; Larkin *et al.*, 2019, p.61). The present chapter responds to these calls by following Collins and Bilge's (2016) approach to intersectionality, acknowledging that 'people's lives and the organization of power in a given society are better understood not as being shaped by a single axis of social division, be it race or gender or class, but by many axes that work together and influence each other' (p. 2). Using intersectionality as an analytical tool, we seek to identify forms of resistance

by highlighting how student carers are not just passive receivers of oppression and inequality, but active agents and respondents to these processes (Rosenthal, 2016).

Transitions

The conceptual tool of transitions is widely used in higher education as well as in developmental psychology and the social sciences, with O'Donnell and colleagues (2014) identifying definitions that go from movement from one institutional context to another and life-defining events or milestones to more fluid conceptualisations in terms of constant change across the lifespan. Sociocultural accounts of transitions understand them as 'becoming' (Gale and Parker, 2014) and as processes used to reduce the uncertainty brought about by ruptures in a taken-for-granted life structure (Zittoun, 2007). In this way, transitions are seen as non-linear, flexible and fluid series of movements through life, with opportunities for meaning-making, identity-positioning and the generation of coherent (if fragmented) narratives in seeking life pathways in continuous renegotiation.

Transitions offer a powerful lens to explore the life experiences of students with caring responsibilities. First, transitions account for the manifold pathways through which students may find themselves caring at different points in their lives, with care organically becoming part of their personal narrative. Second, this concept affords the acknowledgement of meaning-making and identity-positioning when student carers fulfil the simultaneous demands between the family home, higher education and social care services, in relation to their multiple and overlapping roles. Third, transitions convey the continuous, porous and potentially unintentional navigation between spaces, events, self-conceptualisations, aspirations and challenges of caring while studying.

Research methods

This project is a participatory study, drawing on Paulo Freire's (1974/2007) work on education for critical consciousness, whereby the full engagement of research participants and work *with* them is pursued. In engaging student carers, we acknowledge care as relational. Our focus is, however, on the carers as students, for it is our contention that their stories, in the form of words and images, offer a glimpse into the *carer-person cared for* relationship in a fine-textured, policy-relevant way.

Institutional ethical approval was obtained and, recognising the 'hard to reach' nature of the student carer population, a purposive sampling strategy sought to maximise heterogeneity in terms of gender, young/mature, cross-faculty, beneficiaries and non-beneficiaries of an institutional bursary. Seven students from a large university in Southwest England were included in the wider study; all gave their informed consent to take part in the study. Here we focus on two of these participants,

using their narratives as case studies to maximise contrast in terms of intersectionality and transitions.

Data collection followed a threefold step:

a) *Photodiaries over a month*. Participants were asked to take 'a picture a day' that best represented their daily experiences. The project provided digital cameras, and sent weekly reminders via email and text messages. Using a photodiary aimed to address 'the "snapshot" nature that characterises much of the research [which] tends to present care as a static process fixed in time and space' (Milne & Larkin, 2015, p.9).

b) *Photo-elicited biographical narrative interviews*. These focused on biographical elicitation (distant past), the university experience and caring responsibilities vis-à-vis studies. The final stage of the interview was photo-elicited: interviewees were asked to go through each photo, describe it, and explain the reasons for taking it.

c) *Participatory workshop*. This activity sought to garner the views of participants as a group in terms of their experiences with support within the university and beyond. It also served as a preliminary participatory analysis exercise. All seven participants took part in the first two steps, with four participants joining the workshop.

In exploring the data for this chapter we focus on student carers as storytelling agents, on their agency in the narrative action, and on their everyday experiences that respond to multiple and intersecting sources of marginalisation. We consider narrative is a social, cognitive and emotional process to make sense of our experiences and articulate experiential knowledge (Bruner, 1990; McAdams, 1993). Drawing on biographic methods (Holley and Oliver, 2011), we adopt a narrative reconstruction approach that takes interviews and photographic accounts as a coherent unit of analysis, aiming to show how narratives are produced in context (Squire *et al.*, 2014). In representing these stories, we relate individual accounts to wider social and structural narratives around caring vis-à-vis higher education.

