# **Exploring Young Carers' Experiences of Education**

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#### Abstract

#### Background

The term young carer is relatively new but a focus on young carers in policy and legislation within the United Kingdom has highlighted the need to identify and work with young carers. Though definitions of the term 'young carer' and the exact number of young carers across the country vary considerably by study, there is beginning to be an increase in young carer research. The current research sought to find out about the educational experiences of school age young carers, an area which has little information which focuses specifically on the United Kingdom and its education system.

#### Methods

Four participants were part of the current research, all of whom met the set criteria that they needed to be a young carer of school age. Two of the participants attended primary schools, with the other two attending secondary schools. Semi-structured interviews were carried out with each participant online. Findings were explored through the use of Interpretative Phenomenological Analysis.

#### Findings

Three superordinate themes were identified from the analysis: protective factors, adversity and the impact of caring and, lastly support through education.

#### Conclusions

All of the young carers spoke positively about school and they could identify what support they thought would help them the most in school as a young carer. The findings are discussed in relation to previous young carer research and psychological theories which

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underpin the current research. There are suggestions for future practice and implications for the work of Educational Psychologists, particularly in relation to the work Educational Psychologists carry out in conjunction with young carers, schools and families.

Keywords: Young carers, educational psychology, educational experiences



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#### Signature of student

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### **List of Abbreviations**

ACE: Adverse Childhood Experience **BPS:** British Psychological Society CASP: Critical Appraisal Skills Programme **CYP:** Children and Young People DfE: Department for Education DoH: Department of Health EHCP: Education, Health and Care Plan **EP:** Educational Psychologist **EPS:** Educational Psychology Service HCPC: Health and Care Professions Council **IPA:** Interpretative Phenomenological Analysis LA: Local Authority **NEET:** Not in Education, Employment or Training **PPCT:** Process-Person-Context-Time model **RDMP:** Research Data Management Plan **RQ:** Research Question **SDT:** Self-Determination Theory SEND CoP: Special Educational Needs and Disability Code of Practice **SSI:** Semi-Structured Interview **TEP:** Trainee Educational Psychologist **UEL:** University of East London **UK:** United Kingdom UNCRC: United Nations Convention on the Rights of the Child **YC:** Young Carer

#### **Chapter One - Introduction**

#### **1.1 Chapter Overview**

This first chapter will consider what a young carer (YC) is by looking at the differing definitions which have been used by YC organisations and in government policies. The definition for this particular research, which will be used throughout the study will be identified. Information about the prevalence of YCs in the UK will be discussed as will prominent reasons for the discrepancies in identified data across studies and possible reasons for hidden carers. Policy and legislation from the UK which is relevant to the study will also be discussed. Proceeding from this will be an initial exploration of the literature on YCs and listening to the voices of YCs. The researcher will recount their position and the influence of professional experiences on the current research and consideration will be given to the aims and rationale of the current research, including reasons for the need for further exploration of YCs' experiences of education and finally to the role of the Educational Psychologist (EP) when contributing to the work and support of YCs.

#### **1.2 Context for Research**

#### **1.2.1** Definitions and Prevalence of YCs

The term YC is a relatively new one, though with a number of differing definitions. In 1993 Aldridge and Becker were the first to identify YC's in research. Since then, there have been developments in research and legislation within education, health and social care. Aldridge (2008) makes a clear distinction between a YC and a child who completes domestic chores which are in line with a child's development and level of maturity. A YC, according to Aldridge (2008), is a child or young person who actively undertakes disproportionate caring responsibilities on a long-term basis for a parent with a long-term illness or disability. In contrast, the Carer's Trust (2013) defines a YC as a person under the age of 18 who provides

care for another person and does not specify that it has to be the YC's parent. This definition differs further by stating that the recipient of care may have an illness, a disability, an addiction or have mental health needs. As there are multiple YC definitions, within YC research it should be clear which definition the current research will follow throughout. The current research will adhere to the following definition from the Children and Families Act (2014), 'a person under 18 who provides or intends to provide care for another person (of any age, except where that care is provided for payment, pursuant to contract or as voluntary work).' This definition will be adhered to throughout the current research which will enable a range of YCs to be included in the research, whether they care for a parent, grandparent, sibling or any other person in their family or community and includes an array of needs, including sensory impairments and substance misuse (Children's Society, 2013).

Along with differing definitions across YC research in the UK, the reported numbers of YCs also appears to be at odds, with differences of thousands. There were at least 166,000 YCs in England according to the 2011 Census (Office for National Statistics, 2013) was published and cited that there were at least 166,000 YCs in England. This number is in stark contrast to a study carried out by the BBC (Howard, 2010) which claimed that there were nearer to 700,000 YCs in the UK. In the BBC study school children were surveyed with the assumption that children and young people (CYP) did not differentiate between caring for and caring about (Aldridge, 2018). It can be seen that the number of YCs varies considerably, with many seemingly estimates as opposed to an exact number. Leu and Becker (2019) report that data depend on a study's methodology as to who is included and counted. As suggested by Joseph et al. (2020) figures in industrialised societies range from 2% to 8% of all CYP.

In addition to varying methodologies and definitions there is the issue of hidden carers (Smyth et al., 2011). Although there is no definitive evidence of a large number of hidden carers there is also no evidence to the contrary, with Aldridge (2018) reporting that

YCs can be difficult to identify and there can be a number of reasons for YCs to go unidentified based around fear and stigma. Concerns around safeguarding and family separation is seen to be a concern for some YCs and their families. These concerns are not fully unfounded with data from 2015 showing that 2000 YCs in England were removed from their family home due to having a parent with an illness or disability (Zayed & Harker, 2015). Families may actively resist the term YC due to the possible stigma they feel it will bring (Smyth et al., 2011). YCs themselves struggle to self-identify for fear of the impact it will have on their relationships with their peers and concerns that they will be viewed differently (James, 2017).

#### 1.2.2 UK Policy & Legislation in Relation to Young Carers

Within the UK a number of policies and legislation, including the Care Act (2014) and Children and Families Act (2014) highlight young carers (YCs) as being a potentially vulnerable group in relation to the caring role they carry out and its possible impact on their well-being, their lives at home and in the wider community. An emphasis is placed on professionals identifying YCs, as detailed by the Care Act (2014). Prior to this families and CYP needed to identify themselves as either being or having a YC, which could prove difficult as children are often seen as a care recipient and not someone who provides care to others (Becker, 2007). The term 'professionals' includes all of those who work with a child and their family, through social care, health or education. The Children and Families Act (2014) clearly focuses on local authorities as having a duty and responsibility to assess the needs of a YC through a YC's Needs Assessment. This assessment seeks to find out whether it is appropriate for a YC continue to provide care, in light of the needs and wishes of the YC. However, the legislation surrounding the YC's Needs Assessment has left many professionals feeling uncertain about the identification process with many not seeing it as part of their remit or role (Aldridge, 2018). As stated in the Children's Commissioner for England's report

(2016) 94 % of children who had been deemed to require support had not received a YC assessment.

With the responsibility being placed on all professionals (Care Act, 2014) there needs to be some regard for the support provided by schools and education, which typically is where CYP spend much of their time, outside of the family home. As a result of assessments completed by professionals, YCs and their families should then have access to educational, social care and health services, which can support the needs of YCs (Department for Education (DfE), 2016). However, schools may not be aware of the caring responsibilities being carried out by YCs as a significant number do not disclose their role to school staff (DfE, 2016). This can then result in a small minority of YCs not receiving help from social care and other professionals and not being assessed (Becker & Dearden, 2004).

Research carried out by The Children's Society (2013 & 2016) reports that caring responsibilities can affect the amount of time a YC is in school. The research identified, that as many as 1 in 20 YCs were unable to attend school consistently due to their caring role. For those YCs whose role has been identified, support in schools varies considerably. The Children's Society (2013 & 2016) reports go on to state that specific school support, such as flexible attendance and pastoral support has been found to reinforce educational and emotional development and reduces the impact of caring responsibilities. Support in schools can be inconsistent, with a limited understanding of the needs of YCs and a lack of information sharing amongst staff cited as the main reasons (DfE, 2016). The Ofsted Inspection Handbook (2015) described YCs as a vulnerable group, drawing education providers' attention to the need to recognise and support YCs consistently.

Therefore, the information available seems to suggest there is a clear need for services to work together in order for YCs to thrive and succeed in school. In 2014 The Department of

Health (DoH) and DfE communicated the need for collaborative working. School nurses are encouraged to strengthen the health and wellbeing of YCs and to maintain open communication with education providers by developing partnerships with school staff (DoH, 2014). This is reiterated in The Carers Action Plan (2018), in which it states that the DfE promotes the identification of YCs by professionals in health, education and social care and the need for multi-agency working.

#### **1.3 Overview of Young Carer Literature**

In order to find out about YCs and their educational experiences a general search of the literature was carried out. This enabled the researcher to gain an overview of the impact education can have on YCs, primarily from the viewpoint of YCs but also of professionals who work closely with them. It is apparent from the literature that there are many difficulties YCs face in a school environment, but many YCs are still able to identify what they gain from attending school and are even able to provide suggestions of the support they think would be of most benefit to them. It would seem that the majority of the literature concentrates on the difficulties experienced by YCs within the school environment and education system. The current research sought to explore the views of YCs and their perceptions of education. The views expressed by the YCs allowed them the capacity to draw on both perceived difficulties and positive experiences they have encountered.

#### 1.3.1 YCs' Experiences of School

Research in the United Kingdom (UK) by Cree (2003) indicates that those YCs who have been in a caring role for several years are much more likely to experience educational difficulties. It is known that there is a wide variation in the YC role with YC research showing that many YCs struggle to balance caregiving and school (Lakman et al., 2017). Those YCs who have a significant amount of caregiving are found to have lower school

attendance (Moore et al., 2009) and are less likely and able to complete homework (Thomas et al., 2003). As a result of many hours of caregiving YCs are typically tired and have increased levels of worry which in turn impacts on their ability to concentrate in class (Szafran et al., 2016). Adults who had been a YC when they were younger reflected on their time as a YC and reported that they had no recollection of receiving any formal support in school and felt that they were being treated as if they were a problem. Many of the participants explained that they had wanted to share their worries with teachers but felt unable to (Bjorgvinsdottir & Halldorsdottir, 2014).

Research by Ingul et al. (2019) focused on school refusal or avoidance and possible risk factors. In the study risk factors were separated into three categories encompassing the individual child, the school setting and the family situation. Within these three categories are three identified risk factors which bear some correlation to YC research. These factors include worrying about what is happening with family members at home, bullying and feeling isolated and having a parent with mental health difficulties. As stated earlier The Children's Society's research (2013 & 2016) has already identified that school attendance can be affected by having a caring role. Although research by Ingul et al. (2019) is not primarily about YCs there appears to be a link between school avoidance and identified risk factors. This further emphasises the need for professionals to work together in supporting a YC and their family to ensure that their schooling is not further impacted upon (DoH, 2014).

Within the reviewed research there is also a wealth of YC research which describes the benefits of being at school and the potential support that it can offer. Gough and Gulliford (2020) state that school can be a protective factor for any child facing adversity. In order for it to be an effective factor schools need to have staff who are well-informed and provide relevant support to YCs. Having access to positive experiences, opportunities to spend time with peers and being able to develop their own personal identity all contribute to gaining a

sense of social cohesion (Ungar et al., 2019). School can be seen as a distraction to YCs who could experience challenges in their home life and for some it is reported to be a safe haven (Moore et al. 2009). Following on from this Choudhury and Williams' (2020) research found that giving YCs time to share their experiences with other YCs helped them to feel less isolated in school. Attending school and completing homework may feel like additional tasks for YCs but, for many, education is considered to be important and some YCs remain positive about the benefits of being at school (Thomas et al. 2003).

What is clear from the reviewed research is that many YCs' education is affected in a negative way and it would be easy to over-generalise believing that these were the only educational outcomes for all YCs. However, caution should be taken as the breadth of the YC role is vast and diverse. Though there will be similarities for many YCs there will also be many differences and these unique experiences can only be heard through listening to them.

#### 1.3.2 YCs and Mental health

All of these factors can lead to other challenges for YCs including participating in social interactions with peers (Earley et al., 2007) and having mental health difficulties, alongside low self-esteem (Aldridge, 2006). Many YCs claim to have been bullied in school and to have experienced feelings of isolation (Sieh et al., 2013). As reported by the Children's Commissioner for England's (2016), a quarter of YCs have needs (mental health or learning) of their own which adds to their difficulties in accessing education (Choudhury & Williams, 2020). A YC who has additional needs but does not have an Education, Health and Care Plan (EHCP) is at a much greater risk of lower educational attainment, psychological difficulties and overall poorer life outcomes (Choudhury & Williams, 2020).

It is unclear why some YCs seem to struggle with their mental health and others do not show any outward signs of difficulties (Becker & Becker, 2008). Whilst some YCs report

that their caring contributes to their emotional well-being and makes them feel closer to their families, others are found to struggle with their role (Moore & McArthur, 2007). Research has found that those YCs who support family members with mental health or substance misuse difficulties are at most risk of them experiencing their own difficulties (Thomas et al., 2003). The need to provide high levels of emotional support can impact on their mental health and in turn on their educational attainment. (Roberts et al., 2008). Spratt et al. (2018) state that a child's resilience is based on having a secure base and predictable routines both of which may not be in place if there are mental health and substance misuse difficulties in the immediate family. However, positive relationships outside of the family home have been evidenced to make a significant difference to the lives of YCs (Spratt et al., 2018). This could further suggest the importance of positive relationships with staff in schools.

#### **1.3.3 Future Prospects for YCs**

As a result of receiving limited or no support in school, some YC research shows that YCs not only experience difficulties in school but then also have limited future prospects. If a YC is unable to fully access education they may struggle to acquire qualifications to enable them to move into higher education or employment (Banks et al., 2002). The Children's Society (2013) states that YCs who are aged between the ages of 16 and 19 years are more likely than the national average to not be in employment or education (NEET – Not in Education, Employment or Training). By having limited support and low attainment levels it should not be surprising that many YCs utilise the skills that they already have and tend to move into care work as adults (Bjorgvinsdottir & Halldorsdottir, 2014).

#### **1.3.4 Professionals Around YCs**

Narratives shared by YC project workers highlight that they are willing to share information with schools and other professionals but feel dismissed and that their

contribution is not valid. They also report that it is rare for them to be invited to multi-agency meetings (Pakenham et al., 2007). In relation to this, research by Choudhury & Williams (2020) found that project workers reported that the interactions between themselves and schools were invaluable and noted that a key worker system in school was essential to developing relationships with families and for supporting YCs psychologically and emotionally. That key person may then have the ability to recognise the needs of families and YCs and to help reduce the stigma of disability within schools.

This information has clearly been gained from adults and professionals, but YCs in the UK and Europe state that if there is support available to them, that they would like to access it (Warren, 2007). Also, many YCs say that they do not know where to go and who to go to for support (Ali et al.., 2013). Therefore, support for YCs needs to be clearly identified with professionals being able to signpost them correctly. Whilst services continue to work separately, the greater the divide between services becomes and the greater the difficulty YCs experience in finding and receiving support.

Some of the views of the professionals working with YCs can be countered by the YCs themselves who are able to pinpoint what they know works and what they think schools should be doing. YCs voice in several studies that being part of a support group is helpful and being able to share their experiences with others (Choudhury & Williams, 2020). Groups ensured that YCs did not feel alone, helped them to develop friendships with other YCs and to feel more positive about their education (Gough & Gulliford, 2020). Being identified as a YC in school was also seen to be of benefit at times of transition, such as from primary to secondary school (Choudhury & Williams, 2020). For those YCs who want school staff to be aware of their care-giving role, they expressed that they would like school staff to encourage them through the use of flexible school policies in relation to homework. Suggestions made

by the YCs included being mentored, having access to more information and the option for extensions when needed (Warren, 2007).

#### 1.4 Listening to the Voices of YCs

Since the publication of the United Nations Convention on the Rights of the Child (UNCRC, 1989) all professionals across education, health and social care who work with children have been made aware of the importance of seeking the views of CYP. Not only do the views need to be acquired but they must also be an influence within decision making processes which directly affect that child or young person. Whilst seeking the views of CYP they should not feel as though adults are putting them under any pressure or are being restricted or dissuaded from sharing their thoughts and beliefs. In order for CYP to express their views they need to be provided with information which is relevant to them and their situation and in addition CYP need to know why their views are being requested (Pearlman and Michaels, 2019). The SEND Code of Practice (SEND CoP, 2015) and Children and Families Act (2014) highlight the need for CYP to participate in making decisions about their current situation and the future. Morris (2003) reports that CYP stress how important it is for them to feel listened to by the adults and professionals around them. Listening to CYP is seen as an important way of identifying interventions, as well as being seen as an intervention on its own (Ingram, 2013). Alongside the literature, which puts a spotlight on the importance of speaking to children and of respecting their views there have been positive movements towards listening to and including CYP. One example of this would be Ofsted, who speak to CYP during school inspections and write to them to let them know the outcomes (Aston & Lambert, 2010). Some of the YC literature has already observed the benefits of speaking to YCs, who have been able to articulate the difficulties they have encountered and the benefits of being respected and listened to.

If a YC is to feel comfortable sharing their views they must believe that what they say is going to contribute to change. In order for that to happen adults around them need to be both encouraging and enabling (Aston & Lambert, 2010). The beliefs and practices of professionals may be challenged when the stance is taken that CYP are capable of decision-making. Professionals can make decisions based on good intentions but it does not mean that they have a sufficient insight into the lives of these individual YCs or that the decisions being made are in the best interests of CYP. In western culture it is a powerful assumption that adults know best (Lansdown et al., 2014) and it can be difficult to challenge and change working practices. Simply asking CYP for their views can be seen as part of a tokenistic process. It is key that local authorities and schools look beyond simply speaking to children and address and acknowledge the issues such as culture, attitudes, environment and systems within the school and community (Aston & Lambert, 2010).

