

# **Student Carer Experiences of Higher Education and Support: A Scoping Review**

Dr J. Runacres<sup>a\*</sup>, Dr D. Herron<sup>a</sup>, Ms K. Buckless<sup>c</sup>, Ms S. Worrall<sup>c</sup>

*<sup>a</sup>Department of Midwifery and Allied Health, Staffordshire University, UK;*

*<sup>b</sup>Department of Psychology, Staffordshire University, UK; <sup>c</sup>Department of Psychology, University of Derby, UK*

Dr Jessica Runacres (Orcid ID: 0000-0003-3429-4054). Staffordshire University, Department of Midwifery and Allied Health, School of Health, Science and Wellbeing, Blackheath Lane, Stafford, ST18 0YB. [Jessica.runacres@staffs.ac.uk](mailto:Jessica.runacres@staffs.ac.uk) (corresponding author)

# **Student Carer Experiences of Higher Education and Support: A Scoping Review**

Student carers are students who provide unpaid support to an individual who could not manage without their care. A scoping review was undertaken to determine the themes and concepts which underpin student carers' experiences within higher education, examine student carers' experiences of support, and identify any gaps in the literature. A comprehensive literature search was conducted between February and May 2020. The search yielded 2,484 items, of which 14 articles were included in the review. Data from each article were extracted, charted, and analysed using a thematic analysis. The articles revealed that caring responsibilities can have a negative impact on student carers physical and mental health, university performance, and financial status. Both formal and informal sources of support were referenced. Further, it was noted that universities had rigid rules and policies which did not suit the flexible needs of student carers. A paucity of research examined the impact studying had on student's ability to provide care. Finally, issues relating to research design were observed, and a lack of demographic information, or detail on the caring duties performed was found. A more robust evidence base is required to facilitate the development of interventions to support student carers in education.

Keywords: caregivers; students; long-term care; scoping review; university; mental health.

## **Introduction**

Student carers are students who have a commitment to providing unpaid support to a family member and/or friend who could not manage without their care (UCAS, n.d.), including, but not limited to, illness, disabilities, and/ or physical and/or mental health issue(s). A National Union of Students (NUS) report highlights that student carers undertake a diverse range of tasks as part of their caring role, including practical help (e.g., preparing meals), personal care, administering medication, support with financial matters, and physical help (2015).

Given the diverse demographics of the student population, which includes a significant number of mature students (those aged 21-years-old or over at the start of their undergraduate studies), there is likely a section of the student population who have a range of caring responsibilities (Hussain et al., 2011; Office for Students, 2018). However, currently, the exact number of students in higher education who are carers is unknown (Hussain et al., 2011). Complicating this, students may not disclose their caring responsibilities, or their status as a carer can change throughout their time studying (Carers Trust, 2015).

Having access to, and attending higher education can provide benefits, including a sense of accomplishment, life skills, and independence (Wiseman et al., 2017). However, unpaid carers may not have the same opportunities in higher education as those not providing care. To address this, carers need to be supported to fulfil their ambitions and maintain their wellbeing. Within the UK, local authorities have a duty to consider and support carers' access education (Department of Health, 2014). Yet student carers still report barriers (e.g., a lack of support) to accessing and succeeding in higher education (NUS, 2015). Consequently, student carers are underrepresented within UK higher education (NUS, 2015).

In general, there is a dearth of knowledge and understanding of student carers' experiences of higher education. A small but growing body of international research has started to provide some insight into this. It has highlighted that caring responsibilities can influence students' decisions and experiences within higher education. For instance, student carers' choices of what and where to study have been found to be linked to their caring role, and many sacrificed elements of the student experience, such as social events, to provide better care (Burns et al., 2019). Research has also identified that student carers may experience lower wellbeing than those without caring responsibilities (Day, 2019; Hussain, 2011; NUS, 2015), and face increased financial strain (NUS, 2015). However, current understanding of this diverse group is limited. Further investigation is required to understand the experiences of student carers in higher education, to facilitate the development of services to support this group, and to better understand the barriers and facilitators to higher education.

To the authors' knowledge there has been no structured approach to reviewing and summarising the student carer literature. This has negative implications for our understanding of the student carer experience, and how we can provide an environment which facilitates positive student carer experiences. Furthermore, without this structured approach, the extent, range, and nature of research activity and gaps in existing literature are not known. To address this, the current study undertook a scoping review to collate, summarise, and map key concepts from across the literature. The scoping review aimed to examine and identify any gaps in the literature, and to identify key concepts which underpin student carer experiences within higher education, including the supports drawn upon.

## **Methods: scoping review**

Scoping reviews provide a useful approach to establishing the scope or coverage of the field of literature within a specific topic; illustrating the volume of literature available, an overview of its focus, and allowing for the relevant literature to be rapidly mapped (Munn et al., 2018). Arksey and O'Malley (2005) identify four reasons for utilising a scoping review, all of which are relevant to this review: (1) to examine the extent, range and nature of research activity; (2) to determine the value of undertaking a full systematic review; (3) to summarise and disseminate research findings; (4) to identify gaps in existing literature.

This study adopted Arksey and O'Malley's (2005) framework for conducting a scoping review, which consists of five stages: (1) identifying research questions; (2) identifying relevant studies; (3) study selection; (4) charting the data; and (5) collating, summarising, and reporting the results. How each stage has been applied in this scoping review is detailed in the following sections.