Narratives of care intersecting with higher education

Sydney came to the UK from Southeast Asia as an infant, with her mum and maternal grandmother. They have lived together since, and were all present when the interview was conducted. Sydney lost her father aged three-weeks, and narrated mixed memories from her childhood, with experiences of being an interpreter for her grandmother and enjoying the dividends of her mother's job. However, she also recounted '*low level bullying*' at school and how even now '*occasionally I'll walk down the*

street and I'll get someone doing the slanty eyes going ching chong'. Despite obtaining good GCSE results, Sydney attained lower than predicted A-level grades, which she related to attendance problems and depression. She also recalled having panic attacks at school and being prescribed anxiolytic medication around this time. Turning eighteen was important for her, she acknowledges, as school was over and she could now represent her mother more fully at an institutional level and avoid *'bilingual problems'*. Being an adult, she was now able to *'take over some bills'* directly.

Finances have influenced Sydney's education: after Year 9 she moved from a fee-paying school to what she describes as a *'voluntary contribution'* institution, when her family's financial circumstances changed due to her mother's deteriorating health. She was in *'the final year to get the £3K fees'* and this weighted into her decision about starting university immediately after school. She only had sporadic jobs, as her mother wanted her to focus on her studies and go to university.

With brief interjections from her mother, during the interview Sydney recounted many examples of how she progressively became a carer for her grandmother, before caring for her mother as well. She reminisced her first caring responsibilities: *'Taking Grandma to the hospital, taking Grandma to the GP, to the dentist, the cancer stuff [...] I had to take her to her radiotherapy appointments'*. This coincided with the time in which to make the decision to go to university. While Sydney acknowledges that she chose a specific university because the course *'was the first on the search results [...] it had the best outcomes'*, she also stated that there was *'almost a silent agreement that "oh, you need to come back and get things taken care of"'*. She took the train back home from university *'at weekends, but then the weekends became longer'*. Despite these responsibilities, Sydney acknowledged she *'can't be listed officially as a carer [...] Mum's listed officially as a carer for Grandma, even though Mum has her own issues'*.

About her academic experience, Sydney narrated

'It was good during the first year and second year because I had a friend like me who was there, but then when I had to repeat the year, they'd gone on placement [...] the second half hasn't been that great [...] The academic advisors during my first year weren't great [...] when I came to them with "oh, I have these mental health things" [...] you know men, they're very awkward [...] when I came back for the second year, after I had to repeat, I think I went to additional learning support [...] they diagnosed me with dyspraxia'.

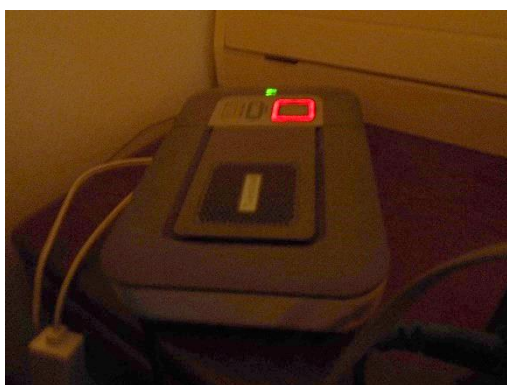
Sydney's mental health problems are inextricably related to her university and caring experience, having had to repeat her second year due to *'mitigating circumstances'*. She explained how she has used some strategies gained from cognitive behavioural therapy, but also how providing evidence

repeatedly is taxing: *'when I came back to start the final year the administrator didn't know [about my diagnosis], and then I had to submit letters and submit the things again [...] the programme administrators aren't too understanding'*. Finally, *'having to deal with stuff at home and then having to sort out the course and stuff, until in the end it got overwhelming and I just suspended it'*. Before going back home, however, Sydney received one important act of support from university staff: *'[social services] came in the beginning mostly because my academic advisor wrote some letter to my MP [...] they knew they were sending me back here, they wanted me to have some sort of support [...] our priority moved to the top of the pile'*.