#### **1.5 Researcher's Position**

It is important that the researcher has an understanding of why they have chosen to focus on YCs by reflecting on the impact of their own professional and personal experiences. Prior to becoming a Trainee Educational Psychologist (TEP), the researcher worked as a teacher for twelve years both in schools and for a local authority (LA). It was during the researcher's time as a Pre-school Specialist Teacher that they began to think more about family members around a child. In the role the researcher worked with pre-school aged children with complex needs which entailed working closely with their families and health and education professionals. During home visits the researcher would try to include all family members in playing with and supporting the child with needs. In some of the families it became apparent that some children were dedicated to supporting their sibling but this was not often recognised in the family.

One particular piece of work with a family was especially meaningful and influenced the researcher's thinking. The researcher worked with a family who had two children who were twins, one with additional needs and one without. The children were due to start nursery for the first time and the team around the child meetings were held to support transition. The key difference for this family were concerns they felt for the child without needs and how they would transition. The meetings and focus then turned to the sibling who did not have needs to think about how best to ensure they had a smooth and successful transition. When the child started nursery, some difficulties were identified. The child spent much of their time making sure their sibling was okay to the detriment of them making friends and learning through play. It was clear that the child had lost confidence and the family reported that the child had become withdrawn at home. This was the first time that the researcher had really thought about the impact of caring on CYP. This then spured the researcher on to find out more about caring which led to an interest in YCs.

#### **1.6 Research Rationale and Aims**

The current research has the primary aim of finding out what are YCs' lived experiences of education, to gain an insight into a YC's world in the education system and to find out what those experiences mean to them. Whilst the amount of literature on YCs is increasing, there still continues to be a limited focus on YCs' educational experiences and the findings to date have detailed some of the negativity that YCs feel towards school and relationships with staff. The current research examined what support YCs received through school to help them academically and emotionally. As the current research takes a qualitative approach it was hoped that the data gathered would provide detailed accounts of individual YCs' experiences in schools which could then contribute to and inform future practice in education, contributing to school policy and to the work of EPs, teachers and other educational professionals.

#### 1.7 The Role of the Educational Psychologist

Educational Psychologists are perfectly situated to aid the identification and support systems for YCs in school through working collaboratively with YCs and educational staff in schools. An EP can foster an understanding of YCs through direct work with YCs and school staff in order to consider ways of working and sensitively supporting YCs (Beaver, 2011). Eliciting the views and experiences of CYP is a prominent factor within the EP role and as such EPs are adept at finding new ways to explore and listen to the voices of CYP. Harding and Atkinson (2009) emphasise the need for CYP to be given the opportunity to share their thoughts on matters which pertain to them. As stated by Harding and Atkinson (2009) CYP who are included in discussions and decision-making processes are far more likely to share information around their skills and abilities and their ideas around interventions. Including CYP's views enhances the likelihood for successful outcomes.

The traditional model of the role of the EP, as discussed by Curran et al. (2003) focuses on the three levels at which EPs are most likely to operate: the individual, organisation and system. However, it is the EP's distinctive perspective that can make them instrumental in supporting YCs and schools, through adopting a psychological perspective, using evidence-based strategies for change and the ability to identify potential opportunities for effective change (Cameron, 2006). All EPs are trained in supporting the emotional well-being of CYP and can provide appropriate interventions directly to YCs and indirectly through school staff. EPs have a good understanding of the education system and are able to promote multi-agency working to facilitate change when focusing on and supporting YCs.

#### **1.8** Conclusion

This first chapter has considered different definitions of YCs and has identified the definition which will be used throughout the current research. Relevant policy and legislation from the UK have been explored and the researcher has reflected on their own professional experiences to understand the influences on researching YCs and their experiences of education. The aims and rationale of this research have been discussed and the role of the EP in supporting YCs within education. The following chapter will detail the systematic literature review.

#### **Chapter Two – Literature Review**

#### 2.1 Chapter Overview

This chapter begins by focusing on the systematic literature review which prioritises those studies which incorporate the views of YCs and include findings pertaining to education. The two searches will be described, with further information relating to inclusion and exclusion criteria and how the core studies were reviewed. The shared themes from the core studies will be discussed and critiqued before looking at the different systemic theoretical frameworks which underpin the current research, namely Bateson's Systems Theory (1972), Bronfenbrenner's Bioecological Model (2005) and Deci and Ryan's Self-Determination theory (1985).

#### 2.2 Systematic Literature Review

The ensuing section chronicles the systematic literature review which was carried out to find relevant YC studies, which will include the search terms and keywords, databases searched and the application of specific inclusion criteria to ensure that the most suitable literature around YCs and education were located. The current research follows a qualitative design with the aim to explore YCs' lived experiences of education. It was thought appropriate to implement a search strategy which presents coverage of previous research, which is both systematic and comprehensive. As part of the systematic approach inclusion and exclusion criteria were applied and determined which studies were the most relevant to the current research (Appendix A).

#### 2.2.1 Initial Search

The first search was initiated in June 2020. The literature search was performed through the electronic database, EBSCO, using the advanced search system facility. The search was carried out with key words and terms split under 'title', 'abstract' and 'full text'.

The combined terms of 'young carer or young caregivers or hidden young carers', was included under 'title'. The next set of key words under 'abstract' were 'experience or perspective or view or voice'. Lastly, under 'full text' the key words combined were 'education or school'. Studies were assessed against the inclusion/exclusion criteria which can be found in Appendix A. Studies were discounted if they were not peer reviewed and were published outside of the years 2010-2020. They were also discounted if they were not written in English, In addition, a further exclusion criterion ensured that only studies related to children (aged 6-12 years) and adolescents (13-17 years) were included. A hand search was completed of the references of the found studies. In total there were 20 results. In the next step all of the studies' abstracts were read to find out their relevance to the current research and from this a further 8 studies were excluded. The final stage focused on the whole study and its links to YCs and education, with a further 7 studies being excluded as a result. The process can be seen in the PRISMA flow chart (Appendix B). A total of 5 core studies were considered appropriate. Information about each study can be found in Appendix D.

#### 2.2.2 Second Search

The second search was carried out in March 2021 and was performed in the same way, using the same criteria, the same search terms and databases as search one. EBSCO, the electronic database was again utilised for the search. The search yielded a total of 21 studies, resulting in 20 studies after duplications. No additional records were found through hand searching through the 20 studies. The exclusion/inclusion criteria detailed in Appendix A was used to filter studies which did not meet the criteria. Each abstract from each study was read to ascertain its relevance to the current study and subsequently 5 further studies were excluded. A further 10 studies were excluded after reading the full articles as there appeared to be no specific detail around YCs and education. The process for the second search can be

found in the PRISMA flow chart (Appendix C). By the end of the process a total of 5 studies were deemed to be appropriate and matched the five core studies which were found during the first search. Information pertaining to these studies can be found in Appendix D.

All of the five core studies identified in the first and second search were reviewed using the Critical Appraisal Skills Programme Qualitative Checklist (CASP, 2018). The checklist was adopted to analyse and critique each study. The analysis of the five studies using the checklist can be found in Appendix E.

#### 2.2.3 Additional Search

To ensure that all relevant studies had been found a further search was completed through the University of East London's repository. The search term was 'young carers' and from this search a thesis, by the title, 'Young Carers' Experiences of Caring in an Inner London Borough – an Interpretative Phenomenological Analysis (IPA), written by Wadey (2015) was found. The study was screened in the same way as the other studies had been throughout the systematic literature review. The title was considered to be relevant to the current study and the abstract was then read. The information contained in the abstract included areas relevant to the inclusion criteria (Appendix A), such as voice of the YCs and it was age appropriate (participants were aged 11-18 years old). The abstract did not reference any link to the study and educational experiences and was therefore excluded. The thesis' focus was on the experiences of young carers. However, it should be noted that within the main body of the thesis reference is made to educational experiences. Within the findings and discussion chapters Wadey (2015) provides quotes from participants who described school and teachers as being a form of support. The discussion chapter details the impact the caring role can have on school work and that caring can prepare CYP with preparation for adulthood. Although most of the participants seem to have received little support or

acknowledgement from their schools, one participant was positive about their own school experiences.

The study, 'The Voices of Young Carers in Policy and Practice', by Phelps (2017) was identified when carrying out research around policy and legislation for the first chapter of this study. From the title the researcher thought that it would have been appropriate to include this particular study. Upon closer reading of the abstract, it became clear that it did not meet the inclusion criteria (Appendix A). The study did not focus on listening to the voices of young carers or highlight any links to educational experiences of YCs. The study by Phelps (2017) looked at and considered different participatory practice which enabled YCs to contribute to policy and practice. Forums and programmes for YCs are detailed and the study looked at ways to improve YC engagement.

Finally, the study, 'Happiness and Well-Being of Young Carers: Extent, Nature and Correlates of Caring Among 10 and 11 Year Old School Children', by Lloyd (2013) was found through hand searching. The study was referenced by Joseph, et al. (2020) and the researcher, having read the title and abstract, felt that it was relevant to the current study. The study by Lloyd was carried out with 899 primary school across Northern Ireland in 2011. Questionnaires were distributed, with a total of 4,192 children aged 10-11 years of age completing it. The study aimed to find out about the possible connections between caring and educational outcomes, well-being, health and school experiences of YCs. Results indicated that many YCs were unhappy in school and were likely to achieve poor educational outcomes. Limitations of the study are identified by Lloyd, who discusses the questions used to identify possible YCs. It is highlighted that those questions do not specifically identify a YC as the description of tasks being completed at home could also be completed by all children at this age. The participants were also asked if they helped someone that they lived with. Again, this does not clearly differentiate YCs from other children of this age. Due to

this it is not clear how many of the actual participants were YCs and therefore the author of the current study questions the validity and reliability of Lloyd's findings and chose to exclude this study.

#### 2.3 Emerging Themes from the Studies

After reading the five core studies several times it seemed that there were dominant themes which appeared across the studies. A synthesis matrix (Appendix F) was created to ascertain which themes could be identified and the frequency with which they appeared across the core studies. One of the reasons for doing this was to find out if there were consistent findings across the studies. The aim of this section is to synthesise the reviewed research articles, looking at the five core studies. The synthesis examined the strengths of the available evidence and established any gaps, which may require further research. Findings from the studies can be grouped together under four themes, education and the future, relationships and support, identity and impact of caring. The studies' methodologies, data collection and analysis, findings and discussions were all assessed, resulting in the identification of the four themes.

#### 2.3.1 Education and the Future

The studies show that YCs are thinking about their education and the future. An emphasis is placed on doing well at school and having future academic aspirations. Research carried out by Lakman et al. (2017) sought to explore the educational experiences of YCs in Canada. A total of 145 YCs aged between 8 and 18 years old were included in a quantitative study. Surveys were given to participants to complete. Findings of the research showed the importance of education to YCs. Lakman et al. (2017) found that 87% of participants had a set goal of accessing post-secondary education. A difference was found between males and females, with females placing more importance on getting good grades. The study noted a correlation between the amount of time caring and how much time in school was missed.

This was then seen to impact on the possibility of choices about future education. When this was explored further it was revealed that for the majority of the participants, they had not missed any days in school. The participants included in the study were believed to be academically strong, with most of them reporting limited caregiving each day. The study concluded by stating that most YCs want to be successful in school and aspire to continue their education.

Education is once again a priority for YCs as reported by Hamilton and Adamson (2013). The study interviewed twenty-three YCs and young adult carers in Australia. Participants were said to have ambitions to go to university and that their caring role did not affect this. Having caring responsibilities did play a part in the location of the university, with some preferring to consider universities which were nearer to home. The majority of participants wanted to go to university and did not see that their caring responsibilities would hinder them from doing so. Inevitably there were differences between YCs' responses and those of the young adult carers. Several of the young adult carers had adjusted possible education and career aspirations to ensure that they could continue their caring role. Prioritising education will depend on past experiences and current opportunities which all shape a YC's thoughts about future educational goals. Although Hamilton and Adamson's (2013) study does not directly seek to find out how YCs have experienced education it does show that the YCs from their study value education and wish to develop further through higher education.

#### 2.3.2 Relationships and Support

Relationships are found to be key in many of the studies, showing the benefits of friendships, YCs' groups and trust in school staff. Semi-structured interviews (SSI) were completed with twenty YCs aged between 12 and 23 years old by Barry in the UK (2011). In

this particular study friendships and relationships were found to be of high importance. The study reports that YCs have to work hard to maintain friendships whilst also caring for their families. Participants stated that going to school was the ideal time to see friends as they were unable to meet with them in the evenings or visit friends at home. YCs feel a sense of normality with their friends, free from their responsibilities of caring for their family. Friendships with other YCs helped participants to openly share experiences without fear of ridicule or some form of disapproval.

The study by Barry (2011) additionally looks at the relationships YCs have with school staff. In a divide between male and female participants, females were more likely to feel negatively about school and school staff, namely due to the perceived attitudes of staff. Many YCs in this study were cautious about confiding in school staff as they felt a lack of trust or that the teacher would not understand their situation. For those school staff who knew about a YC's situation there was still a sense of uneasiness as YCs felt that they were not being supported. Contrary to this, some of the participants said that specific teachers were understanding of their situation and received welcomed support. The study finds that the most trusted adults are those who are project workers in YC groups. These adults are seen differently by YCs as they are linked to respite and feelings of release. YCs reported mixed needs with some needing the time to speak to project workers about their caring role, whilst others appreciated having typical conversations in order to forget their role. Barry states that in either case YC project workers are able to meet the needs of both sets of carers. Project workers are discussed as having a greater insight into the role of a YC and know how to effectively support them.

Kavanaugh's study in 2014 in the United States concentrates on the views of forty YCs aged between 12 and 20 years old, who are carers for parents with Huntington's disease. This study partially seeks to understand how the relationship between carer and their cared

for parent correlates with difficulties in school. The results confirmed that YCs who experienced more difficulties in their relationship with their cared for parent were much more likely to face difficulties in school. YCs in this study state that there is a distinct lack of support in school, with few people for them to speak to. In support of Kavanaugh's findings, Lakman et al. (2017) report that YCs do not feel that teachers will provide support and therefore do not see the need in revealing their caring role to them.

#### 2.3.3 Identity

The literature finds that often YCs do not want schools to know about their caring role and try to keep it a secret from school staff. The literature finds several reasons for this. Doutre et al. (2013) analysed the responses of six YCs aged between 11 and 13 years old. Each participant was interviewed about the care they provided to a parent with mental health difficulties. Identity is a strong theme throughout this study and participants were found to experience tensions between their identity as a caregiver and their own individual identity development. Doutre et al. (2013) found that in some instances, YCs seek to find another identity away from caregiving. They did this by seeking affirmation and approval in other areas of their life with people separate to their own families. Though there are apparent tensions between a carer and non-carer identity participants reflected that caring was something that they needed to do and were happy to continue being a YC.

The theme of identity continues in the literature with participants in Barry's (2011) study stating that they did not identify as a YC in school because they feared unwanted preferred treatment from staff or alternatively, they worried that they would face negative reactions which could possibly lead to complications for themselves and their families. Participants explain that they want to be treated in the same way as all of the other students in school. This was also found to be the case in the study by Lakman et al. (2017). Participants choose

to keep their caring role a secret as they worry there will be negative consequences and feared judgement from others. Resilience also plays a part in the identity of a YC. The study, by Lakman et al. (2017), states that YCs see themselves as self-sufficient and not in need of the support of adults around them and therefore do not see the need in identifying as a YC in school. To some extent professionals are viewed by YCs with suspicion and are seen as more of a threat than support. Barry (2011) raises the issue of how differently YCs are treated by people. At home a YC holds some sense of power and is sometimes called 'the parental child'. By contrast in school YCs are often powerless and are seen only as a child. It may prove tricky for a YC to reconcile the two identities (Barry, 2011).

## 2.3.4 Impact of Caring

Research by Hamilton and Adamson (2013) show there to be discrepancies between the impact of caring on YCs and young adult carers. The YCs who were questioned did not see any detrimental effect of caring on their health or well-being. In contrast the young adult caregivers spoke about feelings of anxiety, stress and depression, with some struggling to sleep. They also discussed how physical their role was and that they frequently became ill. The results of Kavanaugh's study (2014) found that there was no correlation between poor emotional well-being and being a YC. The study hypothesised that the participants may have a higher level of social support which will have a positive effect on a YC's well-being. The study proposes that the participants may be more resilient due to their YC's role.

The impact of caring links with the earlier education theme. Kavanaugh's (2014) findings discussed how time-consuming caregiving can be and how this connects to difficulties in school. The practicalities of cooking for the family, shopping and cleaning, amongst a wealth of tasks, will take time away from completing homework, getting to school on time and attending school regularly. This, according to Barry's study (2011) can create a

barrier to academic and future success. Doutre et al. (2013) highlight that not all caring experiences are negative and depend on several factors including the illness or disability of the person being cared for, the age and gender of the YC and the value of caring in the child's social context.

## 2.4 Summary of the Literature

The review of the literature proves that there are some consistent findings across the five studies. Not all of the studies set out to explore children's experiences of education but were still able to determine themes which were relevant to YCs and school. Findings pointed to YCs feeling optimistic about their current education and their future goals. Hamilton and Adamson (2013) stressed that the participants of their study were all achieving well in school, but do not elaborate as to why those particular YCs are excelling. Looking into the reasons for the YCs' success in education could be further explored to see what, if any, effective strategies or interventions are in place. In Hamilton and Adamson's (2013) study the aspirations of children and young adults are compared. It could be argued that it is difficult to compare the two age groups who are clearly at different stages in their lives. The amount of time spent caring does affect access to school and learning. Lakman et al. (2017) reported that the study's participants did minimal daily caregiving tasks and so did not find it challenging to continue with their schooling.