### ***Stage 1: identifying the research question(s) and operationalising terms***

Three broad research questions directed this scoping review to understand the type of literature and its underpinning concepts, and to provide insight into any current gaps in the literature:

- (1) What themes and concepts underpin student carers' experiences within higher education?
- (2) What are student carers' experiences of support?
- (3) What gaps in the literature can be gleaned from this review?

Within this review, a student carer was defined as anyone over the age of 18 studying within higher education and providing unpaid care to a family member or friend who could not cope without their support (UCAS, n.d.). For this review, this does not include parents of children with typical development.

### ***Stage 2: identifying relevant literature***

Searches were undertaken in nine electronic databases between February and May 2020: Pubmed, Medline (MEDical Literature Analysis and Retrieval System), Psycinfo, Cinahl (The Cumulative Index to Nursing and Allied Health Literature), Scopus, Web of Science, ASSIA (Applied Social Sciences Index & Abstracts), Embase (Excerpta Medica database), and Cochrane Library. To maximise the amount of relevant literature and ensure the inclusion criteria were met, truncation (\*) and Boolean operators 'AND/OR' were applied when searching databases (see Table 1). Reference lists of all included primary and review articles were manually searched for additional articles.

#### Table 1. Search Strategy

In addition, the authors reviewed the grey literature by searching the following databases using the term 'student carer': The Kings Fund, The Health Foundation, NESTA (National Endowment for Science, Technology and the Arts), Nuffield Trust, Department of Health, NICE (National Institute for Health and Care Excellence), NHS (National Health Service), OpenGrey, Google, and Google Scholar.

A more simplistic search strategy that just included the core term (student carer) was adopted for use with the grey literature, due to the limited searching power of many grey literature locations. Finally, the reference lists of all included articles were searched by hand to identify any further relevant papers.

### ***Stage 3: study selection***

Using the key search descriptors 2,484 articles were identified. The results from all searches were combined using the reference management software Endnote X9 and duplications were removed. Initially the title and abstract of all articles identified were screened by one of the authors for eligibility. Articles were included if they (1) focussed

on students enrolled in higher education who also had an unpaid caring role; (2) were written in the English language; (3) presented research. Articles were excluded if they: (1) also included students who were not enrolled in higher education courses; (2) included parents caring for children with typical development (this meant excluding papers that consider typical parenthood as a caring role). There is limited literature available on this topic, and whilst some factors, such as support available, may differ between countries, it is likely that the experiences of student carers are comparable, therefore the decision was taken to review academic literature from all countries. Guided by the inclusion and exclusion criteria, 77 articles were initially identified as being relevant to the research topic. Full text versions of these 77 articles were then obtained and reviewed in full against the inclusion and exclusion criteria by the authors. This process also provided an opportunity to identify any additional relevant literature from a review of the reference lists of each article. In total, 14 articles adhered to the inclusion and exclusion criteria and featured in the final synthesis. Following the scoping review processes outlined by Arksey and O'Malley (2005), studies were not screened based on methodological rigor or quality. The process of article selection followed the Preferred Reporting of Items for Systematic Reviews and Meta-Analyses (PRISMA) Statement and is displayed in figure 1 (Liberati et al., 2009).

Figure 1. PRISMA flow diagram for article selection

#### ***Stage 4: charting the data***

This stage involved charting key information from the selected literature. The research team collaboratively identified key items of information and developed a data-charting form specific to this scoping review, which allowed the authors to address the scoping review questions. This form included the author(s) and year of publication; study geographical location; type of publication (e.g., literature review, research study); type

of data collected (e.g., quantitative or qualitative); carer responsibility (e.g., supporting family member with mental health needs); and key findings.

Two of the authors piloted the data-charting form by independently extracting data from one of the identified articles; any differences were discussed. Next, another author charted data from the remaining 14 articles. Finally, two of the authors independently charted data from a sample of the 14 studies; any differences were discussed and resolved by consensus between the authors (Li, Higgins, and Deeks, 2021). Detail of included studies is provided in appendix 1.

### ***Stage 5: collating, summarising and reporting the results***

The fifth and final stage of Arksey and O'Malley's (2005) scoping review framework summarises and reports findings. Charted data were collated and presented both numerically and thematically. Numerical data are presented on the characteristics of included articles, namely the date of publication, geographical location, type of publication, and type of data in table 2. A summary of the included articles is provided in appendix 1. The remaining extracted data are presented under the six themes developed through a thematic analysis of the articles identified: 1) impact of caring on student carer physical and mental health, 2) negative impact on university performance, decisions, and social life, 3) finance and employment during higher education, 4) negative impact of being a student on caring ability, 5) formal support, 6) informal support.

Table 2. Characteristics of included articles

## **Results**

### ***Theme 1: impact of caring on student carer physical and mental health***

The analysis revealed that caring responsibilities could have a negative impact on student carers physical and mental health (Crandall et al. 2014; Morgan 2019; Soliz and Merai 2018; Van Der Werf et al. 2019). Research found that student carers experience lower wellbeing than those who do not have caring responsibilities (Areguy et al. 2019); this was identified as an area of concern by student carers (NUS 2015). Moreover, much research reported that student carers experience mental health issues such as stress, anxiety, and low mood (Crandall et al. 2014; NUS 2015; Yiengprugsawan et al. 2012). Such issues are thought to impact students' attendance and ability to complete work, subsequently leading to poor academic performance (Crandall et al. 2014; NUS 2015). The impact of caring responsibilities was not consistent across the types of care provided. Those who provided care for someone with mental health issues were found to report higher caregiving burden (Crandall et al. 2014) and experience higher levels of emotional issues (Crandall et al. 2014; Van Der Werf et al. 2019).