Sydney's placement year seemed to serve as a bridge between the world of work, university life, and caring for her relatives, insofar as it allowed her to gain experience, receive an income to support her family and apply her course: *'During my placement I was doing okay, we were coping, we were getting enough money to get by but when the financial stuff stopped because I went back to uni, that's when it became difficult [...] because at the time my mum had to stop [work] because her hands were getting worse'*. Being a student carer comes at a cost at different levels: *'I'm suspended from the Union at the moment until I go back but there are some things I can't claim that other carers would be able to claim, because I am a student [...] Carer's Allowance'*.

All of Sydney's images in her photodiary express a domestic environment in which actions to care for her relatives are foregrounded. The sharing of activities in her family was also present in the process of completing the photodiary, as Sydney's mother joined her in taking a number of photographs. Sydney verbally expressed that *'right now I have nothing, I have not a lot going on, I just need to take care of people and go to the support worker and sort out bills and that's my life [...] Every day is the same, carer comes, gives Grandma a bath, at some point she has her food, at some point Mum goes out, we go out, it's the same routine'*. These intimate images corroborate her present as a carer: her

suspended university studies were not in the picture.



'Oh, that's just my grandma's carer alarm thing so if she falls over it will I think that day it kept going off, yes 'cause I think the phone alarm went off and it kept going off so no one got any sleep [...] it like fills the whole house when it goes off'.



'Grandma's bath board at the time to show that she needs equipment and just the change in equipment because before she was using a shower stool, which was wobbly and creaky but then the occupational therapist came and they put that in instead'.



'And then the food. Grandma only eats [Southeast Asian] food so she has to have her food specially prepared [laughs]'.

At the time of the study Sydney had been at home for months, dedicated exclusively to caring, and was not planning to go back to university the following academic year, as a surgical procedure for her mother was scheduled during term-time. About her future, she hopes *'actually finishing uni at some point maybe, because my course is only four years and I've taken so long'*.

Joseph started university in his thirties, and was in the last year of undergraduate studies when the interview took place in the university premises. When asked about his background, he narrated:

'a lot of things in my life have led me to this particular path [...] I was born in [City] [...] I didn't seem to develop normally [...] I just plodded along [...] My mum and dad separated, divorced when I was about five [...] I had a brother a couple of years younger than me [...] I went to secondary school and probably for them six years it's probably like one of those

chapters I'd like to forget [...] my grades were very poor [...] they found out I was slow [...] finances were very difficult so you know I just stuck with this school and at sixteen I left'.

Despite recounting having travelled to more than fifty countries in his twenties, Joseph felt he was *'up and down like that, zigzag, zigzag, and relationship after relationship and kind of dead-end job to dead-end job, and kind of sleep-walking from late twenties to thirty'.*

When he was twenty-nine, Joseph recalled, *'I just had absolutely no direction in my life'* but wanted to *'make something of myself'* and, after travelling to Australia on a working holiday visa, he came back to the UK to pursue a number of qualifications with the financial support of his mother. At this point, he decided to pursue a university access course at a nearby college. Joseph recounted applying to *'loads'* of courses in universities in different parts of the UK, but was accepted only by the university in the city where he lives. He was offered a university bursary, which was supplemented by a £5,000 compensation award for injuries after being victim of knife crime.

Joseph's role as carer has been intermittent, and intensified during his university studies. He narrated:

'I remember as an early child I used to wake up my mum every day [...] I shouldn't have really had that role as a kid of making her dinner, doing the dishes, making cups of tea, making sure my mum woke up [...] I see that this was taking on care responsibilities at an early age [...] it was just put upon me, and my mum got ill, I mean we are going back eighteen years ago [...] and she hasn't worked since [...] My mum had a subarachnoid haemorrhage [...] it started like the first week I started the second year so it took about a year for her to be out of the woods and it has been a bit of a nuisance'.