Maintaining relationships is important to YCs and research shows that friends and YC project workers are those who are trusted the most. School staff are highlighted in a negative way (Barry, 2011) with few participants in the studies stating they trusted teachers and felt at ease sharing information with them. It may not be a surprise to learn that YCs trusted project workers the most. The focus for a project worker is solely on supporting a YC. They will have received training and have more of an insight into the world of a YC. In comparison teachers have the responsibility of supporting larger numbers of children, many of whom may

be regarded as vulnerable and are tasked with ensuring that they all progress. Banks et al. (2002) noted that changes were being made to the teacher training curriculum, which would include how to support vulnerable children.

All of the included studies prioritised listening to YCs to better understand their lives. The sample sizes were comparably small and it could be said that it is then difficult to generalise, but in four out of five studies a qualitative methodology was utilised. This provides much richer, more detailed information from which more stable comparisons can be made. The two UK studies, though relevant to the UK education system, are written before the introduction of key legislation including the Children and Families Act (2014), The Care Act (2014) and SEND CoP (2014). Three of the studies are written about education systems and YC policies outside of the UK. There may be some comparable elements of the education systems but ultimately are different to the one the current research is focusing on.

The researcher is not familiar with the education systems of the United States of America (US), Australia or Canada and it is important to consider the potential differences in pastoral support and understanding, as well as acknowledgement of YCs. There will be differences and variations which are country specific but, in societies which adopt a western culture, despite differences in their welfare systems, the needs of YCs appear to be comparatively uniform (Leu & Becker, 2017). Research about YCs from countries such as Canada and Australia show the common experiences and characteristics shared by YCs, regardless of where they live (Evans & Becker, 2009). Leu and Becker (2017) report that Australia is considered to be the closest to the UK in terms of policy and awareness of YCs. Research findings from culturally similar countries are expected to be similar but, having a research evidence base which is country specific is important for developments in policy and professional practice. The researcher acknowledges that there will be differences between

different countries but as stated by Leu and Becker (2017) the characteristics of YCs are typically the same and that developing YC policies can be closely aligned with the UK.

## 2.5 Theories Underpinning the Current Research

The YC literature resulting from the systematic search and the wider literature reviewed in chapter 1 show there to be a common theme for YCs, which is the importance of their interactions with people and environments around them, directly and indirectly. The lives and experiences of YCs are affected and influenced by a range of factors across systemic levels. The foundation for this YC research is based upon the view that YCs are part of different complex systems which can be affected by cultural and social circumstances (Woodhead et al. 1998). The theories underpinning the current research on YCs focuses on systems and motivation, namely Bronfenbrenner's Bioecological model (2005) and Deci and Ryan's Self-Determination theory (1985). By adopting these frameworks there is a recognition of the multiple systems which influence the school experiences of YCs and the interactions between those systems.

# 2.5.1 Systems Theory

In 1950, von Bertalanffy moved away from mechanistic systems and instead looked at biological systems, which were found to adapt and respond to environmental demands. In essence, a biological system will change and adapt accordingly. According to Bateson (1972) systems consist of different parts which interact. These different parts communicate and have an influence on each other. Dowling (2003) effectively drew on both Bateson and von Bertalanffy's theories by stating that biological organisms are reliant on the environment which is external to them. Dowling (2003) emphasised that systems theory originates from the physical sciences which are more likely to be predictable and exact than social sciences.

Systems around YCs impact in many ways on their ability to be autonomous and to make choices in their lives. Systems including family, school or educational provision, LA and government all play a role in influencing the life of a YC. A YC's circumstance is dependent and a result of the interactions between these systems and does not happen in isolation (Barry, 2011). Research by Grant et al. (2008) and Packenham et al. (2007) identified which systems are key protective factors for YCs in relation to emotional wellbeing and engagement with education. These were found to be school staff and YC project workers. The aforementioned studies show a YC's circumstance can be the result of different systems interacting and should not be seen in isolation.

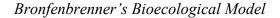
An article by Burden (1999) reflects on systems theory and concludes that the perspective of the individual and the ways in which they make sense of their education and schooling is downplayed within the theory. Instead, the theory focuses heavily on the systems that surround the individual and the influences that they have on each other. Dowling (2003) summarised that systems theory originates from physical sciences which are exact, predictable and has clearly defined boundaries. This is somewhat difficult to directly compare to people and environments such as homes and schools, which are not likely to be exact or predictable.

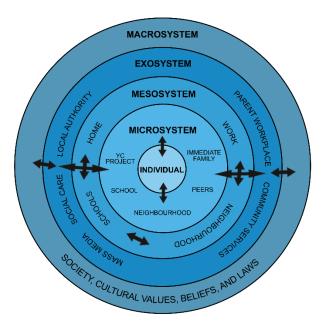
## 2.5.2 Bioecological Model

In 1979 Bronfenbrenner developed the ecological systems theory that was amended and added to resulting in the bioecological model (Bronfenbrenner, 2005). Research carried out by Choudhury and Williams (2020) which focused on the educational inclusion of YCs with additional needs, recognised the different systemic levels that are around a YC and the impact that they can have on the educational inclusion of these YCs. Within Bronfenbrenner's bioecological model (2005) a child is viewed as being at the centre of

multiple systems (Figure 2.1), interacting with several different settings, such as school, home and a YC project, for example. These interactions, between child or YC and different settings form the YC's microsystem (Choudhury & Williams, 2020). Key adults for a child within the microsystem could include the child's class teacher, a family member or a YC project worker.

## Figure 2.1





Choudhury and Williams (2020) go on to state that the mesosystem comprises of two or more interactions between a child's settings. These interactions could be between family members and school staff or school staff and project workers. As demonstrated in the research reviewed earlier in this chapter if the interactions between the settings are collaborative and focus on sharing information the child can benefit from a supportive and understanding environment (Barry, 2011). The next level to the Bioecological model is the exosystem. This is described by Choudhury and Williams (2020) as a system that a child or YC will not directly interact with but will still be affected by it. An example could include a LA in which a child attends school. A YC will not directly interact with any systems in the exosystem, but they will interact with other systems which will have an impact upon them. Educational policies introduced by a LA will directly affect schools and, in turn, the child or YC.

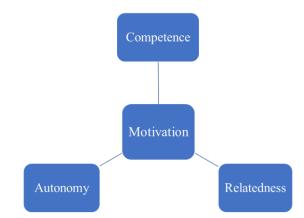
Society, government and legislation are suggested by Choudhury and Williams (2020) to be all part of the macrosystem. Again, they do not directly interact with a child but will have an effect on their situation through the LA, school, YC project and family. An example would be the Children and Families Act (2014) which specifies that the needs of YCs should be assessed. Alongside factors such as legislation, discourse that is prevalent within a society and culture will have a significant influence on a YC. Research by Smyth et al. (2011) looked for reasons as to why YCs may not be identified. Participants in that research reported that often YCs were not identified for two main reasons, one being that they did not identify with the term 'carer' and instead associated it with adults and older people. The second reason identified was that within western society it is thought that CYP do not provide care and are instead looked after by the adults around them. It was also found by Smyth et al. (2011) that some illnesses and disabilities were stigmatised in some societies and so contributed to carers not wanting to be identified. The systems within the macrosystem may seem distant and separate to the lives of YCs but the reviewed research shows how societal and cultural norms can heavily affect YCs and their families.

Tudge et al. (2009) evaluated the application of Bronfenbrenner's work and how his theory of human development changed over the years. They state that Bronfenbrenner had maintained that his theory was always focused on the ecological but was self-critical of the fact the emphasis was so heavily placed on the context, potentially ignoring the role a person plays in their own development. This too is also acknowledged in the current research that although the different systems around a YC will impact upon them, they also play a role in their own development, giving another reason as to why the voices of YCs need to be heard and valued when looking at ways to support their school experiences. Bronfenbrenner went on to develop the Process-Person-Context-Time model (PPCT, Bronfenbrenner, 2005). This model included a focus on the reciprocal interactions between the individual and immediate environments and how the individual can influence change within their context. This can be simply by being part of the environment or through the use of an individual's motivators and own resources (Tudge et al. 2009). The model considers the context and the time and how systems change over time for an individual, such as change in teacher, school, LA or government.

#### 2.5.3 Self-determination Theory

Social psychology has a central focus on how social environments can affect people's behaviour, attitudes, motivations and values. Essentially people's thoughts and feelings are all shaped by the different social contexts in which they interact (Tooby & Cosmides, 1992). The development of people's values, behaviours, attitudes and motivators are all a product of their social environment, which is a key focus of self-determination theory (SDT). This theory assumes that people are motivated to develop but that development is shaped by social interactions. Ryan (1995) proposed that people need psychological and biological nutrients for development and psychological well-being. SDT is primarily concerned with psychological nutrients, which are competence, relatedness and autonomy (Figure 2.2).

## Figure 2.2



# Self-Determination theory – psychological nutrients

According to the SDT these three basic needs must be met in order for a person to develop healthily (Deci & Ryan, 2012). To satisfy these three needs the social environment plays a key role in promoting intrinsically self determined development. When people are intrinsically motivated, they are able to engage in activities without the need for prompting or threats. Well-being and engagement are enhanced by intrinsic motivation, as opposed to extrinsic motivation which relies on a reward that is separate to a person's behaviour.

Ryan and Deci (2000) propose a self-determination continuum which details six stages of motivation, all of which work towards self-determination. The benefits of selfdetermination and of being autonomous include psychological well-being, increased selfesteem, positive emotions and greater satisfaction (Deci et al., 1989). People who consider their actions to be autonomous are found to enjoy and gain a higher level of satisfaction from school and to have better mental health (Deci & Ryan, 2002).

Motivation can quickly decline when a person is threatened with negative consequences, is given deadlines and has their performance evaluated, all factors which are likely to be seen in many different schools. However, if professionals and family members wish to facilitate intrinsic motivation, they can adopt different methods to support the three basic needs. (Ryan and Deci, 2017) propose that autonomy can be promoted through giving people choices, listening to and respecting people's views and supporting people's initiatives. Positive feedback supports competence, as does complimenting successes and providing constructive suggestions. Relatedness can be encouraged through the development of trusting relationships by investing time and paying attention (Boniwell & Tunariu, 2019). By aiding and strengthening YCs' autonomy they are given choices and shown that they have a voice and their views are to be respected. Recognising the efforts made by YCs in their school work and the caring activities they complete through positive feedback can boost and reinforce their competence. Giving attention to and developing relationships with YCs can establish and maintain relatedness.

Ryan and Niemic (2009) have identified that schools have the ability to support YCs and the three areas as identified by SDT. When a classroom, school and social conditions are right YCs can flourish and develop. In school environments that are pressurised and demanding YCs will struggle to attain the three basic psychological needs of autonomy, relatedness and competence. Therefore, if a YC is part of different environments which are not conducive to supporting these psychological needs it is likely that their capacity to develop interest, curiosity and confidence may well be affected (Ryan & Niemic, 2009). Another area for consideration is that of a child's age and stage of development. As a child grows and develops, they are more likely to be motivated by intrinsic rewards, as opposed to a younger child who may be motivated by external rewards (Deci & Ryan, 2012). This is not addressed by SDT but is important to the current research to recognise that YC participants may be motivated extrinsically or intrinsically according to their age. Secondary age participants, may for example, have the intrinsic motivation to seek out the help and support that they would like to receive in schools.

#### 2.5.4 Summary

All of these theories suggest a strong association between CYP and the world around them and how people, the environment and systems can have such a powerful influence on a child's healthy psychological development and motivation. To ensure YCs feel a sense of belonging and are able to engage with their learning the input of all professionals is required and not just those within the education system. To effectively support and understand the needs of a YC as a unique individual, the different systems around the YC need to work in collaboration (Doutre et al., 2013). If, for example, a YC has frequent encounters with social care and health professionals as well as school staff it could be thought that having so many professionals would ensure that the YC's needs are being met. Despite this appearance of a high level of support there can often be a narrow focus, with professionals only addressing the needs of what they think their role fulfils. If this is the case then services are fragmented with little to no information being shared or collaborative working being observed, with YCs bearing the burden (Seifer, 2003). Referring again to the breadth of the role of a YC it would be a challenging task for one agency to meet all of their needs adequately (Robotham et al., 2010).

It could be argued that school staff are ideally placed to identify and support YCs yet it would seem that project workers are the most trusted adults. The literature veers between positive and negative findings and at times it is unclear exactly how supportive schools can be to YCs. However, the research all points to the need for greater school awareness and support to be provided in schools (Lakman et al., 2017). The most effective way to understand what is happening in education is to speak directly to YCs. Enabling YCs to be autonomous and to share their voice may aid their understanding in how they can shape support and make a difference to other YCs. It could also help educational professionals to better understand the world of YCs.

# 2.6 Conclusion

This chapter has detailed the systematic literature review around YCs and their educational experiences, along with the two searches which were completed. Shared themes which were found within and across the five core studies were described as were the theoretical frameworks for this study. The following chapter will look at the researcher's epistemological and ontological positions and the research process for the current research.

#### **Chapter Three – Methodology**

## 3.1 Chapter Overview

In this section an explanation is provided about the researcher's current world view and the paradigm which frames this study. A summary of the research framework can be found below (Table 3.1). Reasons for choosing a qualitative and phenomenological approach are provided. The chapter contains a detailed description of the research process including data collection and data analysis using Interpretative Phenomenological Analysis (IPA). Ethical considerations for qualitative research, IPA, working online and working with children in the current context are discussed and summarised.

## Table 3.1

Epistemological and ontological positions	Ontology – Relativism
	Epistemology - Constructivism
Theoretical Perspectives	Phenomenology, idiographic &
	hermeneutics
Methodology	Qualitative
	IPA
Data Collection	Interviews: Semi-structured
Participant Information	Four young carers aged between 8 and 18
	years of age

Research Framework

#### **3.2 Philosophy of Research**

In order for a researcher to effectively carry out research, it is important for them to make clear their view of the world, including philosophical assumptions. These views and assumptions are shaped and reinforced through life experiences, education, reading and being part of different communities (Creswell, 2013). Due to this, assumptions can change and be dependent upon factors such as work or community ethos. For example, a researcher may

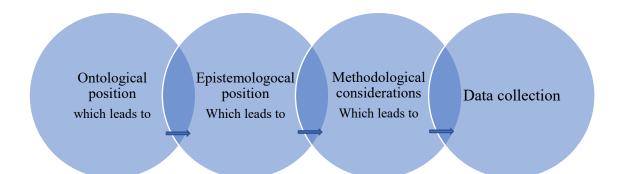
hold certain assumptions which could then change when moving into a work-based position which is multi-disciplinary (Creswell, 2013). It is the researcher's responsibility to be aware of these views so that any influences on the research can be identified (Creswell, 2013). According to Mertens (2010), philosophical assumptions and positioning influence decisions made during the research process. Huff (2009) suggests the importance of philosophy in research and how it helps to construct formulations, research questions and how those questions are answered. Having an understanding and an awareness of their own assumptions helps to explain why a researcher would make a choice between quantitative, qualitative or mixed methods (Creswell, 2013).

#### **3.2.1 Research Paradigms**

A researcher's world view is encompassed within a paradigm, which is characterised through its epistemological and ontological position and its methodology which leads to data collection (Figure 3.1).

## Figure 3.1

## Methodological Process



Throughout the research process the paradigm both supports and guides the researcher's thinking and actions (Denzin and Lincoln, 2011). Mills et al. (2006) state that researchers must choose a philosophical paradigm which best aligns with their beliefs to ensure that the research design is strong. Paradigms are explained by Guba and Lincoln (1994) as a

worldview which defines a person's place in the world and the possible relationships and connections they have to that world. It is a set of beliefs which cannot be proven in a typical way. They go on to state that paradigms rely on influence as opposed to proof when determining their position. There are four alternative inquiry paradigms which were proposed by Guba and Lincoln (1994). A fifth paradigm was added in 2005.

The current research began with the aim of wanting to explore the different educational experiences of YCs and what their reflections were of those experiences. Due to this it was felt, by the researcher, that the constructivist paradigm should be adopted. The constructivist paradigm assumes that reality is socially constructed and that knowledge can only be constructed by those people who are involved in the research (Guba and Lincoln, 1994). As a result of knowledge being constructed by individuals there will be multiple realities (Creswell & Creswell, 2018). It is key that researchers following the constructivist paradigm must try to understand the lived experiences of the people who have experienced them (Mertens, 2010). The current research with YCs seeks to find out about their lived experiences of education and to find out about their own unique experiences. This perspective is most closely aligned with the constructivist paradigm. The researcher seeks to understand the lived experiences of YCs from their perspective ensuring that participants are active throughout the research process (Mertens, 2010).

It could be argued that the constructivist paradigm shares some similarities with the participatory paradigm. The research process with both paradigms is equally shared between researcher and participants and there is an emphasis on participants having an equal voice throughout the process (Howell, 2012). There are also clear differences making the constructivist paradigm more clearly aligned with the aims of the current research. The participatory paradigm looks to examine issues which are related to the oppression of individuals and has been criticised for focusing on identifying problems resulting in research

becoming politically motivated. This can result in participants feeling isolated from their own communities (Howell, 2012). The purpose of the current research was not to place an emphasis on oppression or to identify problems but to share lived experiences with the prospect of supporting YCs effectively in education. It was hoped, by the researcher, that the constructivist standpoint will better present these lived experiences as they have been shared by the participants.

# **3.2.2 Ontological and Epistemological Positions**

Constructivism has been identified as the ascribed inquiry paradigm for the current research. The perspectives which define a paradigm are interconnected and as such if one of these beliefs has been ascertained there will be constraints on the other beliefs. These perspectives are ontology, epistemology and methodology (Guba & Lincoln, 1994). A researcher is required to have clarity about their ontological and epistemological stance (Crotty, 1998). In relation to the constructivist paradigm the ontological position, which questions what there is to know, accepts that there are multiple realities or truths. These multiple realities are constructed through a participant's response to and the way in which they make sense of an experience (Creswell, 2013). Epistemology looks to make sense of the world and to understand what counts as knowledge. The primary concern for epistemology is the theory of knowledge and what kinds of knowledge there are (Crotty, 1998). By being clear and identifying specific objectives for a piece of research and understanding what is possible to find out an epistemological position can be established (Willig, 2013).