Some articles also noted the physical impact of a caring role on students.

Commonly, student carers were found to experience increased fatigue which impacted their ability to study (Day 2019; Kirton et al. 2012; NUS 2015; Soliz and Merai 2018). In other research, students reported experiencing physical pain as a result of their caring responsibilities. One student in Burford et al's (2019) research stated that they suffered significant back and shoulder pain, and Yiengprugsawan et al. (2012) found that carers were more likely to suffer from lower backpain than those who had no caring responsibilities. There are a multitude of factors which could explain poor health, such as inadequate support, social exclusion, time limitations, and lifestyle (Day 2019). Yiengprugsawan et al. (2012) found that student carers were more likely to engage in

risky health behaviours such as smoking and drinking, and they were more likely to have a higher BMI (body mass index) compared to non-caregivers; all factors which can lead to an increased risk of negative health outcomes. However, there is insufficient research in this review to substantiate a direct link between the student caring role and risky health behaviours.

### ***Theme 2: negative impact on university performance, decisions, and social life***

Students commonly referred to the link between their caring role and decisions made. For example, students considered their caring responsibilities when making choices about where to live and study, such as staying near the individual they were caring for (Burford et al. 2019; Day et al. 2019; Kettell 2018; NUS 2015). Providing care also impacts the course chosen as student carers reported finding it challenging to complete a course which requires placements (Kettell 2020). Finally, student carers explained that they created a study plan around their caring responsibilities, for example studying late at night when they had fewer distractions (Day 2019).

Caring responsibilities were thought to negatively impact upon academic performance (NUS 2015). A high number of student carers reported being unsatisfied with their academic achievements due to the impact of their caring responsibilities on their education (Day 2019; Morgan 2019). Student carers experienced time constraints which resulted in them being sometimes unable to complete work (Day 2019), meet deadlines (Kirton et al. 2020), or attend face-to-face sessions (Day 2019; Kettell 2018). They reported that they are commonly interrupted when trying to complete work at home (Day 2019), and that their workspace at home was not suitable (Burford et al. 2019). This is a particular issue as many student carers live with the individual they support whilst studying (NUS 2015). Kirton et al. (2012) found that as a result of the pressures experienced, student carers reported doing the minimum work required to get

through the course; therefore, missing out on wider educational opportunities and improved grades.

It is not just academic aspects of university that student carers are unable to benefit from. Due to time constraints student carers had to forgo wider opportunities offered by their university, such as work experience and extra-curricular activities (Day 2019). Research reports that this, alongside reduced academic performance led students to be concerned about their future employment prospects (Day 2019; Kettell 2018).

### ***Theme 3: finance and employment during higher education***

Many studies from the search illustrated that students reported a financial strain while attending university. For example, two thirds of UK student carers regularly worry about not having enough money to meet their basic living expenses (NUS 2015), and they often take on the additional pressure of their family's financial situation (Kettell 2018). An NUS report (2015) found that student carers in the UK were less likely to be in receipt of a student loan compared to students without caring responsibilities. This will have a significant impact on their financial situation, however this may in part be explained by the higher number to part-time students within this group as many are unable to attend university full-time due to their caring role.

Aside from student loans, UK student carers are more likely to be in receipt of other forms of financial support, such as grants and discretionary funding from their institution (NUS 2015). However, the NUS (2015) reported that half of UK student carers felt that there was insufficient financial support available through both their institutions and the government. Furthermore, a qualitative report undertaken on healthcare students who were also carers, found that by attending university full time they had to relinquish their right to carers allowance issued by the UK Department of

Health (Kirton et al. 2012). This is surprising given that most student carers who attend university full time report no reduction in the number of hours they spend caring as often they remain living with, or near the cared for individual (Burford et al. 2019; Day et al. 2019; Kettell 2018; NHS 2015). This may, in part, explain why a greater proportion of student carers in the UK opt to undertake part-time study (NHS 2015). It must be noted that all literature was interpreted in consideration of the UK context. Financial support may differ between countries, but it is likely that the experiences of student carers are comparable.

Student carers are less likely to be in paid employment than students without caring responsibilities; this is to be expected given the time required to provide care. However, research has found that many student carers in the UK do undertake paid work (60%), although their motivations for doing so differ from students without caring responsibilities. The most common reason for student carers working is to cover their or their household's costs. Student carers were less likely than other students to indicate that they worked to pay for items for themselves (NUS 2015).

It has been found that student carers have a greater total of debt compared to students without caring responsibilities, and they are more likely to have taken on high-risk debt (NUS 2015). This places them in a disadvantaged situation financially, especially when considered in conjunction with the lower uptake of student loans and fewer available hours to undertake paid employment. Research suggests that this disadvantage can be partially explained by a lack of access to accurate information about the support available to student carers (Kettell 2018; Kirton 2012; NUS 2015). Many student carers are eligible for multiple streams of financial support (NUS 2015). However, each student carer's situation is unique, consequently universities need to provide financial

support that is tailored to the individual (Kirton 2012; Morgan 2019). Kirton (2012) argued that this targeted information is needed to help student carers successfully complete their studies. This is pertinent as there is a relationship between financial issues and student retention (Kettell 2018), and students who leave without successfully completing their programme experience financial implications, such as student debt (Kirton 2012).