Joseph's father was absent during most of Joseph's childhood. Joseph, in turn, changed his name to reflect the distance between them. After they renewed contact, his father had a stroke and found himself homeless. For a year, Joseph assisted his father with accommodation, he *'kept going back and forth to [City] doing all these appointments [...] then I've gotta start working on my assignment and then be back at college in the morning'*. At this point Joseph offered for his father to be brought to the city where he lives: *'I thought about, "we could live together, he could get like housing benefit, I could be his main carer whilst doing my studies", but I knew that would be counterproductive because he wouldn't get better, he has got this learned helplessness, so I don't want to be a live-in carer [...] he was asked to leave [...] his shared accommodation. I thought "aw, this is all I need when I am at university"'*.

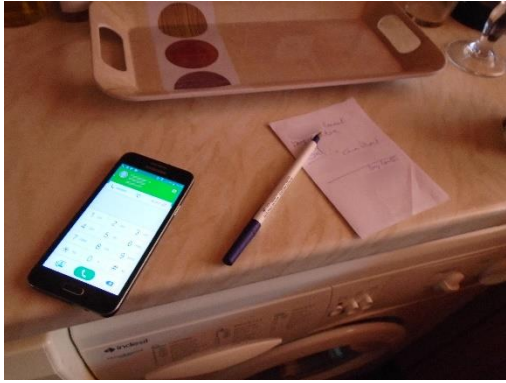
Joseph saw his caring role as a barrier to attaining higher marks: *'In many respects I wish my dad hadn't come down, I hadn't been caring you know I wish I'd actually been uncaring like I did years ago [...] because caring for him here has had a strain on my life, an impact on my studies, which is unfair'*. Furthermore, Joseph also felt that his efforts were not reciprocated with his father's appreciation, which is compounded by his father's dementia: *'I tried to cut my visits because emotionally it's too much [...] I want the relationship to be fairly equal and [...] you feel there's, you know, no light at the end of the tunnel [...] this place that I want him to go, I used to take him to the Alzheimer's Club, and then I had to change my lessons at uni on a Monday so I couldn't go, so he never went'*.

Despite acknowledging that he *'never told people about my problems so I've been completely alone, I didn't know what kind of help there was out there'*, Joseph has been *'registered with this [County] carers resource centre and had little bits of pickings'*. Being a carer gives Joseph the recognition he does not obtain from his father. For example, at university he has been able to access hardship bursaries and a carers' bursary: *'it's just really great, not just financially but just for [University] to give that recognition, that we recognise that there are a handful of students who deserve that little extra help'*.

Joseph was prolific with his photo-taking, producing more than a hundred pictures. He classified them into a number of categories: 'caring' for his father; 'uni' (*'visiting the library, my desk at home, all that kind of thing'*); 'leisure' (*'myself going out getting a coffee'*); 'home', with domestic scenes; 'wellbeing' (*'went to the doctor's a couple of times'*); 'achievement', documenting everyday life gains (*'I have done various piles of ironing'*); 'stress', with the most photographs (*'waiting at bus stops, doing lots of heavy shopping, going for walks because I am stressed'*). While numerous, Joseph's photographs document his interactions with a reduced number of networks, including the university, health and social care services, and his immediate family, as illustrated below.



'...this was father's day, with me and my brother taking my dad out and it was meant to be a nice day, and he just had what we call the strops, he didn't want to be there. We done it all for him, got him drinks, a little bite to eat, and he just wanted to go home'.



'...this was like a kind of like a work call. This was to do with the carer's thing, I do that quite a lot. You know, get a message, pen and paper, this was about the day centre and then I was quite stressed about it'.



'This is like my little domain, this is my section of books, so they look really neat there but certainly when I leave, whenever I leave uni at some point, I will really miss that...'