The researcher's ontological position is relativist. Adopting this position characterises a perspective that not only do people's experiences differ but that their worlds are different (Stajduhar et al., 2001). Essentially, there are as many realities as there are people (Levers, 2013). The purpose of a relativist ontology is to understand subjective experiences. The

epistemological stance of the researcher is constructivist. A constructivist epistemology is characterised through having a relativist ontological stance. The constructivist position assumes that people create meanings as a result of their engagement with the world and their interpretations of this. How a person engages and makes sense of the world is dependent on their own perspective and experiences (Crotty, 1998). A relativist and constructivist position assumes multiple, subjective realities (Willig, 2013). As stated by Guba and Lincoln (1994) a constructivist researcher assumes participants and researchers are part of an influential and interactive process.

The constructivist paradigm, relativist ontology and constructivist epistemology all focus on an understanding that there are multiple realities due to the different worlds people are a part of. Meaning is constructed, not discovered as individuals will construct meaning in a number of different ways. Even if a group of people are experiencing the same phenomenon they will still view and describe it in very different ways (Crotty, 1998). The researcher assumes this to be the case for YCs and that even though they are all labelled as YCs their experiences will be quite different to each other. As the researcher believes that reality is built upon multiple perceptions and the experiences of participants the research was designed to be inductive. Inductive research is considered a bottom-up approach which takes a qualitative, phenomenological position (Willig, 2013). This approach guided the researcher to explore the different worlds of YCs with the goal to limit bias and distortion of individual views.

#### 3.3 Research Aims

The research conducted was a qualitative exploratory study. Exploratory research looks to investigate a topic or phenomenon that has not been thoroughly researched, which appears to be the case for YCs and their educational experiences. Through exploratory research the researcher is able to acquire further knowledge of the existing phenomena and to

gain additional and new insights (Davies, 2011). The aim of the research was to gain an insight into what it is like to be a YC within the UK school system and to begin to understand what those educational experiences might mean to a YC. By asking YCs their views directly, which aligns with the phenomenological approach, enabled them to highlight the educational experiences which they believe are most supportive to them. It has already been identified that there is limited research in the area of YCs and their educational experiences and so the study sought to listen to YCs to develop an understanding based on their own experiences (Creswell, 2013). From this it is hoped that future EP practice and development of policies at both LA and school level can be informed by some of the findings of this research. To support the exploratory nature of this study the research question and sub-questions will also be exploratory.

# **3.4 Research Questions**

The central research question and sub-questions for this study were developed and guided by the researcher's ontological and epistemological positions. They were designed to elicit and produce information from the multiple viewpoints of YCs and are as follows:

Central research question:

• RQ1: What are YCs' lived experiences of education?

Sub-questions:

- 1a: What educational support have YCs experienced?
- 1b: What are YCs' reflections on their educational experiences?

As this area of research is still developing, the questions are not determined by existing YC research. The aim of the questions is to explore the views of YCs whilst forming a coherent picture of their different educational experiences.

The aim of the central research question is to state, in more specific terms, what the purpose of the current study is through an open-ended question which looks for detailed descriptions and possible explanations of a phenomena ((Willig, 2013). The central question provides an overarching question to address the current study's focus, YCs and their lived experiences of education. The subsequent two sub-questions help to refine the central question further and help the researcher to focus specifically on the educational support YCs have received and what their reflections of their educational experiences are. From a phenomenological perspective, the sub-questions support and help to establish the main components of the research (Creswell, 2013).

The central research question of the current study emphasises the need to find out about the lived experiences of YCs from a phenomenological research approach. The research question and sub-questions helped to guide the researcher through exploring the individual experiences and the context of YCs and their educational experiences, so that a deeper and broader perspective could be gained. The phenomenological approach takes the assumption that YCs will view and describe their experiences in different ways to other YCs (Crotty, 1998). The sub-questions focus on what the YCs experienced, in relation to educational support and their reflections, therefore, providing an insight into what and how YCs experienced education and support (Creswell, 2013). Further information about the phenomenological approach can be found in section 3.5.1 (pg. 42). The individual educational experiences of YCs are further explored through IPA. Smith, et al. (2009) stress the importance of speaking directly to people about their own experiences as they are considered to be experts on their lives. This is further explored in section 3.5.2 (pg. 43). In summary, the central research question and sub-questions align with the researcher's ontological and epistemological positions and are in line with the phenomenological approach and IPA.

## 3.5 Research Design

Methodology concerns itself with how to find out information and is seen to be the process behind the choice of particular methods used to gather data (Crotty, 1998), which takes into consideration both a researcher's ontological and epistemological position. Essentially, methodology is shaped by ontology and epistemology. According to Guba and Lincoln (1994) the methodological position of the constructivist paradigm seeks to be hermeneutical and dialectical. Carrying out research within this paradigm focuses on interactions between researchers and the participants and is interactive. The intention is to obtain multiple perspectives which are more likely to produce meanings which can be compared and contrasted. In turn this can challenge previously held ideas and positions (Mertens, 2010).

The current research applied a qualitative design due to the researcher's ontological and epistemological position. This design allowed the researcher more flexibility in order to explore YCs' views (Mertens, 2015). This design ensured that the research enabled experiences and perspectives to be explored when they emerged (Willig, 2013). By gathering subjective data from YCs the researcher hoped to gain a broader understanding of YCs and their educational experiences.

#### **3.5.1 Phenomenological Approach**

Phenomenology is typically attributed to Edmund Husserl, an influential philosopher in the 20th century. Phenomenological research is undertaken in order to understand people and their views of the world by looking to reveal the meanings of life experiences (Robson, 2011). The focus of interest for phenomenology is on the experiences people have within certain contexts and at particular times (Willig, 2013). Husserl suggested that people need to 'bracket' the taken for granted world in order to further focus on perceptions of that particular

world (Smith et al., 2009). Through 'bracketing' a current experience can be viewed on its own through attempts to push aside prior knowledge which may influence interpretations of that current experience (Smith et al., 2009). However, people draw on their previous experiences to make sense of what is happening or what has happened proving it to be difficult for people to be completely detached (Smith et al., 2009).

This type of study provides a description of a commonality for several participants of their lived experiences of a particular phenomenon. The purpose is to collate individual experiences into a universal description. Firstly, the phenomenon is identified, data is then collected from those people who experience the phenomenon with the researcher developing a composite description for all of the participants. What was experienced and how it was experienced by the participants is included in the description (Creswell, 2013). There are said to be two approaches to phenomenology, the first transcendental and the second hermeneutical as written by Van Manen (1990). This approach not only focuses research on lived experiences of participants but also on the interpretation of texts, such as data collected through interviews, for example (Creswell, 2013).

The current research focused on individual accounts of educational experiences before bringing them together to look for any shared thoughts, views and experiences of the YCs. Participants detailed and gave meaning to their experiences of education. In line with the phenomenological approach the researcher not only listened to and explored the YCs' experiences but also focused on the data collected through semi-structured interviews.

# 3.5.2 Interpretative Phenomenological Analysis (IPA)

Interpretative phenomenological analysis is a phenomenological method, the aim of which is to acquire the essence and variety of individual experiences. There is the recognition that although the primary focus is to explore a participant's experience from their own

perspective, the researcher's view of the world will also be implicated in the interaction between participant and researcher. The result of this is that any analysis completed by the researcher is an interpretation of a participant's experience (Willig, 2013). This is termed as a double hermeneutic. The researcher tries to make sense of the participant's experience as the participant tries to make sense of their own experiences (Smith & Osbourn, 2008).

The current research adopted an IPA research design owing to a number of factors. People are thought to be experts on their own experiences and are best able to express their thoughts and views to the researcher (Smith et al., 2009). Therefore, in order to fully understand the experiences of a YC the researcher needs to speak directly to them to gain a greater understanding of their viewpoint. A requisite of IPA is that the researcher explores a person's experiences through listening to and developing interpretations of that specific individual (YC) in a specific context.

Influences upon IPA include hermeneutics and idiography. Hermeneutics phenomenology moves away from Husserl's reductions and instead recognises the connectedness between the world views of the researcher and the ways in which they interpret a participant's experiences. That is why the researcher needs to be reflexive throughout the research (Oxley, 2017). Reflexivity is related to understanding one's own position as a researcher and the possible effect it can have on the research process and outcomes. It is important for a researcher to be aware of their responses to different parts of the research process as this can create deeper insights (Fox et al., 2007). The research process is reliant on the researcher having empathy, an understanding of themselves in relation to other people and critical subjectivity (Howell, 2012). Through the use of a research diary the researcher has been able reflect on the research at different stages of the process (Appendix Y).

The idiographic approach directs attention to and emphasises the uniqueness of personal experiences. As the experiences are considered to be unique, they cannot be generalised to other people (Larkin & Thompson, 2012). Idiography concentrates on the particular which intertwines with IPA's focus on the particular. IPA is committed to the particular in the sense of carrying out a thorough and detailed analysis. It also focusses on how certain groups of people in certain contexts understand particular phenomena. Due to this IPA sample sizes are deliberately small and purposefully chosen (Smith et al., 2009).

As a form of analysis IPA is the most suitable form of analysis for the current research as it relies on a homogenous participant group, such as YCs and focuses on bringing to light, in the case of the current research, the experiences of YCs and their educational experiences. As an inductive approach, hypotheses are not tested, but instead the aim is to establish the meanings YCs place on their experiences, through their reflections, which supports the researcher's epistemological and ontological position.

## 3.5.3 Limitations and Considerations

Historically the majority of IPA studies have been carried out with adults, although it should be noted that there are an ever-increasing number of IPA studies which have now been completed with children and adolescents (Doutre et al., 2013). This could possibly be due to concerns that children are not yet able to detail their own experiences. Smith (2004) suggests that researchers may need to take a more substantial role when guiding children and adolescents through IPA interviews. Researchers are recommended to follow the typical pattern of asking open ended questions with gentle probing but with an increased interventionist stance. For the most part studies (Doutre et al., 2013 & Petalas, et al., 2009) have found children to be positive about their experiences of IPA. One study by Back et al. (2011) stated explicitly that child participants may not be able to fully describe their

experiences due to their language ability in relation to their age. Consideration should also be given to any participant with English as an additional language and participants who may have additional needs (Smith, 2004). Consideration of this particular limitation was apparent during the development of the interview schedule (Appendix O) and interview stage. The researcher guided the participants through the interview and explored thoughts and observations when they arose.

According to Willig (2013) there are several limitations to IPA which need to be considered throughout the research process. Throughout IPA there is a strong emphasis on language and the importance of it being able to fully convey a participant's experience. Answers given during an interview may be more likely to be about the way the participant speaks about their experience rather than about the actual experience (Willig, 2013). There is also the question as to how well participants are able to articulate the extent of their experiences. The purpose of the current research was to find out about the perceived educational experiences of YCs, from their perspective and to understand their reflections of those specific experiences as opposed to the perceived reality of the people around the YC.

Finally, IPA focuses on describing experiences but it has no way of explaining lived experiences. It could be argued that the researcher's understanding of phenomena could be limited due to this. In order to fully understand an experience a researcher needs to be aware of the surrounding conditions to that experience, such as social structures and past and historical events (Willig, 2013). As a part of the information gathering process, when speaking to participants, information was sought about the YC's family, themselves, reasons for caring and schooling to inform the researcher and to provide context to the YC's role.

#### **3.5.4 Alternative Qualitative Approaches**

Although the decision was taken quite early on to use IPA as it aligns with the

researcher's ontological and epistemological position two other approaches were considered and will now be discussed.

**3.5.4.1 Narrative Approach** – Research taking a narrative approach understands that people tell their lives and experiences as stories, which have a beginning, middle and an end. Participants in narrative research are said to make meanings from their stories by selecting what to share and linking together different experiences (Wertz, 2011). Stories about individual's lives are taken by the researcher organised or 're-storied' into a narrative chronology (Creswell, 2013). As this approach relies on participants to tell their stories from memory, Robson (2011) warns that narrative content is potentially selective. In this approach there are no attempts to bracket a researcher's beliefs or their assumptions, unlike IPA (Creswell, 2013). Although this approach could have potentially provided a rich account of a YC's experience, it was discounted due to the reliance on re-storying by the researcher which could potentially alter a participant's account of their experiences.

**3.5.4.2 Grounded Theory** – This approach is considered by many to be the main alternative to IPA and there appears to be some overlap between the two approaches (Smith, et al. 2009). In this approach theories are generated through the interpretation of data. Any emerging theories are checked against data which is systematically collected (Mertens, 2010). To capitalise on potential differences and similarities different groups are sampled (Creswell, 2013). One of the reasons IPA was chosen was because it emphasises the lived experiences of a small number of participants which allows for a more detailed exploration of being a YC, therefore, making IPA a more suitable choice for the purpose of the current research.

#### 3.6 Research Methods & Data collection

## 3.6.1 Recruitment of Participants

As a group YCs can be difficult to recruit for the purpose of research. As already mentioned in the introduction YCs can be a hard-to-reach population and are often hidden. The decision was taken to recruit participants through schools and YC projects, as well as detailing the research on social media to reach out to parents and snowballing through families and YCs who had already participated in the research. By attempting to recruit through schools the researcher was dependent on school staff being able to identify YCs and to liaise with YCs and their families to gain their consent to participate. Greig et al. (2007) suggest building trusting relationships with key adults when looking to carry out research with children. These key adults or gatekeepers were vital to the research and contact was maintained with each key adult throughout the research process which included school staff, YC project leads and parents.

As part of the constructivist paradigm the researcher required a group of participants who would provide rich and in-depth information (Mertens, 2015). A set of criteria was used to recruit participants to ensure that the relevant data to the central research question and subquestions would be obtained. The criteria stipulated that the YC needed to be between 8 and 18 years of age and that they needed to be a YC, as defined by the Children and Families Act (2014). The YC needed to care for a family member but did not need to be the primary carer. Finally, the YC had to be in attendance at school at the time of the interviews. This group of participants could be regarded as homogenous (Mertens, 2010) as they are all share the characteristics of being a YC and were at the time of the research attending school.

Upon ethical approval from the university's ethics board (Appendix CC), flyers (Appendix R & S) detailing the research were sent to schools and YC projects. Schools who contacted the researcher were asked to sign a consent form (Appendix N) and in doing so agreed to help the researcher to find participants in their school. Schools would then have been sent information letters and consent forms (Appendices M & N) but as no schools signed the consent forms, no participants were recruited through them. Interested YC project leads were also asked to sign a consent form (Appendix L) before information letters and consent forms were sent to them (Appendices K, L, G & H). To ensure that as many families saw the flyer as possible the YC project leads emailed the flyer (Appendix S) to their families and posted it on the project's social media. This was the responsibility of the YC project lead to do this and was their choice to do so, after discussing it with the researcher. Colleagues within education and health posted the flyers (Appendix R & S) on their own social media. Anyone who contacted a colleague were directed to contact the researcher via their university email address, which was included on the flyer. The researcher did not use their own social media accounts to recruit participants or to communicate with families or YCs at any stage of the research process.

Families who contacted the researcher directly and expressed an interest in participating in the research were emailed flyers (Appendix S), consent forms and invitation letters. These documents were sent to YCs (Appendices I & J) via their parents. The researcher requested that consent forms were signed by parents and YCs before progressing with the research process. Correspondence with all key adults was through the researcher's university email address. Completing research with children and informed consent are discussed further in this chapter as part of ethical considerations.

In total four participants were recruited to the study. Two of the participants were part of a YC project group in the LA in which the researcher was on placement. However, these two participants were not directly recruited through the YC group. Instead, the two participants were part of a YC group run by the LA EPS, with one of the facilitators of this

group being the researcher. The research was discussed as part of the group and two families within the group volunteered to participate. The two other participants were recruited from two different LAs in different parts of England, through social media. As stated above colleagues of the researcher within health and education shared the research flyers on their own social media. The two final families saw the flyers on social media and initially contacted the researcher's colleagues. They were redirected, by the colleagues to contact the researcher directly, via their university email address. None of the participants were recruited through schools in the researcher's LA or neighbouring LA YC projects. All of the participants met the aforementioned criteria. Information relating to the four participants can be found below (Table 3.2). The names of each participant are a pseudonym with each YC choosing the name that they wanted to use.

# Table 3.2

Name/Pseudonym	Age	Participant number	Gender	Caring role
Jordan	13	01	Male	Brother
George	9	02	Male	Brother
Hannah	17	03	Female	Mother & Brother
Jessica	10	04	Female	Sister & Mother

## Participant Information

Information pertaining to the YC's home life was provided by them during initial conversations. Jordan lived at home with his mother and he provided care for his younger brother. George lived with his parents and younger brother who he provided care for. Hannah lived with her parents and two older brothers. She cared for one of her brothers and her mother. Jessica lived with her parents, younger brother and sister. Jessica provided care for

her sister and her mother, when needed. The first three participants were all part of a YC project group, which they accessed in person and online. Jessica did not access a YC project group at the time of the interview.

## 3.6.2 Sessions with YCs

Smith et al. (2009) recommend that between 4 and 10 interviews are completed as the emphasis is on the quality of the data not the quantity. This details the number of interviews but does not specify how many participants. However, only one session was required with the YCs to complete the interviews and so a sample size of four was considered to be adequate for the study. Research using IPA typically benefits from small sample sizes to ensure a more concentrated focus.