#### ***Theme 4: negative impact of being a student on caring ability***

The literature highlighted that being a student carer not only has implications for education, but also for the ability to provide care. Day (2019) reported that students who were undertaking placements as part of their degree raised several challenges which resulted from their caring commitments. For example, being unable to leave their placement when needed to provide support for the person they were caring for. Other research has found that since becoming a student, carers felt that they were unable to provide the necessary level of care for the person they were supporting (Kettell 2018; NUS 2015). One study found that students felt a sense of guilt when undertaking clinical placements which were part of their degree because they felt that the work they were doing should have been for the family member they were caring for (Kirton et al. 2012). This is supported by Kettell (2018) who highlighted that students believed their degree took them away from their responsibilities as a carer and they felt a sense of guilt because of this.

A NUS (2015) report found that two thirds of student carers felt that their ability to provide care had been negatively impacted due to having less time to spend with the person they cared for. Student carers also noted that the increased stress from their degree resulted in them having less patience. Conversely, one third of the respondents stated that being a student had a positive impact on their ability to provide

care. Commonly this was due to having a more flexible schedule as a student compared to if they were in employment. But some student carers noted that their studies provided a physical and mental break, which resulted in them being more compassionate and understanding when they returned to their caring role.

### ***Theme 5: formal support***

Formal support, such as bursaries and flexible deadlines, were discussed within the literature. When available, student carers accessed formal support offered by universities to better enable them to attend their studies (Day 2019; Kirton et al. 2012; Yeingprugsawan et al. 2012). However, Day (2019) and Kirton et al. (2012) reported that some felt unable to disclose their status as a student carer for fear of being negatively judged by their institutions, for example, being stigmatised as being an incompetent or inferior student. This had implication for the support that they were able to access. Where students did register their caring status with their university, they felt that they received academic and emotional support from some of their tutors and other staff members (Kirton et al. 2012). Some literature reflected the need for universities to adopt clear and transparent formal procedures to ensure that student carers could disclose their carer status without discrimination and access the necessary support (NUS 2015); this is akin to the process by which disabilities are reported.

The literature discussed the need to recognise the diversity of the student carer population. Crandall et al. (2014) and Yeingprugsawan et al. (2012) explained that student carers must not be considered as a homogeneous group owing to the wide variations in personal situations and needs. Due to this, the literature recommends that educational institutions use a flexible approach to support student carers. For example, being accommodating of reduced attendance due to caring responsibilities, facilitating timetable changes, and enabling access to online learning materials and support (Day

2019; Kettell 2018); the latter being particularly relevant during Covid-19. University staff, such as lecturers and tutors, were noted as key figures for identifying when student carers were struggling with their dual role, and in offering early support (Boumans and Dorant 2018; Deal 1999; Kirton et al. 2012; NUS 2015). However, the literature highlighted that to provide early and ongoing support, university staff needed to be trained to understand the issues student carers may face when studying (Morgan 2019), and have access to information and services which provide support for student carers (Van der Werf et al. 2019).

### ***Theme 6: informal support***

A limited amount of literature explored the importance of informal forms of support, such as the support from family, friends, and peers (Baus et al. 2005; Kettel 2018; Kirton 2012). With a lack of access and/or awareness of formal forms of support through their place of education, friends and family may become the student carers main form of support, both emotionally and physically (Kirton 2012). Kettell (2020) found that student carers relied on their peers to take class notes for them and keep them up to date; this supported the student to continue their studies. Interestingly, one study found a high level of instrumental support (e.g., seeking and/ or receiving support from other people) was associated with higher ratings of benefit-finding (Areguy et al. 2019), and used previous research to highlight that benefit-finding relates to positive health outcomes. In the same study, the authors found that student carers with greater communal orientation were better able to find benefits in their role because of this instrumental support.

## **Discussion**

This scoping review provides an overview of what is known from the existing literature about student carer's experiences of higher education and support. A relatively small body of evidence was identified with just 14 eligible articles. These articles were reviewed in full, and conclusions were presented thematically.

Both formal and informal sources of support were identified in this review. Whilst research reported that student carers were reluctant to share information about their caring responsibilities with their university for fear of being judged (Day 2019; Kirton et al. 2012), it also noted that some students who were identified in their role felt that they received support from some of their tutors and other staff members (Kirton et al. 2012). However, research also found that universities had rigid rules and policies which did not suit the changeable needs of student carers (Day 2019). This suggested that universities need to be flexible to support student carers, for example, not expecting full attendance, offering timetable changes, and enabling access to learning materials and support services online (Kettell 2018). The identified research highlighted the important role that lecturers and tutors play in supporting student carers (Boumans and Dorant 2018; Deal 1999; Kirton et al. 2012; NUS 2015) and noted the need for staff to be aware of the available supportive services (Morgan 2019; Van der Werf et al. 2019). Some research also highlighted the importance of informal support such as friends and family (Areguy et al. 2019; Kettel 2018; Kirton et al. 2012).