For his future, Joseph would like to *'look at a career and have a partner, maybe have children [...] I'm worried though, particularly with my mum, when I finish uni, I'll go back to how it was, get into old habits and start seeing them all the time, coz uni's been a wonderful, you know, my excuse, to distance yourself'.*

Discussion

The narratives presented here display fluid, involuntary and sometimes painful life transitions, all brought together by caring vis-à-vis the university experience. Mirroring research into caring, these narratives demonstrate that entering into care is non-linear (McGarry, 2008, p.83, cited in Milne and Larkin, 2015, p.8; Hamilton and Cass, 2017). This study contributes student carers narratives as they evince their increasingly transitioning in and out of caring responsibilities, from home-based to distance caring, from resigned responsibility to undesired duties, with the different demands of caring and university studies evolving in parallel.

Caring intersects with manifold social divisions in terms of age, gender, ethnicity, social class and disability. Sydney's and Joseph's narratives show a sharp contrast in terms of age and the transition into higher education: while the former followed the mainstream route into university, the latter is a mature student with a complex pathway into his degree, including a course transfer after one year. At the same time, while both life stories have been influenced by caring responsibilities before their university studies, it is during their journey as students that these responsibilities deepen and their roles are shaken and renegotiated. Similarly, gendered expectations are subtly played out, as one could assign typical feminine and masculine roles to Sydney and Joseph's physical positioning in relation to caring—she stays at home with her family, while he manages to keep separated from those he cares for. However, this is complicated by *how* their stories were told: both Sydney and Joseph expressed assertiveness, resourcefulness and political engagement, which until recently would have been associated with a specific gender.

The two student carers' ethnicity needs to be understood in the context of social class and disability. As a white male, ethnicity is absent from Joseph's narratives, but not his acute awareness of financial difficulties throughout his life and what he perceives as the significance of higher education for social mobility. In contrast, Sydney's narrative is charged with the experience of racial discrimination. Her experience is in turn shaped by migration, the fact that three generations of women with varying degrees of English proficiency and acculturation live together and mutually support each other, and their fluctuating financial situation. Finally, disability is an analytical layer that permeates all other categories: both student carers report special educational needs, albeit experienced in different manners. While Joseph heard from an early age that he was 'slow', affecting his self-esteem, the onset of Sydney's mental health conditions took place in her adolescence, with the consequence of disturbing an otherwise notable academic performance.

The fluid transitions between education and care show simultaneity, with liminal spaces filled by ambiguity about the present and uncertainty about the future, both of which depend on the relationship and needs of those student carers care for. The apparently seamless move between

different spaces, such as the family home and university, and responsibilities, highlight the need for support in fulfilling those responsibilities and effectively occupying those spaces. While for some student carers it may be the case that 'turning points' or 'life-changing events' are identifiable, these narratives reveal continuous ruptures and adjustments in which student carers reposition their values, priorities and expectations. It is during those moments of identity repositioning that support is needed and when universities could offer assistance that makes a remarkable difference.

Three policy recommendations have emerged from this research. First, due to the multi-layered and fluid nature of caring, the intersection between different social divisions and the dual responsibilities of simultaneously being a student and a carer should be acknowledged. An intersectional analysis of student carers experiences reveals how different characteristics such as age, gender and disability work concertedly to shape these experiences. They intertwine as a coherent whole that can only be understood in context, rather than as factors to be addressed in isolation. Second, it is necessary but not sufficient to offer the opportunity of self-identification at the point of application for a university place. As documented in this chapter, transitions are non-linear and caring responsibilities can appear or heighten at any point of the university journey. Mechanisms should be put in place to allow disclosure and support for students who become carers before and during their studies and, importantly, while they have suspended their studies. Third, tailored support for student carers is needed as a matter of policy, not only driven by individual university contributions and criteria. While this may mean restricting the definition of student carers, institutionalising support for this population would entail foregrounding their presence and recognising that they are doing more, much more, than just saving the government care costs.

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