Due to Covid related restrictions the decision was taken and approved by the university that all interviews were to be completed online and virtually through Microsoft Teams (see ethical considerations). Online invites were sent by the researcher to parents, who had contacted the researcher. Parents were provided with the option to have two online meetings. The first session was introductory so that the researcher could introduce themselves and the YC and their family could introduce themselves to the researcher. It allowed parents and YCs to ask any questions about the research and their involvement and to give verbal agreement alongside their written consent. This initial session was also suggested as a way for the YC to get to know the researcher and to feel more comfortable in speaking to them during the interview. As the sessions were online the researcher felt that this was even more important to develop trust between YC, researcher and parent. All YCs were informed about confidentiality, explaining it so that it was understandable dependent on their age. Each YC was asked to choose a pseudonym so that they would not be identified. The pseudonym was then used throughout the interview, the transcription, analysis and findings of the research.

The second session was at a mutually agreed date and time with an online invite sent to parents. The start of the session was given to answer any further questions and an overview of the interview process. To enable the researcher to keep a record of the interviews all of them were recorded. Recordings included audio and visual of the researcher and audio of the YC, as it was agreed that the YC would switch off their camera for the duration of the interview (as stated in the RDMP – Appendix DD). Open ended and probing questions were utilised during the interviews. When the interviews came to an end the researcher spoke to the YC and their parent about the interview before answering any further questions. Debrief letters were then sent to parents and YCs (Appendices P & Q).

# 3.6.3 Collection of Data / Interviews

Data for the research was collected through semi-structured interviews. Typically, semi-structured interviews are flexible and deemed most appropriate for small-scale research (Robson, 2011). Through the use of a semi-structured interview a researcher is able to listen to a participant talk about different aspects of their life. The interviewing style can be described as non-directive but is steered by the researcher in order to obtain information which is important to the central research question and sub-questions, whilst encouraging the participant to speak freely. It is the researcher's responsibility to ensure that the participant is given time to reflect and speak about what is most important to them (Willig, 2013).

An interview schedule was constructed by the researcher (Appendix O) to find out about YCs' experiences of education. Questions were open ended and worded to try and enable participants to speak openly and descriptively about their experiences with the onus on the participant speaking more than the researcher. Advantages of using open ended questions include the ability to clear misunderstandings and to provide clarification, to encourage rapport between participant and researcher and the opportunity for unexpected answers to be

given (Robson, 2011). Probes were used throughout all of the interviews to encourage participants to further describe their experiences or to help them to reflect. The first question which asked YCs about themselves was intended to help the participant to feel at ease talking about themselves (Smith et al., 2009). Following Robson's (2011) guidance the researcher tried to avoid questions which would have been too long, included jargon or were biased and/or leading questions.

#### **3.6.4 Ethical Considerations for Qualitative Research**

Lincoln (2009) discusses the need for researchers to develop rapport with participants, that is to make attempts to positively connect with the participant through the use of active listening in order to begin to understand their world. Two of the participants were unknown to the researcher prior to the research and time was given for all the participants to speak to the researcher. According to Reinharz (1992) participants can feel more at ease when they already know the interviewer. However, some interviewees prefer to speak to an interviewer who does not know them as they can be more willing to disclose information as they do not need to see the interviewer again.

In terms of reciprocity most researchers want to ensure that participants have received something in return for their involvement in research, particularly when the participant is sharing sensitive information. This could be emotional support or some contribution to a cause that is important to the participant (Creswell, 2013). As the research process is interactive it is the responsibility of the researcher to understand what the participant has received from their participation. There is also the question of how much information a researcher should share about themselves as responses may be triggered or answers biased due to information disclosed by the researcher (Reinharz, 1992).

#### 3.7 Data Analysis

Upon completion of the interviews and the transcriptions IPA was used to analyse all of the data which had been collected. By using IPA, the focus is directed towards participants making sense of their lived experiences. The process of analysis is described by Smith (2007) as being iterative and inductive. In short, stages of the analysis are repeated whilst the researcher is able to detect patterns and themes. The researcher followed the stages of analysis as set out by Smith et al. (2009) in order to gain a better understanding of the participants' perspectives and experiences of being a YC. As stated by Smith et al. (2009) there is not considered to be a right or wrong way when conducting the analysis and researchers are encouraged to be innovative. However, guidance is provided through a clear framework for analysis. The framework allows researchers to focus on strategies and ways in which to process data. The analysis is used to support and encourage the researcher to be reflective, as although the analysis is a product of both participant and analysis/researcher the end product is an account of what the researcher thinks the participant is thinking, i.e., double hermeneutics.

Transcription of the interviews were completed by the researcher to ensure adherence to ethical procedure and anonymity was preserved. None of the participant's real names were used, only pseudonyms chosen by the YCs themselves. Nor were any identifying features such as school attended or area of the UK in which the participant lived detailed in the transcription or any other part of the research process. Each individual transcript was read and analysed, going through each stage by the researcher before moving onto the next transcript and completing the same analysis. The timeline of the research process can be found below.

# Table 3.3

# Research Timeline

Date	Action		
June 2020 - October	Recruitment – flyers sent to schools, YC projects		
2020	Consent forms sent to YC project leads		
	Consenting YC project leads posted the flyer to their project		
	social media accounts		
	Colleagues in health and education posted the flyers on their		
	social media		
July 2020	Contact from parent (1) via email – interest in participating		
	First meeting with participant 1 and parent		
	Consent forms signed by parent and YC		
	Semi-structured interview with participant 1		
	Debrief letters sent to participant and parent via parent email address		
October 2020	Contact from parent (2) via email – interest in participating		
	First meeting with participant 2		
	Consent forms signed by parent and YC		
	Semi-structured interview with participant 2		
	Debrief letters sent to participant and parent via parent email		
	address		
	Contact from parent (3) via email – interest in participating		
	First meeting with participant 3		
	Consent forms signed by parent and YC		
November 2020	Semi-structured interview with participant 3		
	Debrief letters sent to participant and parent via parent email		
	address		
	First meeting with participant 4		
	Consent forms signed by parent and YC		
	Semi-structured interview with participant 4		
	Debrief letters sent to participant and parent via parent email		
	address		
December 2020	Transcription of all transcripts (verbatim)		
	Letters detailing the findings sent to participants and parents		
	via parent email addresses		

December 202- January	Data analysis completed using IPA
2021	

#### 3.7.1 Stages of Analysis

This section will outline each stage of the IPA process which was followed in line with Smith et al. (2009) guidance.

## 3.7.1.1 Stage 1 - Reading and Rereading

During this initial stage the researcher listened to the audio of each interview whilst reading through the transcripts, which ensured that the transcripts were accurate. The transcripts were read and re-read several times. Notable recollections from the interview and interview experience and observations about the transcripts were noted in the research diary in order to 'bracket' these ideas. An example of observations and recollections of an interview can be found in Appendix R. Notes were taken in relations to language used, descriptions and any summaries.

# 3.7.1.2 Stage 2 – Initial Noting

During this stage the researcher engaged with the text by underlining key words and phrases and providing reasons as to why they were important. Comments made were descriptive, linguistic and conceptual. Descriptive comments focused on things that seemed to matter to the participant. The linguistic comments related to the way language was used and conceptual comments focused on looking at the participants understanding of the world around them and ways in which participants understand and think about their experiences.

# 3.7.1.3 Stage 3 - Developing Emerging Themes

During this stage the focus moved to the notes which had been made in stage 2 and the researcher began to look for patterns and connections amongst the notes. By looking

primarily at the notes, the flow of the narrative was broken into sections, corresponding with the hermeneutic circle.

#### 3.7.1.4 Stage 4 - Looking for Connections Between Emergent Themes

This stage looked at how emergent themes fitted together. Each emergent theme was written on a separate post-it note. Themes were looked at and then grouped. The grouped themes were then named. This was then the superordinate theme for that cluster of themes (Appendix Q). A summary table for each participant's transcript was created and included superordinate themes, emergent themes, line numbers and key words/phrases (Appendices S, T, U & V).

#### 3.7.1.5 Stage 5 - Analysis Framework Repeated

In line with the IPA process each transcript was analysed following the steps in stages 1 to 4. This was repeated until all four transcripts had been analysed. It should be noted that the researcher was aware of how the analysis of one transcript was likely to be influenced by reading other transcripts and so in an attempt to 'bracket' ideas notes were written in the research diary before moving on to the next transcript. A table was created of all of the superordinate themes for each participant (Appendix W)

## 3.7.1.6 Stage 6 - Patterns and Themes Across Participants

During this stage patterns across transcripts were looked for to see if there were any shared experiences or concepts between participants. Similar to stage 4, all themes were brought together to create a new set of subordinate and superordinate themes (Table 4.1). Findings of the analysis can be found in chapter 4.

## 3.7.2 Reflexivity

It was important for the researcher to be reflexive throughout the research process as the researcher's own interests, assumptions, beliefs and experiences all have the potential to have an influence on the research process. Due to this a research diary was utilised to capture notes written about each of the different stages. Example extracts from the research diary can be found in the appendices (Appendix BB). Reflexivity is needed as part of the evaluation of qualitative research, particularly so when the researcher's own identity and experiences are so different to the participants. The researcher acknowledged their own biases and beliefs to keep in mind the potential impact it could have on the engagement and relationship building with the YC participants.

The researcher was required to have an awareness of the ways in which they might contribute to the construction of meanings, more so during the analysis of the data. It would be with extreme difficulty for any qualitative researcher to remain separate from the research and it was the responsibility of the researcher to think about how they had influenced and informed the research (Nightingale & Cromby, 1999). Willig (2013) explains that researchers who use IPA to analyse data are implicated in the analysis and need to take a reflexive stance. Insights gained from the analysis are the result of interpretation from the researcher, to better understand the psychological world of the participant. The researcher's perspective is recognised as being important but IPA does not express how their ideas are integrated and involved in the analysis. Researchers discover rather than construct and look to emerging themes and identifying categories.

### 3.8 Quality Assurance

### 3.8.1 Four Guiding Principles

To ensure the quality of this research the researcher has been guided by Yardley's criteria (2000) which encompasses four principles. Smith, et al. (2009) demonstrate how IPA meets each of these principles. The first principle is sensitivity to context. Sensitivity may be shown towards prior literature, to the context or situation of the research and to data collected from participants. Smith et al. (2009) position IPA as being able to demonstrate a certain sensitivity from the start of the research process. They state that due to the difficulties in finding participants who share a lived experience it is important for researchers to develop trust and continued engagement with gatekeepers. Researchers using IPA also need to have the skills and sensitivity to interact effectively with participants through showing empathy and putting them at ease to obtain rich data.

Leading up to and during interviews the researcher ensured that additional online meetings were made available to participants and their families to put them at ease and to be clear about the objectives of the research. Time was also spent contacting gatekeepers and developing relationships with them. There is also an element of sensitivity in the collection of data through tactful and cautious questioning during the interviews. The inclusion of sensitively chosen verbatim extracts of the interviews provides participants with a voice in the research.

The second principle is commitment and rigour (Yardley, 2000). Commitment would be seen through a researcher's ability to attend to a participant during an interview and the attention to detail given to each analysis for each participant. The researcher listened carefully to all of the participants and showed appreciation and consideration throughout. The principle rigour relates to three different areas, the sample of participants, interviews and the

analysis. More specifically it refers to the suitability of the participants in the research, interview quality and the thoroughness of the analysis (Smith, et al. 2009). All of the participants who participated in the research were YCs and were able to speak about their educational experiences. The data was thoroughly analysed using each of the IPA stages to identify themes, drawing on each of the participants' accounts.

Transparency and coherence are Yardley's (2000) third principle with transparency referring to stages within the research, which have been detailed in this chapter in respect of participant recruitment, the interview schedule, interview questions and stages of the analysis. As suggested by Yardley (2000) a coherent study corresponds to the theoretical assumptions, such as that of the IPA approach. The researcher has clearly discussed the reasons for choosing a phenomenological approach and acknowledges hermeneutics within the research process and understands that analysis using IPA is interpretative.

The final principle is impact and importance. Yardley (2000) emphasises the need for research to be interesting and important. The researcher finds the topic of YCs and their worlds interesting and believes that there is a need for a continued exploration in order to understand their experiences and to make sure that they receive the support they are entitled to which is tailored to meet theirs and their family's needs. It is hoped that this research proves interesting to the reader and to the wider educational field.

## 3.8.2 Trustworthiness

Guba and Lincoln (2011) propose a set of four criteria to assess the trustworthiness of qualitative research. The four criteria are, credibility, confirmability, dependability and transferability.

The criteria for checking the quality of qualitative research are strengthened further by Lincoln (2009) who proposes credibility. To be considered credible researchers need to

engage in the field which is relevant to the participants. Researchers must take the time to develop trust and be familiar with the context and setting of the research. The researcher is familiar with educational environments having worked as a teacher for a number of years prior to starting their training. Although the interviews and sessions with the YCs did not take place in a school the researcher was still able to utilise their knowledge about them to engage with participants. Participants were at home when they were interviewed virtually and time was taken to ensure the participant felt at ease before interviews were scheduled.

As part of the credibility criteria member checks are recommended (Mertens, 2010). A researcher completes member checks through checking emerging constructions from data collected and analysis by seeking endorsement from the participants. The checks can be formal and informal. The researcher can check by summarising the answers given by participants at the end of interviews or provide a draft report of the research to participants. Whilst interviewing participants the researcher clarified answers and summarised information given, both during and at the end of the interviews to check for accuracy. A short report detailing the findings of the data analysis was also given to participants and their families to enable them to comment and share their thoughts (Appendix AA).

Data collected through audio recordings during the research process ensured that the information shared by participants was precisely captured as opposed to a reliance on notes made by the researcher. By going back repeatedly to the data through the IPA process and keeping records of doing so this increases the transparency and confirmability during the analysis (Yardley, 2000). Discussing and sharing the data findings with the Director of Studies contributed to transparency in the analysis process as the risk of researcher bias was minimised through supervision. Trustworthiness was also supported through regular supervision as any ethical concerns could be addressed quickly and so too could researcher bias.

### **3.9 Further Ethical Considerations**

## **3.9.1 Online Interviews**

All interviews for the study were completed online using Microsoft Teams. Creswell (2013) outlines the advantages to online interviews, such as efficiency in relation to time and the creation of an environment which is non-threatening which could potentially put participants at ease. Online interviews also enable groups which are typically hard to reach to access research and to participate. However, there are ethical implications that need to be addressed when working online with participants. Alongside expectations of being able to access IT equipment and having the necessary skills to engage with online interviewing, there are issues relating to data collection and ownership and privacy. These concerns have been addressed in the Research Data Management Plan (RDMP – Appendix AA) which was approved by the university. All data has been stored securely through the research process in line with General Data Protection Regulation (Wachter, 2018). Interviews saved contained only the voice of the participant and not their image. Once transcribed all videos were permanently deleted.

During the research process the researcher adhered to the professional code of conduct as set out by the Health and Care Professions Council (HCPC, 2016) and British Psychological Society (BPS, 2018). The researcher followed the updated guidance by the BPS (2020) about working with CYP online. As well as being provided with written consent forms CYP were also asked at the start of online sessions if they were still happy to participate and only to answer questions, they felt comfortable answering. Parents and YCs were given the option of the parent staying nearby or going to another room. On each occasion the YC and parent decided that the parent would stay with them for the duration of

the interview. Parents were encouraged to make sure that interviews did not take place in the YC's bedroom but in a neutral family space.

#### 3.9.2 Research with YCs

As the current study focuses on the voices of the YCs it is important to note that CYP were previously seen to be passive subjects in research. Now, CYP are viewed as active participants who are experts who can contribute to new knowledge (Vaswani, 2018). As stated in the UNCRC (1989) CYP have the right to participate, to be heard and to hold some influence over their own lives. Consideration should be given specifically to YCs as participants in research. Research by Joseph et al. (2020) notes that often YCs bear a burden of commitment and responsibility as part of their caring role and as has already been recognised in the literature review, YCs can struggle to carry out their caring role alongside attending school and maintaining friendships. Including YCs in research can potentially add yet another burden on them, by having the expectation that they will be able to find the time to participate whilst also being a carer and attending school. Time constraints on a YC must be taken into consideration when including them in research (Joseph et al., 2020). In the current study to try and minimise the burden, YCs and their families decided the day and the time of the interview. By carrying out online interviews there was greater flexibility when the interviews could take place. In advance it was explained to YCs how long the interview may last, but that they could withdraw or end the interview at any point before, during or after the interview. As well as time constraints and the potential for feeling additionally burdened ethical practices also need to be considered and will now be discussed.

### **3.9.3 Ethical practices**

### 3.9.3.1 Informed Consent & Right to Withdraw

Each YC provided written (Appendix I) and verbal consent and parental consent (Appendix G) was also sought. Both parents and CYP had to consent. Without consent it was made clear that YCs could not participate in the research. In IPA informed consent must be gained for data collection and outcomes of data analysis. Robson (2011) makes the distinction between assent and consent for CYP. Within a medical context CYP aged 14 and over are considered able to provide consent. In the same context children aged 7 and over have the understanding to refuse or give assent, that is to agree to participate but not necessarily understand the full purpose of the research. All CYP involved in this research were over the age of 8. The researcher discussed the purpose of the research with each YC and their parent. Time was given for them to ask any questions about the study.

The information letters given to parents explained that their child would be able to withdraw from the study if they wished up to the point of analysis. Smith, et al. (2009) emphasised this point and suggested giving participants a time limit of when they would be able to withdraw and to make it clear that once the data had been analysed and written participants could not withdraw.

### 3.9.3.2 Data Protection, Anonymity and Confidentiality

As detailed in the Research Data Management Plan (Appendix DD) and above under further ethical considerations all of the data was stored appropriately. To make sure that the participants in the research were protected their identities were kept anonymous and data was confidential (Mertens, 2010). Participants were made aware of this before being interviewed and were reminded at the end.