There is limited governmental financial assistance for full-time student carers in the UK, as by studying full-time individuals are no longer eligible to receive Carers' Allowance (Kirton et al. 2012; NUS, 2015). Support available may differ in other countries, but it is likely that the experiences of student carers are comparable. There are additional sources of financial support available across institutions, such as grants

and discretionary funding, however this is not always secured (NUS 2015). The NUS (2015) reported that half of UK student carers felt that there was insufficient financial support available. Research suggests that this might be partially explained by a lack of accessible, clear, and accurate information detailing the support available (Kettell 2018; Kirton 2012; NUS 2015). Higher education institutions need to ensure that the appropriate information and guidance is available to potential and current students (Kettell 2018). Furthermore, given that each student carer's situation is unique, and the process of applying for financial assistance can be time intensive and complex, universities need to offer practical and financial support that is tailored to the individual (Kirton 2012; Morgan 2019). This support is important as the relationship between financial issues and student retention is significant (Kettell 2018). Furthermore, financial implications may continue to impact student carers after education due to increased debt (NUS 2015) and reduced employment prospects due to lower academic performance (Day 2019; Kettell 2018).

The literature discussed various implications of caring on education. Students described practical considerations, such as choosing to study near the individual they were caring for and building their study timetable around caring responsibilities (Burford et al. 2019; Day et al. 2019; Kettell 2018; NUS 2015). They also reported that their academic performance was negatively impacted by their caring responsibilities (Day 2019; Morgan 2019; NUS 2015), and that they missed out on wider opportunities offered by their university, such as work experience and extra-curricular activities which may have an impact on future employment prospects (Day 2019). However, the literature also highlighted a lack of formal practical and financial support for student carers (Day 2019), it may be that if such support was provided student carers would not experience the same academic challenges. It is therefore possible that reduced academic

performance is not necessarily a direct result of caring responsibilities, but instead results from a multitude of factors including insufficient support and institution flexibility. No research was identified which quantitatively examined the academic performance of student carers; this should be collected alongside an examination of support available in future research to support existing qualitative findings. The relationship between caring and studying is not linear, some literature instead reported the negative impact of being a student on the individual's caring role (Areguy et al. 2019; Kettell 2018; NUS 2015). Some students in Kettell's (2018) research believed that their studies took them away from their responsibilities as a carer and could feel a sense of guilt because of this. This could also be addressed by the introduction of appropriate support.

Finally, much of the identified literature focussed on student carers health and wellbeing. It is reported that caring responsibilities can have a negative impact on student carers physical and mental health (Crandall et al. 2014; Morgan 2019; Van Der Werf et al. 2019). However, there are a multitude of factors which could explain poor health, such as inadequate support, social exclusion, time limitations, and lifestyle (Day 2019). Furthermore, there are broader demographic factors which may impact health, such as household income. Consequently, it is possible that negative health outcomes are not a direct result of the student carer role, but instead the combination of multiple factors. Distinguishing these factors, and understanding how they intersect, could help us to understand the inequalities student carers experience and how we can better support them in policy and practice. This however is not possible without first identifying the prevalence and demographics of student carers. Universities need to capture this data from their student populations, and research needs to be more rigorous in their reporting of participant characteristics.

### *Gaps in the literature*

The scoping review identified the following salient gaps in the literature. Firstly, limited research within any one country could be identified. This is a concern as the differences in education and healthcare between countries limits the comparisons and generalisations that can be made. Furthermore, no longitudinal research was identified, consequently still relatively little is known about mechanisms and causal links which impact student carers across their life course. A better understanding of these mechanisms is crucial for designing appropriate interventions. This is particularly salient as the scoping review identified concerns with employment prospects (Day 2019; Kettell 2018); this suggests that being a student carer might have an impact in future-life regardless of the continuation of caring responsibilities. Much identified research focussed on student carer's experiences, their health and wellbeing, and academic outcomes, little research has examined the implications of being a carer on broader student life, such as social activities.

The caring role varies considerably. Many factors influence student carers' experiences, such as class, gender, ethnicity, impairment, as well as access to resources, the individual's abilities, and their caring responsibilities (Lynch and Lyon 2009). Knowing details of these factors and how they intersect can help us to understand the inequalities student carers experience and how we can better support them in policy and practice. The reviewed research did not explore how these identities and factors intersected to inform carer experiences, nor were important participant characteristics consistently reported. It is therefore recommended that studies are more rigorous in their reporting of participant characteristics including basic demographic variables, the nature of caring duties performed, and the time spent caring. The vast differences between caring roles considerably inhibits the interpretation of research findings, limits

comparisons that can be made between studies, and subsequently impacts the broader conclusions that can be drawn. For example, some research points towards differing health outcomes for carers of those with mental health conditions compared to physical conditions (Crandall et al. 2014; Van Der Werf et al. 2019), and some highlight differences in the type of care provided by males and females (Baus et al. 2005); however, there is limited research which collects such detail, and therefore such claims cannot be substantiated.

The wider care literature stresses the importance of understanding how social categories, such as gender, class, and ethnicity intersect with inequalities (Akkan 2019). However, to the authors' knowledge, no research has explored this within the student carer population. Therefore, future student carer research should explore the relationship between such social categories and inequities (e.g., in support received).

Little of the identified literature focused on or explored the role of informal forms of support (Kettell 2018; Kirton et al. 2012). Some research reported that student carers were reluctant to share information about their caring responsibilities with their university (Day 2019; Kirton et al. 2012). Therefore, it is likely that instead of formal sources of support, these students value informal support, such as that from friends and family. Further research is required to examine what support students draw upon and value, rather than that which is offered through formal channels. Little research specifically focusses on understanding the barriers and facilitators to higher education for student carers. Further investigation is required to facilitate the development of services to support this group, and better understand possible reasons for this population being underrepresented in higher education. Finally, whilst all identified research examined the impact of being a student carer on the individual and focussed on the impact of caring on the participant's student status, some student carers discussed the

impact being a student had on their caring role (Areguy et al. 2019; NUS 2015; Kettell 2018). Further research is required to examine the perceived impact of being a student on an individuals' ability to provide care. This research will have implications for the practical support needed for students to manage their dual role.

### ***Strengths and limitations of this review***

This review has provided a comprehensive overview of the research related to student carer experiences of higher education and support. In doing so, it has identified both the gaps in knowledge and the practical implications of the identified articles. Arksey and O'Malley's (2005) scoping review framework was utilised which provided a systematic and reproducible search and selection strategy; this allowed for transparency in the results. However, although this framework was followed, when searching a significant body of literature there is still a chance that some relevant articles may have been excluded, for example that from grey literature sources not searched. As is common with the scoping review framework (Arksey and O'Malley, 2005), a quality appraisal of the research included was not performed. However, some methodological weaknesses in the research included were observed, therefore a systematic review might provide further insight into the quality of the current research base; yet this would likely exclude much of the grey literature included in this review. Finally, the initial data extraction and study selection was conducted by only one researcher, and therefore, there is the potential that some research may have been missed. However, these processes were verified by the research team to reduce the potential of this.

### ***Conclusion***

A more robust evidence base, and a better understanding of the population, could aid the development of appropriate interventions to support student carers in their dual role.

Further research needs to focus on the sources of support that student carers value, and on the practical implications of their dual role on both their student responsibilities and their caring responsibilities. The literature reviewed in this article suggests that higher education institutions need to adopt a flexible approach to supporting student carers. For example, being accommodating of reduced attendance, facilitating timetable changes, and enabling access to online learning materials and support. Whilst university staff, such as lecturers, were noted as key figures for identifying when student carers were struggling with their dual role, such staff need to have access to information and services which provide support for student carers. Finally, higher education institutions need to provide accessible, clear, and accurate information detailing both the financial and practical support available to student carers. Furthermore, given that each student carer's situation is unique, and the process of applying for support can be time intensive and complex, universities need to offer guidance that is tailored to the individual (Kirton 2012; Morgan 2019).

### **Disclosure statement**

No potential competing interest was reported by the authors.

## References

- Akkan, B. 2019. "An egalitarian politics of care: young female carers and the intersectional inequalities of gender, class and age." *Feminist Theory* 21 (1): 47-64. doi.org/10.1177/1464700119850025
- Areguy, F., S. E. Mock., A. Breen., T. Van Rhijn., K. Wilson., and D. S. Lero. 2019. "Communal Orientation, Benefit-Finding, and Coping Among Young Carers." *Child and Youth Services* 40 (4): 363-382. doi: 10.1080/0145935X.2019.1614906.
- Arksey, H., and L. O'Malley. 2005. "Scoping Studies: Towards a Methodological Framework". *International Journal of Social Research Methodology* 8 (1): 19-32. doi: 10.1080/1364557032000119616.
- Baus, R., D. Dysart-Gale., and P. Haven. 2005. "Caregiving and Social support: A Twenty-First Century Challenge for College Students". *Communication Quarterly* 53 (2): 125-142. doi: 10.1080/01463370500090068.
- Boumans, N. P., and E. Dorant. 2018. "A Cross-Sectional Study on Experiences of Young Adult Carers Compared to Young Adult Noncarers: Parentification, Coping and Resilience". *Scandinavian Journal of Caring Sciences* 32 (4): 1409-1417. doi: 10.1111/scs.12586.
- Burford, J., and G. Hook. 2019. "Curating Care-Full Spaces: Doctoral Students Negotiating Study From Home". *Higher Education Research and Development* 38 (7): 1343-1355. doi: 10.1080/07294360.2019.1657805.
- Burns, F., N. L. Soh., R. Shackel., and G. Walter. 2019. "Financial and Caregivers' Stressors in Australian Law Students - A Qualitative Analysis". *Psychiatry, Psychology, and Law* 26 (3): 343-354. doi: 10.1080/13218719.2018.1485525.

- Carers Trust. 2015. "Supporting Students with Caring Responsibilities: Ideas and Practice for Universities to Help Student Carers Access and Succeed in Higher Education". *The Carers Trust*. Accessed 20 July 2020.  
<https://carers.org/downloads/resources-pdfs/supporting-students-with-caring-responsibilities-in-higher-education-england-version.pdf>
- Crandall, E. K., C. J. Ruggero., K. Bain., and J. Kilmer. 2014. "Adjustment Difficulties and Caregiving Burdens Faced by College Students with a Parent with Bipolar or Depressive Disorders". *Journal of College Student Psychotherapy* 28 (1): 47-58. doi: 10.1080/87568225.2014.854678.
- Day, C. 2019. "An Empirical Case Study of Young Adult Carers' Engagement and Success in Higher Education". *International Journal of Inclusive Education*. doi: 10.1080/13603116.2019.1624843.
- Deal, K. H. 1999. "The Effects of Student Caretaking History on Clinical Performance". *Smith College Studies in Social Work* 70 (1): 47-68. doi: 10.1080/00377319909517582.
- Department of Health. 2014. "Care and Support Statutory Guidance. Issued Under the Care Act 2014". *Department of Health*. Accessed 20 July 2020.  
[https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/315993/Care-Act-Guidance.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/315993/Care-Act-Guidance.pdf)
- Hussain, Z., V. Pickering., D. Percy., J. Crane., and J. Bogg. 2011. "An Analysis of the Experiences of Radiography and Radiotherapy Students who are Carers at one UK University". *Radiography* 17 (1): 49-54. doi: 10.1016/j.radi.2010.08.006.