### **3.9.3.3 Power Imbalances**

It can be argued that typically there is a power imbalance between adults and CYP, with this power difference becoming more apparent between an adult researcher and a child participant (Kirk, 2007). Researchers, such as Aldridge (2012) maintain that power can be restored through CYP participating in research as they are positioned as experts. Using methods such as interviews allow CYP to decide what and how much information they decide to share with a researcher (Hill, 1997). Nevertheless, it should not be assumed that power is equalised due to a choice of method or by simply including CYP participating in research (Holland et al., 2010). The YCs in the current study could decide which questions they wanted to answer and how much they wanted to share and this was explained to them. The hope of the researcher was that participants felt at ease and only shared what they felt comfortable sharing and did not feel pressured into discussing topics which they were not happy to share. The researcher tried to ensure, through meeting with the YC to develop a research relationship and explaining the process and expectations, that YCs did not feel a power imbalance but it is not possible to say if this was fully achieved.

#### 3.9.3.4 Vulnerability and Minimising Distress

Participants who have experienced adverse life experiences can be seen as vulnerable. The YCs who participated in the current study may have found discussing their caring role and wider life experiences as challenging and, in some cases, upsetting. To avoid this, thought was put into the questions to try and minimise any potential distress for the YCs. As explained to participants they could refuse to answer questions or stop the interview, if they wanted to. Participants had family members nearby, should they have felt upset. At the end of each of the interviews, participants were invited to speak to the researcher, alongside their parent to go through anything further that they wanted to question or discuss. Debrief letters (Appendix P & Q) were sent to YCs and their parents, containing information of where to go for any additional support. While the researcher was mindful of not causing the YCs to experience any negative emotions during the research process, sharing emotions is a key part of understanding the experiences of YCs (Vaswani, 2018). The expression of emotions during the interviews, or at any time during the research process should not lead to the assumption that the research is unethical (Hynson et al., 2006)

## 3.9.3.5 Debriefing and Support

Debrief letters (Appendix P & Q) were sent to parents and YCs after the interviews. Specifically, the YCs letters provided information should they need any additional support (Smith et al. 2009). It was suggested that they contact their school SENCo or YC project lead. The contact number for Childline was also included for those YCs who did not feel or have access to the YC project or a member of school staff they could speak to.

## **3.9.4 Ethical Principles**

Underpinning the SEND Code of Practice (2014) are three key principles. Professionals should have regard for the wishes, feelings and views of a CYP and their parents. Parents and CYP should be provided with the necessary information to make an informed decision and should be supported so that the best outcomes are achievable (Fox, 2015). All of these principles were taken into consideration during the research so that YCs and their parents felt that they could take ownership of their role within the study.

The four moral principles (Beauchamp & Childress, 2009) which act as a framework for the researcher's work as a TEP and in this study ensures the rights of the child are prioritised. By doing good and ensuring that YCs are not put in the way of harm covers beneficence and non-maleficence. Whilst autonomy respects a CYP's right to make their own decisions, social justice highlights the inclusion of all CYP regardless of their circumstances.

It is the researcher's hope that all of these principles have been fulfilled in this study, through focusing on the child's voice and prioritising their views.

# 3.10 Conclusion

This chapter has defined the methodology and methods used in this research as well as the researcher's philosophical position in relation to epistemology and ontology. The aims of the research and the central research question and sub-questions have been included alongside a rationale for the use of IPA and the alternatives considered by the researcher. The data collection and analysis stages have been described in detail. The importance of ethical practices and principles have been discussed. The following chapter will focus on the findings.

#### **Chapter 4 - Research Findings**

## 4.1 Chapter Overview

This chapter provides an overview of the analysis of the findings which emerged through completing IPA. The chapter focuses on the researcher's interpretations of the participant's lived experiences of being a YC. Through a process of repeated reading, analysis and interpretation of each transcript superordinate themes were identified for each participant (Appendix Z). An example of this process can be found in Appendix Q. Further analysis, looking for any similarities but also differences, resulted in the identification of superordinate themes across participants, which encompassed subordinate themes (Figure 4.1). Each superordinate and subordinate themes are discussed with a focus on both shared and unique participant experiences. Quotes are used throughout the chapter, which include the participant's pseudonym and line number from the transcript, in order to illustrate the themes generated by the analysis. The central research question and sub-questions are restated below were held in mind throughout the analysis and interpretations to ensure that they were fully addressed.

- RQ1 What are YCs' lived experiences of education?
- 1a What educational support have YCs experienced?
- 1b What are YCs' reflections on their educational experiences?

Three superordinate themes emerged from the analysis using IPA. These were, protective factors, adversity and the impact of caring and support through education (Figure 4.1). Key findings discussed include the importance of support from friends and family, duty and the obligation the YCs feel and experience and support the YCs identify in relation to support they have received or would like to receive in school.

# Table 4.1

Master/Superordinate themes	Subordinate themes
Master theme 1: Protective factors	<ul> <li>Friends and family as support</li> <li>Outside support</li> <li>Respite and self-care</li> <li>Connecting with care receiver</li> </ul>
Master theme 2: Adversity and the impact of caring	<ul> <li>Duty and obligation</li> <li>Role reversal</li> <li>Helper and protector</li> <li>Disruption and difficult feelings</li> </ul>
Master theme 3: Support through education	<ul> <li>Identity as a student</li> <li>School as a positive</li> <li>Support with learning</li> <li>Active school support</li> <li>Missed opportunities</li> </ul>

Master superordinate themes with subordinate themes

# 4.2 Superordinate Theme 1: Protective Factors

Protective factors link to a number of different areas the participants raised in relation

to what they as YCs enjoy and in addition, what helps them in their everyday lives as a YC.

The four subordinate themes, found in table 4.2, look at friends and family as support,

support they receive from others, respite and self-care and connections with care-receivers.

# Table 4.2

Subordinate themes for superordinate theme, 'Protective factors'

Superordinate theme – Protective factors	
	Friends and family as support
	Outside support

Connecting with care-receiver

# 4.2.1 Subordinate Theme 1: Friends and Family as Support

Friends and family seem to be a very strong support for the participants, as they were mentioned frequently in the interviews and all of the participants were able to say which person or group of people, they were more likely to speak to and who they felt supported by. Friends, in particular, were seen by the YCs as understanding, supportive and at times a welcome distraction from their caring role. Hannah, when asked about who she felt most comfortable sharing information with, chose her friends.

"Uh my friends, a lot, cause they're the same age. And, uhm, that they'll understand to an extent" (Hannah, lines 172-173)

"Uh yes because they are very understanding and I'm lucky to have friends like that" (Hannah, line 183)

*"Just taking a day out with my friends and spending all day with them" (Hannah, line 337)* 

Hannah relayed that she is fortunate to have her friends and that they have some level of understanding, suggesting that they know about her being a YC. At the end of the interview Hannah is asked who she would like to spend her perfect day with and she once again focused on her friends.

For those participants who access YC projects they spoke about having friends at school and friends at the project and some of the differences between them.

"Uhm, none of them go to the same school as me but uhm (background noise), yeah, but uhm, I do keep in contact with some of them" (Jordan, lines 136-137)Friendships with other YCs who do not attend the same school as Jordan are maintained, signifying that he values their friendship and connection that they have together as YCs.A distinction is made between school friends and YC project friends by Hannah.

"Uhm, well there's (name – YC project), I talked to the workers there and also my friends there, uhm unlike my friends from school they can relate cause they're also young carers" (Hannah, line 177-178)

"Uhm, the I-I guess the only difference is our backgrounds in terms of, (name – YC project) my friends are young carers and at school my friends aren't young carers" (Hannah, lines 186-187)

Hannah stated that her school friends do not fully understand her role as a YC but that her friends at the YC project do. She related the differences between the two groups on background and whether or not they are a YC. She goes on to say, "*But they are both supportive in (two second pause) the same way" (Hannah, line 189).* In a similar way to Jordan, Hannah values both friendship groups. She likes to spend time with her friends and is receiving what she needs from the two groups.

At school Jessica is friends with another child who is a YC. "*She's a friend of mine, we still play together*" (*Jessica, line 225*). Jessica spends time with the peer but does not explicitly state whether the relationship is due to or continues because of their similar caring roles. In the interview when Jessica was asked how she feels when she gets to school after a busy morning at home, she identified her friends as a good distraction. "*I feel ok cause my friends usually have something to talk about so it'll take my mind off it*" (*Jessica, lines 353-354*).

It is not only friends who the participants find to be a support, as family members are spoken about too. George was asked during the interview who he would share information with, such as exciting news. "*Uhm. Probably my brother*" (*George, line 137*) This was followed by, "*Then my mum and dad*" (*George, line 139*). This would imply close and trusting relationships with those family members, including his brother who he provides care for.

Family is also an important part of Jessica's life. "Uhm definitely my mum and I like to spend time with my dad and my brother as well" (Jessica, lines 200-201). She spent time talking about her close family. "Uh my mum she bakes a lot" (Jessica, line 68) and described the activities she liked to do with them. "Uhm, probably like baking with my mum 'cause I really like doing that" (Jessica, line 416). Jessica is a football fan and shares this interest with her dad, "My dad is a Leeds fan as well" (Jessica, line 72). Spending time together as a family seems important to Jessica and she is still able to do this with separate family members whilst also having caring responsibilities for her sister. Jessica places trust in those people who are close to her family. "Uh like maybe (name), one of my mum's friends and that" (Jessica, lines 207-208). This was the response when asked who she could turn to for advice. After her family Jessica prioritised her mum's friend.

## 4.2.2 Subordinate Theme 2: Outside Support

The YC participants explained the importance of support away from their family and friends. This linked to people who knew that they were a YC.

"So, in the activity club they have uhm, so they have like arranged activities basically so, we play games uhm sometime we go on trips once in a while. And uh, they talk to us about uhm, they-they really help us bear in mind that uhm, going there shows us like there are other people in similar situations to you and it does help quite a lot actually" (Jordan, lines 127-130)

The YC project Jordan is a part of fulfils a number of roles. It provides activities and time away from thinking about being a YC and promotes shared understanding amongst the attendees. Jordan also mentioned that the project workers are there for the YCs to speak to.

School and the YC project are seen to be supportive outside agencies for Hannah. "Uhm, well there's (name - YC project), I talked to the workers there..." (Hannah, line 177). As a member of that project Hannah will know that staff are there for her to speak to and she could feel more comfortable speaking openly to them as they are aware of her experiences at home. Similarly, teachers at school know of Hannah's YC role and she will seek them out. *"teachers in my school, cause then I'll get advice from someone who is professional, and older" (Hannah, lines 173-174).* As the teachers in school are seen to be professionals and older than Hannah, she sees that they are able to give her the advice she is looking for and the reassurance of somebody older guiding her through any difficulties.

## 4.2.3 Subordinate Theme 3: Respite and Self-care

The theme of respite and self-care encompasses all of the activities the YC participants do that they enjoy, which may not include other family members. These chosen activities are times just for the YCs, perhaps with friends. Many of the activities involve the YCs being active and are sports based.

*"I like playing piano, uhm and I like basketball" (Jordan, line 23) "I do basketball at school. Uhm, I play with my friends sometime-sometimes" (Jordan, line 25-26)* 

"I like bike riding and I got a bike it was my birthday recently and I got a bike. I like riding that" (Jordan, lines 28-29)

"Uhm I go to uhm, kickboxing" (Jordan, line 168)

Jordan accesses a range of sporting and non-sporting activities. His time engaging in these activities does not appear to be affected in any part by his YC role and would be considered typical for many young people who are Jordan's age. George and Jessica named football as one of their hobbies.

"Uh football, playing video games" (George, line 22) "I like to play football" (Jessica, line 24) "I usually train on a Thursday and play a match on Saturday" (Jessica, line 28) George does not elaborate on how frequently he plays or watches football, whereas Jessica has clear days when she knows that she will be playing football and she will have a time away from her caring role and that football is a time just for her.

The YC participants name activities most people would typically expect children and young people to do in their spare time. Hannah has developed interests through school which have now become her hobbies.

"I'm into music and drama" (Hannah, line 21)

"because, not only are they the subjects that I study at school but is, hobbies that I enjoy outside of school as well" (Hannah, lines 25-26)

George and Hannah share an interest in watching films and television. George stated the following when asked what his favourite things to do outside of school are. "*Watching movies*" (*George, line 24*). This was followed by George explaining that he liked the Harry Potter films and spent time watching them. Hannah's response to the same question provided a list of activities she found to be interesting but did include having time to spend watching the television. "Uhm, a lot of dramas and TV shows I like to binge so, quite a lot of the popular ones right now" (Hannah, line 55-56).

Aside from hobbies elements of self-care are thought about too. Hannah detailed what she would like to happen on a perfect day.

*"Where I'm away from home, away from school and just with them [friends] where I can be myself" (Hannah, lines 339-340)* 

"Uh just, shopping or going to restaurants, or going to the cinema just having a whole day to ourselves" (Hannah, lines 342-343)

Hannah wants to have a day away from school and home and just to be with her friends, doing the things that she would like to do. As this is a description of a perfect day it is difficult to ascertain whether Hannah has the opportunities to do these things or that these are things that she would like to do. The phrase, 'where I can be myself' suggests that Hannah takes on a number of different roles or identities that are expected of her due to her caring role. These roles may not feel natural to Hannah unlike when she spends time with her friends. When spending time with friends Hannah is more comfortable with the role she has and perhaps there are fewer expectations attached to being in the role of a friend as opposed to a carer.

Overall, the YC participants do have time away from being a YC and have opportunities to engage in activities their peers are also likely to participate in. They all have their own interests and hobbies, mostly away from their family home and from school. None of the participants describe not being able to do the hobbies they enjoy, due to any additional responsibilities and are therefore able to access some form of respite from their YC role.

### 4.2.4 Subordinate Theme 4: Connecting with Care-receiver

All of the YC participants have a caring responsibility for one of their siblings. Three of the participants have a connection to that sibling as a brother or sister in conjunction with caring. George and Jessica explain the kinds of games they play with their siblings at home.

"play games, uhm I'll go in goal for him so he can take shots against me" (George, line 111)

"I usually play with her and that" (Jessica, line 89) "We usually, I like to play dolls with her and that" (Jessica, line 92) "Well, me and my brother usually make up games about superheroes and she'll join in like she's got princess dresses. So, we'll either be one of them, from a movie" (Jessica, lines 390-391)

The descriptions of the different play activities, such as going in the goal when playing football, dressing up and playing with dolls would be representative of many siblings playing

together. There is no mention from either participant about their YC role in these situations and there is nothing to suggest that these activities do not happen frequently at home.

Jordan's descriptions of the times he spends playing with his brother seem to be an equally enjoyable experience for him.

"I like uhm, jumping with him on the trampoline. We like doing that and uhm we like playing with our dog" (Jordan, line 31-32)

"I play with him uhm, he likes building blocks and uhm he likes marble runs and he likes being tickled" (Jordan, lines 55-56)

"I like, I watch films with him sometimes, and uhm yeah, I just I like spending time with him" (Jordan, lines 68-69)

"I just-we just enjoy each other's company sometimes" (Jordan, line 71)

Each statement inferred Jordan's fondness for his brother and the time that they spend together. He knows his brother well and knows what activities to initiate, such as building blocks and tickles, to engage him. Jordan expresses that he likes to spend time with his brother and that they enjoy each other's company, which suggests that Jordan sees these games as reciprocal and fun. Jordan switches between what he likes, what they both like and what his brother likes. This may mean that they both get times to do the things that they enjoy and have activities that they both mutually enjoy. This does not seem to be a chore or given responsibility but a genuine interest in spending time with his brother.

Descriptions of play with their siblings from George, Jessica and Jordan do suggest a connection to their caring role. The three participants adapt their play so that their siblings are able to access it and it also stimulates their interest. They all seem to know what activities and games their siblings most enjoy and they utilise this understanding to support and care for their siblings.

## 4.3 Superordinate Theme 2: Adversity and the Impact of Caring

Adversity and the impact of caring is the second superordinate theme. This theme was identified by participants discussing what they found challenging as a YC and the possible reasons for that. As well as some of the YCs feeling a sense of obligation in contrast they all also describe how they help their care-receivers. The four subordinate themes, as shown in table 4.3, are classified as a sense of duty and obligation, role reversal in the sense of performing parent-like tasks, being a helper and protector and the disruption and difficult feelings some of the YCs experience.

# Table 4.3

Subordinate themes for superordinate theme, 'Adversity and the impact of caring'

Superordinate theme – Adversity and the impact of caring	
	Duty and obligation
Subordinate themes	Role reversal
	Helper and protector
	Disruption and difficult feelings

# 4.3.1 Subordinate Theme 1: Duty and Obligation

The YC participants seem to approach becoming and being a YC in different ways, depending on the needs of the care receiver and the support which is already available in the family. George was asked what he thinks about being a YC, to which he replied, *"Well, it just makes me, feel (two second pause), like I'm doing the right thing" (George, line 71)*. This could suggest a feeling of obligation that the right thing to do is to look after your brother. The feeling of doing the right thing is further expressed by George's following statements:

And, uhm. Yes, it just started and then my mum said do you wanna be a young carer and I said yeah sure. And... (George – 97-98) I started being a young carer (George, line 100) The first statement appears almost blasé, as if he had been asked an everyday question and he thought that he thought he would give it a go. A possible reason for this is that George simply wants to support his family and agrees to the YC role as that is what he thinks he should do.

Jordan, who is an older YC than George seems to take the responsibility of being a YC much more seriously.