- Kettell, L. 2018. "Young Adult Carers in Higher Education: The Motivations, Barriers and Challenges Involved—a UK Study". *Journal of Further and Higher Education* 44 (1): 100-112. doi: 10.1080/0309877X.2018.1515427.
- Kirton, J. A., K. Richardson., B. A. Jack., and A. M. Jinks. 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. doi: 10.1016/j.nedt.2012.01.010.
- Li, T., Higgins, J. P. T., Deeks, J. J. 2021. "Chapter 5: Collecting data." In *Cochrane Handbook for Systematic Reviews of Interventions version 6.2 (updated February 2021)*, edited by Higgins, J. P. T., Thomas, J., Chandler, J., Cumpston, M., Li, T., Page, M. J., Welch, V. A. [www.training.cochrane.org/handbook](http://www.training.cochrane.org/handbook).
- Liberati, A., D. G. Altman., J. Tetzlaff., C. Mulrow., P. C. Gøtzsche., J. P. A. Ioannidis., M. Clarke., P. J. Devereaux., J. Kleijnen., and D. Moher. 2009. "The PRISMA Statement for Reporting Systematic Reviews and Meta-Analyses of Studies That Evaluate Health Care Interventions: Explanation and Elaboration". *Journal of Clinical Epidemiology* 62 (10): e1–e34. doi: 10.1016/j.jclinepi.2009.06.006
- Lynch, K., and Lyons, M. 2009. Gender, Social Class and Lone Caring: The Intersectionality of Inequalities. In Lynch, K., Baker, J., Lyons, M., Cantillon, S., Walsh, J., Feeley, M., Hanlon, N., and O'Brien, M. (Eds.). *Affective Equality: Love, Care and Injustice* (pp.93-113) Palgrave Macmillan. doi: 10.1057/9780230245082\_6
- Morgan, F. 2019. "Student carers in the Faculty of Health, Education and Wellbeing: Supporting Their Educational Success". *University of Wolverhampton*. Accessed 20 July 2020. <https://www.wlv.ac.uk/research/the-doctoral-college/early-researcher-award-scheme-eras/eras-fellows-2016-17/dr-fiona-morgan/>

- National Union of Students [NUS]. 2015. "Learning With Care". *NUS*. Accessed 20 July 2020. <https://www.nusconnect.org.uk/resources/learning-with-care>
- Office for Students. 2018. Regulatory Advice 6. Good Practice Advice on the Preparation of Access and Participation Plans for 2019-20. *Office for Students*. Accessed 22 July 2020. [https://www.officeforstudents.org.uk/media/1105/ofs2018\\_06.pdf](https://www.officeforstudents.org.uk/media/1105/ofs2018_06.pdf)
- Soliz, M. K., and P. G. Merai. 2018. "A Millennial Caring for a Septuagenarian with Dementia". *Journal of the American Geriatrics Society* (66): 180.
- UCAS. (n.d.). "Students with Caring Responsibilities". *UCAS*. Accessed 26 July 2020. <https://www.ucas.com/undergraduate/applying-university/individual-needs/students-caring-responsibilities>
- Van der Werf, H. M., M. L. A. Luttik., A. L. Francke., P. F. Roodbol., & W. Paans. 2019. "Students Growing up with a Chronically ill Family Member: A Survey on Experienced Consequences, Background Characteristics, and Risk Factors". *BMC Public Health* 19 (1): 1-8. doi: 10.1186/s12889-019-7834-6.
- Wiseman, J., E. Davies., S. Duggal., L. Bowes., R. Moreton., S. Robinson., T. Nathwani., G. Birking., L. Thomas., and J. Roberts. 2017. "Understanding the Changing Gaps in Higher Education Participation in Different Regions of England. Research Report". *Department for Education*. Accessed 26 July 2020. [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/604393/Higher\\_education\\_understanding\\_participation\\_gaps.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/604393/Higher_education_understanding_participation_gaps.pdf)
- Yiengprugsawan, V., D. Harley., S. A. Seubsman., and A. C. Sleight. 2012. Physical and Mental Health Among Caregivers: Findings From a Cross-Sectional Study of

Open University Students in Thailand. *BMC Public Health* 12 (1): 1111. doi:  
10.1186/1471-2458-12-1111.

## Appendix 1

Article	Location	Type of Publication	Type of Data collected	Carer Responsibility	Key findings
Areguy et al. (2019)	Canada	Journal article	Quantitative	Various care for long-term health conditions, disability, and ageing needs.	Benefit-finding is important in psychological adaptation to becoming a young carer. Research has found social support to be instrumental in carer adjustment. Communal orientation was negatively associated with life and family satisfaction, this is in opposition to adult carer findings.
Baus et al. (2005)	USA	Journal article	Quantitative	Transportation, companionship and emotional support, chores and meals, phone calls for medical matters, personal care, and legal and financial matters.	Female caregivers provided more difficult forms of hands-on support compared to male caregivers. The findings suggested that data college caregivers are differently challenged by the life stage of the person for whom they provide care. It was also found that more supportive acts were undertaken if caring for a family member than of a friend.
Boumans and Dorant (2018)	Netherlands	Journal article	Quantitative	Various care including emotional support and household chores	Carers scored significantly higher than noncarers on three out of six of the parentification dimensions studied. No differences were found for problem-focused coping behaviour and resilience, however carers demonstrated higher scores for emotion-focused coping. The results highlighted that young carers require special attention due to undergoing extensive changes in

					their personal lives. This requires the activation of specialised support.
Burford and Hook (2019)	Australia	Journal article	Qualitative	Various un-defined care	The research concluded that the university does not bend to caring needs. There is limited information available to students as to how the university could be flexible around their needs. Students expressed a lack of ability to make decisions about the future as they do not know how long they will need to provide care for. The article concludes that productive home-working spaces are important to facilitate students' education.
Crandall et al. (2014)	USA	Journal article	Mixed methods	Various un-defined care for parents with bipolar or major depressive disorder	Students with a parent with bipolar or major depressive disorder found it significantly harder to adjust to college life, this difference persisted after controlling for students who also experienced these conditions. Students who provided care experienced caregiver burnout. The research concluded that universities need to not only be aware of those students who are caregivers, but also what type of support they are providing as this has an impact on the student.
Day (2019)	Australia	Journal article	Qualitative	Various un-defined care for relative with chronic condition or disability.	This research was guided by a theoretical model developed for this research titled the Young Adult Carers at University-Student Experience Framework (YACU-SEF). The research found that very few carers completed assignments on time citing 'time-poverty' as a reason for this. Carers

					reported that they needed a flexible approach to education as they study where and when they can and thus have trouble with prescriptive routines. Carers experienced significant challenges due to the competing demands of their student and carer roles, and persistent worrying was evident. Intervention to support this group is essential for their retention in higher education.
Deal (1999)	USA	Journal article	Mixed methods	Various un-defined care	Social work students were found to have a higher history of family abuse and trauma compared to others. All students who rated as having 'high' caring responsibilities scored low on competency. They also experienced difficulty moderating overextending for clients and caregiver burnout.
Kettell (2020)	UK	Journal article	Qualitative	Various un-defined care	Carers identified that they had split loyalties between being a good student and being a good carer. They struggled with courses which required placements as these were inflexible. They also had reduced attendance and a higher drop-out rate compared to the general student population. Students gave mixed reviews about support offered by their university. The research concluded that increased support was needed to retain this student population.
Kirton et al. (2012)	UK	Journal article	Mixed methods	Various care for physically disabled children, chronically ill	Most carers spend more than 6 hours per day providing care. This had a significant negative impact on their ability to study. In interviews,

				parents, and terminally ill grandparents	some carers reported that they did not want to make the university aware that they were carers as they did not want to receive special treatment. This was thought to relate to stigma surrounding the carer role. The research concluded that more information relating to the support available needs to be provided to students to support this group.
Morgan (2019)	UK	Report	Mixed methods	Various care for an adult or child with additional support needs.	Student carers have no specific demographics, therefore more procedures to identify this group is required. The duties performed by student carers can be complex, and these can vary from week to week, therefore there needs to be an understanding of these flexible needs at a university level. Universities need to provide academic, financial and pastoral support which is tailored to the individual.
NUS (2015)	UK	Report	Mixed methods	Various care for family members or friends without which they would be unable to function	Student carers face unique barriers and challenges in accessing and succeeding in education. There is a gender difference in the number of student carers in higher education, with an increased number of males than females. Support provided by the university was found to be integral to the carers ability to engage with their studies. More than half those surveyed stated that they had considered leaving their course, this was significantly higher than the general student population. The support received

					<p>from the university varied between carers, however it was concluded that there is a lack of coordinated support for this group.</p> <p>Student carers' choice of what and where to study was found to be linked to their caring role. It also impacted their ability to be involved in the wider aspects of university life, such as social activities. Finally, various financial challenges were experienced by student carers, including issues with Carer's Allowance. The research concluded that more data on the student population is needed, and this group need to be included in all widening participation work.</p>
Soliz and Merai (2018)	USA	Journal article	Qualitative	Various care for father with a range of disabilities	Case study of a student whose father had been admitted to psychiatric care for investigation. The research found that the students were displaying signs of caregiver burnout.
Van der Werf et al. (2019)	Netherlands	Journal article	Quantitative	Various care for chronically ill family members	The research found that strain and demand on the carer was greater when the family member they're caring for was mentally ill compared to physically. The research concluded that further research with student carers was required to identify the type of challenges that they face, and what support could be adopted to address this.

Yiengprugsawan et al. (2012)	Thailand	Journal article	Quantitative	Adult carers.	Both male and female caregivers reported experiencing lower back pain and poor psychological health. Female caregivers also experienced poor self-reported health and psychological distress. Research concluded that the needs of student carers need to be realised to provide support for the group.
------------------------------	----------	-----------------	--------------	---------------	---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------

Table 1. Search Strategy

Search Terms										
“carer”	OR	“caregiver”	OR	“unpaid care*”	OR	“family care*”	OR	“informal care*”		
AND										
“student”	OR	“university student”	OR	graduate”						
AND										
“higher education”	OR	“university”	OR	“college”	OR	“tertiary education”	OR	“education”	OR	“post-18 education”

Table 2. Characteristics of included articles

Characteristic		Number (n= 14)
Date of publication	2020	1
	2015-2019	8
	2010-2014	3
	2005-2009	1
	2000-2004	0
	<1999	1
Geographical location	Australia	2
	Canada	1
	Netherlands	2
	Thailand	1
	United Kingdom	4
	United States of America	4
Type of publication	Journal article	12
	Report	2
Type of data	Mixed methods	6
	Qualitative	4
	Quantitative	4

Figure 1. PRISMA flow diagram for article selection