I think when I hear young carer I think of like, of-of like a huge responsibility that you have to take really seriously (Jordan, lines 48-49) Well, sort of but I mean upon the the older Last the mean I'm able to do (Jordan

*Well, sort of but, I mean uhm, the-the older I get the more I'm able to do (Jordan, lines 99-100)* 

As a secondary aged YC, Jordan has been caring for his brother for longer, he is part of a YC project and so hears about the different responsibilities other YCs have. By stating that YCs have a huge responsibility he is also placing this on himself, which in turn could lead to feeling pressured and overwhelmed. However, he does not state that he has to take it seriously as he does not use the word, 'I', instead Jordan uses the word, 'you', as if removing the responsibility from himself. He does state that with age comes more responsibility so that perhaps Jordan sees huge responsibility coming with age and that he is still too young to experience that. This is further emphasised by Jordan's next quote. "*I try to uhm help around the house do what I can I like doing his homework with him, so reading, writing, spelling*" (*Jordan, lines 39-40*). Jordan does what he can by helping his brother with practical tasks, such as homework.

Jordan recognises the differences between himself and his brother and knows that his brother needs to have the help as he cannot do some things independently.

> "Well, it would be different at home cause um, it'd be easier for him to do things on his own because uhm, he needs a lot of uhm, there's a lot of things he can't do on his own. But, if I wasn't a young carer then he would, be able to do a lot of things by himself like we can" (Jordan, lines 91-94)

This quote refers to Jordan's duty. It suggests that Jordan feels that his brother needs his help. He considers what it would be like if his brother did not need his help and knows that his brother would likely be able to do a lot more on his own and not require Jordan to be his carer.

Hannah sees her duties as being practical for her brother and mum.

"So, in terms of, 'cause, with autism you have to have a daily routine in order to function so you have to make sure his routine is going the way it should be going" (Hannah, lines 94-95)

So, uhm making sure he has food at certain times making sure, that he's just happy and there's nothing wrong, and knowing that if there is something wrong there's something, uh you're there to help (Hannah - 97-99)

But then, like uh she can't really get around so she can't leave the house without me pushing her or my brother or anyone. Whenever we go out someone has to be with her (Hannah - 135-136)

Uhm yeah so, I tend to cook a lot in my house and do shop runs. And then chores around the house. Uhm, whenever, like, my dad is working. Or no one else is home so (Hannah - 146-147)

All of these quotes identify the practicalities of Hannah's YC role at home. She knows her brother well and wants to make sure that what he needs, he gets. Hannah mentions the importance of routines for her brother and ensuring that everything is in place for them to happen, including meal times. Hannah has many adult responsibilities from cooking, to completing chores, food shopping, as well as being there to ensure everything runs smoothly for her brother and her mum is supported when she needs to go out.

# 4.3.2 Subordinate Theme 2: Role Reversal

This theme seeks to understand the role reversal, in doing parent like tasks, as experienced by the YC participants. Hannah was a YC for her older brother for several years before she also took on further caring responsibilities for her mum. "Uhm, my mum became an amputee. - that was when I mainly became a young carer, I've always been a young carer for my older brother, but then obviously I was a lot younger and my mum was a lot more able-bodied then, so she did a lot more than I did" (Hannah, lines 76-78)

This is the point when Hannah started to see herself as a YC. It was as though Hannah had not really seen herself as a YC until her mum needed help. Hannah no longer had her mum to perform all caring duties and she was instead expected to take on elements of a parental role. By using the past tense Hannah implied that her mum did do a lot but could not do as much now, particularly as she is an amputee and needs support herself.

The idea of parental role reversal is further emphasised by Jessica. When she is at school Jessica thinks about her sister and states, "*I'm just wondering if she's ok cause usually she's a bit better if not, like, if everybody's home she's a bit overwhelmed" (Jessica, lines 363-364).* Whilst thinking about her sister Jessica worries about her mum during the day and thinks about how her sister may be having an impact on her mum when there is no-one else at home. "*I hope she's ok and hopefully it's not that bad" (Jessica, line 368)* Jessica takes on the carer role to ensure that her mum is happy when she perceives that her mum is struggling. "*Well, I just try to make her happy when she's a bit down" (Jessica, line 121).* Jessica attempts to comfort her mum using actions which have no doubt been used with Jessica to make her feel better when she is sad. "*I like hug her or I stroke her" (Jessica, line 124).* 

From the quotes it can be seen that Hannah's view of the situation is much more practical. Her mum is unable to do the tasks she was once able to do and it is now Hannah who will take on that caring role. For Jessica it feels a lot more emotional as she is tuning into how her mum is feeling and worrying about her. Both participants show themselves to have taken on a parenting role, in different ways.

### 4.3.3 Subordinate Theme 3: Helper and Protector

As helper and protector, the YC participants describe what they do to help their sibling or parent. Very early in the interview with Jordan he proclaimed, "*And uhm I'm a young carer of my little brother*" (*Jordan, line17*). Jordan had been asked to talk about himself and it seemed that by calling himself a YC so early on in the interview signalled that this was a part of his identity. The use of the word, 'little' to describe his brother brings many thoughts to mind. His brother is younger, smaller, more vulnerable and in need of protection, which Jordan sees himself as doing and being as a YC. Jordan is positive about being a YC. "*Well, I sort of enjoy being a young carer, so even if I wasn't, I think I would like to even, even if I wasn't, I'd like to help in that situation in a way*" (*Jordan, lines 74-75*). Jordan spoke highly of his brother and the time that they spent together. Being a YC could be a positive in Jordan's life and maybe something he continues with in the future. Jordan maintains his 'helping' position by providing support to his brother when he needs it. "Well usually he comes to me and uhm he tells me what he wants" (Jordan, line 59).

George's description of how he helps his brother is very practical. "*Uhm, oh* sometimes turn on the fan when he wants it, on" (George, line 105) and "*uhm open the door* for some, some lighting not too much" (George, line 107). Both of these quotes are all about how George helps his brother, when he needs to. This shows that he is aware of his brother's needs and knows what he needs to do to help.

Hannah is able to identify ways in which she helps her mum and brother.

"Uhm, not as much now that I'm older and he has other professional adult carers, but then, I guess, if they need help with stuff like finding clothes or laundry or anything like that, I would be there to help them" (Hannah, lines 101-103)

"Uh, helping, go with her to hospital appointments, and helping her out in that way" (Hannah, line 138)

Hannah provides help to not just her family but additionally helps others who are in the family home so that it all runs smoothly. She states that her brother has his own carers but this does not stop her from helping. Hannah sees herself in a helping role when her mum needs assistance in attending hospital appointments.

Jessica's role as a helper continues to develop. She was asked to think about when and why she became a YC. "*I started to just like help out with her 'cause she started like acting up and that (Jessica, lines 95-96)*. Jessica's role as sister started to change and she felt that she should help. She did not state that she asked to do anything to help but decided to initiate the support herself. She continues to try and help and considers the things that her sister likes to try and create distractions. "*Well, I gotta try take her mind off it, and I've got Tik Tok so I try to do dancing with her. It usually calms her*" (*Jessica, lines 108-109*). Whenever her sister hurts somebody Jessica steps in and tries to help. "*I just try to change her mind and that, or take her away from whoever she's hurting*" (*Jessica, lines 112-113*).

## 4.3.4 Subordinate Theme 4: Disruption and Difficult Feelings

For the most part the YC participants speak positively about their role and the help they provide, but being a YC can raise difficult feelings, which can be about themselves, others or the situation itself. Hannah recollected what it was like before being a YC for her mum and when things began to change when her mum entered hospital.

> "Uhm, it was me being the one who was looked after, it was a lot easier, uh I had more time to do stuff, there was less chores, less jobs for me to do, less stressful over time" (Hannah, lines 151-152)

"Uhm, so when my mum was in hospital, uhm it was during a time when I was doing exams and it was very stressful" (Hannah, lines 212 - 213)

"And it wasn't good, for my mental health" (Hannah, line 215)

Hannah states how much less stress she experienced before becoming a YC for her mum and how the emphasis was on her being the one who was being looked after in a typical mother/child relationship. She is aware of how the stress of becoming a YC had affected her mental health.

As a sister to a younger sibling with additional needs Jessica is having to adjust to change at home, something she may not have experienced before. "*Well especially with my sister*. *She uh makes the place a bit more, uncalm and that*" (Jessica, line 162). Jessica goes on to explain some of the things she experiences. "I just kept getting things thrown at me and taken away from me" (Jessica, line 175). Whilst Jessica adjusts to being a helper and YC within her family she is also having to adjust to quite an unsettled home environment.

Jessica stated throughout her interview how much she enjoys spending time with her family and how important they are to her. She knows that some of the routines will now have to change at home and is quite matter of fact about it. "*Right, my mum can't come to my games I have cause of (sisters name) she'll have a meltdown and that or run off. So, she can't come and has to stay at home" (Jessica, lines 375-376).* Initially it would seem that Jessica is adapting to this but reveals through the course of the interview how she feels. "Just a bit down" (Jessica, line 177) and elaborates further, "Sometime I just get a bit sad about it but sometimes I just think its life" (Jessica, line 386). Jessica acknowledges that being a YC is hard and is not afraid to admit how it makes her feel. The changes to the family unit and Jessica's changing role within the family clearly affects how she feels but does accept that this is what family life is now like.

# 4.4 Superordinate Theme 3: Support Through Education

This theme relates to the educational experiences each of the participants discussed. The participants expressed what they thought about school and how they felt that they had or had not been supported at school, whilst also taking into consideration support, they may have experienced outside of the school environment. The five subordinate themes look at the ways in which the participants identify as students, how they consider school to be a positive, support they receive for their learning, support they have received in school and ideas of what they think could be put into place in school to help YCs.

# Table 4.4

Subordinate themes for superordinate theme, 'Support through education'

Superordinate theme – Support through education	
	Identity as a student
	School as a positive
Subordinate themes	Support with learning
	Active school support
	Missed opportunities

# 4.4.1 Subordinate Theme 1: Identity as a Student

Whilst discussing school and their experiences of it two of the secondary school

participants, Hannah and Jordan, raised the idea of being a student. Jordan in particular, made reference to his role as a YC whilst speaking about school.

I find it like, it doesn't affect me too much because (background noise) despite being a young carer I do manage to uhm, get good grades while I'm at school and uhm I don't think it's too hard (Jordan, lines 154-156)

Jordan makes it clear through this quote that being a YC does not affect his time at school and that he is able to get good grades. The use of the word "despite", used by Jordan would suggest that being a YC should prove difficult for him to be successful at school and could be a potential barrier to his learning but it has not hindered him. It is almost as though it goes against what is expected of a YC in school and that it is unlikely that YCs, in his view, will succeed in school. Jordan instead finds that his YC role does not affect his education and that allows him to achieve and maintain good levels of progress. Jordan further emphasises his interest in school by stating, "*I like history and P.E. those are my main two subjects (Jordan, line 160)*. Jordan has already said that his YC role does not affect his learning and his quote shows the breadth of his interests, including an academic and more practical subject.

When asked about the differences between being in primary and secondary school Hannah focused on the responsibilities and the pressure which are likely to be encountered when attending secondary school.

"Uhm, yeah because, yeah there's a lot more responsibility in secondary school 'cause you have to think about GCSEs, A levels qualifications, the future, your career" (Hannah, lines 273-274)

"The teachers put a lot more pressure on you in that way, and then the way they teach you as well the teaching styles are different. Everything is sort of handed to you, so you wanna play when you're in primary but in secondary, especially in sixth form, there's a lot of independent learning that you do so that's, that's the main difference" (Hannah, lines 276-279)

Hannah defines the differences she has experienced between primary and secondary school. Her time at primary school appears to have been a time when she was being led, as opposed to secondary school where she has to take more of the lead. The "responsibility" she feels in secondary school and sixth form is not linked to her YC role but places the reason for this on the teachers in schools and the need for "independent learning". Hannah places importance on "the future", showing that she is looking to and possibly planning for what may come next.

Further on in the interview Hannah switches her focus to the expectations of school and the pressures these can bring.

But then there's always that pressure of exams and stuff that I always get stressed out about. And I know a lot of teens do. And the way, the education system just messes with your mental health in that way, uhm (Hannah, lines 292-295)

*Uhm, just, uhm the pressure of it, if I'm honest. Uh the failed exams I'm not really the best when it comes to exams (Hannah, lines 310-311)* 

It should be noted that Hannah recognises that taking exams is something she finds stressful but also acknowledges that this is similar to her peers and again is not linked to her role of being a YC. Hannah is aware that the pressures she feels in school can have an impact on her mental health. Her use of the word "failed" indicates feelings of negativity towards the exam process.

Jordan and Hannah identify as students showing a clear distinction from their YC role. Their experiences of secondary education differ, but this may be due to a difference in age between the two. Jordan sees his school life as being successful, whereas Hannah aims her attention towards the pressures she feels. The difference could also be related to the amount and type of caring they each carry out, with Hannah completing the more practical tasks around the home and Jordan engaging in play and learning activities with his brother.

## 4.4.2 Subordinate Theme 2: School as a Positive

School for three of the participants is seen to be a positive place for different reasons. As a continuation from the first subordinate theme Jordan maintains his feelings of positivity towards his life at school. "*I do enjoy school quite a lot to be fair*" (*Jordan, line 200*). Here Jordan explains his enjoyment of school and goes on to state, "*I enjoy my lessons and I*'m *able to concentrate well and I*'m *able to learn well*" (*Jordan, line 202*). This second quote from Jordan links well to his earlier statements in subordinate theme one in which he reports that he is doing well and is able to learn.

School is also a source of enjoyment for Hannah. "*Uh I mean, I enjoy school, uh not many people do but I enjoy it*" (*Hannah, line 292*). Although Hannah has already identified school as being a cause of stress it is still something that she likes and emphasises how much she likes it by repeating the word "enjoy" twice within her statement. When asked to think about what she thinks about school and if she has any favourite subjects Jessica explains, "*Uh, kind of like 'em all*" (*Jessica, line 310*), implying that she enjoys lessons in school.

From a different perspective Hannah and Jessica see school as a positive through the development of relationships with certain members of school staff.

...there are professional ones who are in inclusion whose job it is for you to talk to if there are problems at home, but then there are also the teachers who are very nice who you just want to talk to who you might see, as a friend as well as a teacher (Hannah, lines 195-197)

Hannah makes a distinction between those members of school staff who she describes as professionals who are there to advise and support and the ones who she sees in a less formal way. She expresses that she sees them as teachers but that there is also the possibility of a friendship, which alters the nature and boundaries of the teacher/pupil relationship. By seeing the teachers as potential friends indicates some levels of trust in these adults and a feeling of mutual respect.

Jessica too had made a connection with a member of staff in school. "*I usually talk to my teaching assistant cause she's there all week 'cause I get a teacher different half way through the week*" (Jessica lines 242-243). Although Jessica does not explicitly state an enjoyment of speaking to a member of school staff, she had established a connection with a professional in school, whom she saw often. The consistency of having the same teaching assistant seems to be a factor in Jessica feeling able to speak to them, as opposed to the change in teacher during the week. Finally, Jessica's statement, "*I just like the peace from my sister*" (*Jessica, line 305*), sees a different way of looking at school. Instead of seeing school just as a place to learn or to develop connections with others, Jessica now sees school as a space separate to her sister and in that way separate to her role as a YC. School brings some form of "peace" to Jessica signalling within that environment she is undisturbed and may experience school as a calm place.

Within this theme participants see school as a positive for various reasons. Some of them clearly state their enjoyment of school, with two of them extending this by reflecting on their connections with school staff. Jessica's explanation of school being a place of calm and time away from her sister would hint at her seeing school as a good place to be.

## 4.4.3 Subordinate Theme 3: Support with Learning

During the interviews all four participants were asked discuss any support they received in relation to their learning which linked to being a YC. Participants Hannah and Jordan access their local YC project for support. Jordan reflected on what kind of support he accesses. "*Uhm so uhm, without if it wasn't lockdown then uhm I would usually go to a homework club" (Jordan, line 118).* He typically attends a homework club which is run by the YC project and goes on to say, "*it helps me to concentrate and because my brother loves like to play with me and stuff like that and it just helps me to concentrate a lot more" (Jordan, lines 120-121).* These quotes show that the separate space of a homework club helps Jordan to concentrate and enables him to complete his school work without having the distraction of his brother and the need to fulfil his YC role.

Hannah also relies on clubs away from home to complete school work and cites the inability to concentrate at home.

I think it does contribute to it in a way, where I do, uhm but my home environment isn't the best place to work in 'cause you can't concentrate as much, so I mainly rely on (name – YC project) homework clubs. Clubs at school, libraries, uhm stuff like that (Hannah, lines 318-320)

Hannah does not specifically state why she is unable to concentrate at home but makes it clear that her home environment is not conducive to completing work. She relies on not just the YC project but also groups at her local library and clubs run by the school. This shows that she is aware of where help is available to support her in her learning. Aside from clubs Hannah looks also to school staff to reinforce her support network.

> "Uh just making sure that you're ok, and taking the time to sit with you and then get you through whatever you need to get through, whether that be a mental health or if you're behind in work, or if you just want something to be explained to you, but slower" (Hannah, lines 303-305)

She highlights that the support she receives from school staff is not just for her learning but her mental health too. The idea of getting through whatever you need to get through, demonstrates that school signifies more than just learning for Hannah and that she trusts school staff will provide support with her mental health.

The difficulties that have ensued due to not being able to access school or clubs fully is expressed by Hannah.

"Uhm yes, because I wasn't allowed in school, and that's the way you learn the most so I wasn't able to concentrate at home, and learn by myself" (Hannah, lines 325-26)

Hannah sees school as the place in which she will learn and makes the distinction that at home she is unable to learn and most importantly, not by herself, demonstrating Hannah's want for support.

Jessica is certain what she finds the most challenging about being at home and not having direct access to the school environment and school staff. "*Definitely homework, I've*  got homework 'cause I was isolating, and I haven't been able to do it all" (Jessica, lines 167-168). This quote is a response to Jessica being asked if there were any differences between what it was like to be a YC before Covid-19 and presently as a YC. There is also the added issue of the national lockdown which was a further contention. Jessica does not find support for learning through home and is accepting of the fact that she is unable to complete school work. At this stage Jessica does not detail why she cannot complete school work at home but further on in the interview she conveys the difficulties she encounters due to her sibling's difficulties.

The word 'concentrate' appears several times in this theme and for different participants. Looking through the transcripts the word 'concentrate' is not used as a prompt during preceding questions and so the inability to concentrate at home is important in relation to their learning. None of the participants speak of encountering any support for their learning through home and look externally for that support. The information relayed by the participants show the difference between support received, through school and clubs and support that they want.

## 4.4.4 Subordinate Theme 4: Active School Support

This theme draws upon the support some of the participants have received in connection with their role of being a YC. When George first became a YC to his brother, school included him in an activity. "at school uhm I did a thing called draw and talk and I went out of with the teacher every afternoon on Tuesday" (George, lines 168-169). He goes on to describe the sessions. "And uhm, uh, she would ask me a couple questions and then I'll just draw whatever I want and then I'd have to explain what that picture means to me" (George, lines 171-172). Although not a recent activity, George remembered this support which was put into place to aid his transition to being a YC. "Uh I'd had enough when they finished" (George, line 177). George states that by the time the activity sessions came to an

end he did not wish for any more. "*I did enjoy it yeah" (George, 179).* This shows George enjoyed the sessions but does not indicate in detail how it supported his transition to being a YC. George expressed what he felt he got from attending those sessions each week, "*the drawing in just, being able to have some time alone" (George, line 183).* The key word 'alone' could indicate that George felt the need for alone time, possibly to process the changes occurring at home. By the end of the conversation on this subject George states, "*Uhm, I'd like to do more things like that, yeah" (George, line 256),* but gives no specific reason as to why he would like to do more of those types of activities.

Prior to Hannah becoming a YC for her mum she was a carer for her older brother. However, it is the time in which Hannah experienced becoming a YC for her mum that she focuses on during the interview. In this part of the interview Hannah is asked at what point did school staff become aware of her YC role.

> "Uhm, so when my mum was in hospital, uhm it was during a time when I was doing exams and it was very stressful" (Hannah, lines 212-213). And it wasn't good, for my mental health (Hannah, line 215) So, I guess teachers could tell that there was something wrong. And I was crying and I was upset (Hannah, lines 217-218)

> *Uhm, so they, uhm they helped me with that. They would like take time aside and talk to me and be like "are you ok?" (Hannah, lines 220-221)*

Through the interview Hannah explained the situation she faced and the impact it was having on her and how it was evident in school that things had changed for her. School staff recognised that Hannah needed help, rather than Hannah seeking out the help, that she may have been unaware was available to her. She speaks positively about school staff who took the time to speak to her, during a significant change in her life. This active support in school does not diminish as time progresses and Hannah relays that school staff continue to be a source of support. *Uh they do tend to check in. I do see quite a lot of the same teachers on a daily basis, ok, but even if I don't have them, I'll still see them (Hannah lines 227-228)* 

Well, I'm quite lucky in that my school's always been very supportive, I know how a lot of schools aren't like that, but, uhm I would say, understanding, that uh, that children, have life at home as well as in school. Some teachers don't understand that (Hannah, 232-234)

From Hannah's perspective school staff continue to check-in with her and she finds this to be supportive. For the most part Hannah stresses how much she gains from school staff, but shows an awareness that not all schools or all school staff will provide the same level of support she has experienced.

Links between school staff and the YC project have been established, according to Hannah, not just for herself but for other YCs who may be in school and attend the project.

> Uhm, they've spoken to each other now and then, whenever they were concerned about me. But uh yeah, they started that communication 'cause they also refer other students apart from myself and others (Hannah, lines 257-259)

This shows understanding on the part of the school and the need to share information as part of their support process for YCs. For Hannah there is the part that she is being held in mind by school and the project and that the team are there to contain and safeguard Hannah at the times when she needs it the most.

## 4.4.5 Subordinate Theme 5: Missed Opportunities

The theme of missed opportunities looks at and compares what the YCs feel may be missing from their school experiences, with them giving ideas and examples of ways in which schools could adapt their practice to meet the needs of YCs. Each of the participants were asked if there was anything they felt that school as a whole or school staff could do to make not only themselves but other YCs feel helped and assisted.

I think they would uhm, I think they should acknowledge the fact that there are young carers in their school a bit more (Jordan, lines188-189)

Like maybe do something, I don't really have any examples of what but like do something to help them maybe to make that support group for example (Jordan, lines 191-192)

*Or like have a club where some of the people a bit like me can just play games with and socialise (Jessica 276-277)* 

At that point in time of the interview Jordan and Jessica explained that they had not received any additional support from school in relation to being a YC. In spite of this both were able to suggest ideas of what schools could put into place. Jordan wanted there to be more of an acknowledgement in school of YCs and gave the idea of a support group. Jessica suggested a club in school for YCs to access. These statements show that they have both thought about the support that they may like, showing that they both do think that there is a need in schools. The two ideas, although closely linked, reflect the age and developmental differences between a primary age student and a secondary age student. One preferring the time to play games and the other looking more for specific support.

Jessica is aware that she does not receive any help from external organisations, including her school, but has thoughts on what she would like for herself.

*Uh, I think it would be nice to actually have some time to speak to them (Jessica, line 261) Well, they don't really do anything but I'd like for them to actually, have* 

somebody for me to sit down and talk to (Jessica, lines 273-274)

There is an emphasis in these quotes in Jessica having somebody to speak to. The fact that she repeats this shows how important it is to Jessica. Earlier in the interview she mentioned the option of being able to speak to the teaching assistant in class and later on, when asked Jessica explained that she would not feel comfortable seeking out help. These suggestions from Jessica inferred that she would like school staff to take the responsibility for providing and arranging times to talk, instead of the onus being on her to work out what support is available to her. Another potential missed opportunity, highlighted by Hannah and George is the sharing of relevant information between school staff.

So, only the teachers I've been with in the classes know that I'm a young carer so... (George, line 154)

So, so if I've been so busy and haven't had time to do my homework, uh there was a teacher who knew my mum was in hospital, and I said "I haven't done it for you today but can I give it in tomorrow?" And she said "Ok." But then there are teachers who didn't know, yelled at me and gave me detention, so I guess some teachers to have that understanding, uhm or ask why instead of just making the assumption that uh a child wasn't bothered to do the work (Hannah, lines 236-241)

Whilst George may not be aware of what information is being shared at his primary school, his guess would be that only the teachers who have taught him directly have an idea of his family situation and his YC role. This could be the case with the decision taken within school that information is only shared with key members of staff. Hannah considers the different reactions she has had from teachers in school. With some being understanding and aware of her situation and others not knowing and making assumptions about her. The missed opportunity could therefore be an awareness of YCs in school but also an understanding, as stated by Hannah, of what it is to be a YC.

Hannah reflected on her time in primary school when she was a YC for her brother.

Uhm not really. Uhm, so well we, me and my brothers went to the same primary school, so then they knew what was going on. But I guess at the time when my brother was at school, they did focus on him (Hannah, lines 284-286)

It is made clear by Hannah that school knew of her brother's additional needs as he too was a pupil at the school, but that school staff had not put anything in place to support Hannah as a sibling and YC. The focus remained on her brother, during that period of time, with school staff not considering the support that may be needed and could be provided for Hannah and

other YCs. This statement assumes school staff had an awareness but perhaps they had a limited understanding of the impact caring has on siblings and YCs.

# 4.5 Conclusion

This chapter has presented the three master or superordinate themes across participants and their subordinate themes. Through analysis using IPA of the findings all of the YC participants have experienced protective factors, with most of them acknowledging the impact of caring on their lives and in particular school. Participants have experienced varying degrees of support for their learning and for their well-being in school. What is clear is that all of the participants know what support they feel is or should be in place for YCs. In the following chapter psychological theory and YC research will be discussed in relation to the finding of this research.

## **Chapter 5 - Discussion**

#### **5.1 Chapter Overview**

This chapter explores the current study's findings in relation to the central research question and sub-questions. Additional key findings are presented and compared to YC research and psychological theory. A critical review of the research is carried out, including challenges and strengths and limitations of the study. The implications for EP practice and their work with schools and YCs is considered. This chapter concludes with reflective and reflexive comments from the researcher and final conclusions.

## 5.2 Current Findings Related to Research Questions

CYP who are considered to be YCs are recognised and included in the Children and Families Act (2014), signalling the importance not only of the identification of YCs but also in highlighting the need for different services to support them. As already stated in the introduction, research about YCs has a tendency to seek the voices of those adults who are around YCs, such as teachers or YC project workers with only a limited focus on YCs and their views. This is beginning to change and it should be noted that more research is beginning to focus on seeking the voice of YCs, e.g., Choudhury & Williams, 2020 and Becker & Sempik, 2019. The aim of this research was to find out about the educational experiences of YCs, to see what support in schools was felt to be effective and to identify any gaps in school support. In order to achieve this the researcher explored the following central research question and two sub-questions:

RQ1: What are YCs' lived experiences of education?

1a: What educational support have YCs experienced?

1b: What are YCs' reflections on their educational experiences?

The findings from the current research will be discussed in relation to the central research question and sub-questions, paying particular attention to educational experiences and support. Three superordinate themes were identified during the analysis and included protective factors, adversity and the impact of caring and support through education.

# 5.2.1 RQ1: What are YCs' lived experiences of education?

The findings suggest that school is seen to be a positive space and somewhere YCs want to spend time. Jordan and Hannah are explicit in stating that they enjoy school. Jordan further explains his reasons for enjoying school which connect with enjoyable lessons and his ability to be able to concentrate and learn in school. Jessica too implies that she likes all of her lessons at school. Research shows there are mixed findings when reporting on YC's educational experiences. Hamilton and Adamson (2013) report that YCs face a number of challenges in trying to balance their caring responsibilities with school work. In contrast to Jordan stating that school is a good place for him to concentrate, Smyth et al. (2011) report that YCs often have low concentration levels due to increased worrying and tiredness from their caring role. This is further echoed by Becker and Sempik (2019) who state that YCs have difficulties at school often as a result of poor concentration. However, they do go on to explain that research has not demonstrated a direct link between caring and educational difficulties but that there is an inferred link between the two.

Looking more specifically into the participants' school experiences it is apparent from the current findings that YCs like to spend time at school and see the benefits in attending. This was also demonstrated by research carried out by Moore et al. (2009) in an Australian study with YCs, who reported that YCs felt positive about school and deemed it to be important, thus showing education as being a valued resource. The value of education and school is highlighted as key protective factors linked to resilience (Ungar, 2015). The protective factor is split into three levels: individual, familial and societal. Whilst many

factors feature throughout the three levels, having a positive school experience is considered to be a key protective factor at a societal level (Masten et al., 1990). A YC's connection or relationship to school plays an important role in developing and maintaining resilience. Their engagement and attachment to the school act as an important community resource (Gilligan, 1998).

Along with positive views of school and wanting to attend YCs also spoke about school being a place separate to home and their caring role. Notably Jessica's experiences of education are of a place of peace and time away from her sibling. School could also be seen as facilitating YC's thoughts away from their caring role and allowing them time to think about different aspects of their lives. A combination of enjoying spending time at school and the distraction of lessons enable YCs to focus on other topics away from their home life (Visser-Meily et al., 2005). For some YCs school is a place of respite, with some of them finding it to be a relief to be in school and be seen simply as a child or young person and not as a YC (Martin, 2006).

Whilst overall school has been found to be a positive experience, two of the study's participants, who are secondary age students, described school in different ways. Jordan linked his school experience to being a YC stating that he was able to get good grades even though he was a YC and did not find it to be too hard. Hannah on the other hand, was slightly older and felt that there were additional responsibilities and pressure from school. Hamilton and Adamson (2013) highlight the importance in recognising the life-course stage of a YC. The stage is shaped by the YC's responsibilities and different aspects of their lives. These additional responsibilities and pressures felt by Hannah link to where she is in life and her hopes for the future. She is at the stage of sitting exams and having thoughts about future careers. Hamilton and Adamson (2013) go on to suggest that the stage a YC is at in their life can impact on decision making around transitions to further education or moving to an

independent household. Hannah compares her educational experiences across primary and secondary school and reiterates the increased responsibilities she has encountered as she has got older. She does not, at this stage, discuss differing school support across primary and secondary, although studies have found that YCs often report the same difficulties in experiencing a lack of support and understanding from school staff (Hamilton & Adamson, 2013).

The superordinate theme, 'support through education' encompasses two subordinate themes, 'active school support' and 'missed opportunities'. Both Hannah and George spoke about support they had received in school and shared their views of that support. Whilst George experienced one-to-one sessions for a set number of weeks, Hannah received ongoing flexible support from school staff, which she knew she could access when she really needed it. The other two participants, Jordan and Jessica did not receive any support in school. Jordan did not seek support in school, although Jessica did and she stated what kind of support would be most useful for her. Barry's research (2011) looked at school staff as a form of support noting that having a particular teacher to speak to as contributing to a positive school experience for YCs. Within that same study some of the YCs expressed that they did not find teachers to be supportive enough and that they needed to do more to ensure that the YC's educational experiences were acceptable and enjoyable. For some YCs who look for support they are not aware of who to go to and where to find it (Ali et al., 2013). This implies that professionals working with and around YCs need to be proactive in the support they provide. Bjorgvinsdottir and Halldorsdottir (2014) look to a lack of or inadequate school policies for school staff to follow as a reason for the inconsistency of support. They do however stress the importance of schools in supporting YCs.

In this study the YCs have reported that overall, their school experiences have been positive. Many of the participants enjoy going to and being at school, with some finding it to be a place of respite and time away from their caring role. The stage at which YCs are at in their lives would seem to have an impact on school life and perceived levels of stress and responsibility. There are some inconsistencies in the support YCs have received in school, although for some support is more important than to others. For the most part research aligns with the study's findings which promotes a supportive school system to enhance educational experiences for YCs.

# 5.2.2 Sub-question 1a: What educational support have YCs experienced?

Those participants who have received educational support have received support in different ways and from different professionals. Both Hannah and Jordan discussed homework support with Hannah receiving help from school and the YC project she attends, and Jordan accessing a YC project homework club. Interviews with the YCs revealed that any attempts to work and complete homework at home were difficult with participants stating that they were unable to do so due to the needs of the care-receiver. Research by Szafran et al. (2016) found that YCs had difficulties completing homework due to the amount of time spent caring. This may not fully reflect the findings of this study but it does show that YCs can struggle to complete their homework for various reasons. Conversely, research by Lakman et al. (2017) found that the YCs who participated in their research had no struggles with completing homework. This is explained by the fact that those particular YCs engaged in minimal caring responsibilities. They go on to report that YCs, particularly females prefer to work in a quiet space away from distractions in order to complete homework. This study was completed in Canada and homework expectations may vary in comparison to the UK.

The subordinate theme 'active school support' focused on the findings which looked at specific support provided by schools. As mentioned previously George received some sessions with an adult in school shortly after his sibling's diagnosis. George was not sure who it was who provided the support and so it could be a possibility that it was a member of

school staff or an external professional. He spoke positively about the sessions but did not feel the need for additional support. Hannah spoke about the support she has received in school which centres around her being able to access and have time to speak to school staff. She experienced a mix of school staff approaching her but also, she knew that she could approach them when she needed to.

Wherever the YCs received educational support from, YC projects or schools, they tended to mention particular adults, such as teachers or YC project workers. Ungar's (2014) research which looked at the three levels of protective factors, supportive adults are included in the second level, familial. Not only do these key adults provide support for education they have a positive influence on YCs and are cited as people who YCs want to share their problems with (Barry, 2011). Given that YC project workers and school staff are seen to be key adults in the lives of YCs, in this research but also in others it would seem important for these two sets of professionals to work together to further enhance the lives of YCs. Choudhury and Williams (2020) relayed information shared by YC project workers who want to work with school staff as they feel that they hold useful information about YCs and through working together there could be an increase in inclusion and engagement from YCs. The project workers report that any attempts they make to reach out to schools are often dismissed and that they are not invited to multi-agency meetings about the YCs they work with. This is reflected in the findings in which Jordan spoke about the YC project fulfilling many roles, with one of them being the option to speak to the project workers. Hannah too spoke about speaking to project workers and also teachers in school.

Focusing specifically on the support that is provided to YCs in school, Lakman et al. (2017) state that in order for schools to have the greatest impact all schools and teachers need to offer support to YCs. This is further supported by Gough and Gulliford (2020) who appreciate that school is a protective factor for children who may experience adversity,

including YCs. School can lessen the effects of a home life that can seem challenging and demanding and provide resources and positive experiences. Three out of the four YCs are reported to enjoy spending time at school, highlighting important factors such as time with friends, lessons and supportive school staff.

Three of the YCs in this research have received some form of educational support. Jessica discussed that one of the school staff who worked in her class was aware of her caring role but she was not provided with any additional support, educational or well-being. Jessica's school experiences reflect the findings of Bjorgvinsdottir and Halldorsdottir (2014). In their study YCs recollected not having any support in school even though school staff were aware of them being YCs. The YCs themselves wanted to have somebody to speak to and also have educational support as they experienced difficulties managing their school work along with their caring role. Jessica raised that she found it hard to complete school work at home and also spent some of her school day worrying about her mum and sister at home and wanting to know that they were ok. When asked how she could be supported Jessica stated that she wanted somebody in school to speak to. Research with young adult carers and YCs (Hamilton & Adamson, 2013) about education and educational support found that both groups shared concerns about a lack of support, understanding and flexibility within the school system.

It is clear that some YCs are receiving educational support, whether it be through school or a YC project. Alongside school being identified as a protective factor so too have supportive adults. Most of the YCs in the findings spoke about adults who either listened to or supported them in some way. Jessica could identify an adult in school but had not received any specific support from them. Support appears to vary between schools and for different YCs. As needs vary between YCs there needs to be a greater emphasis on listening to them and consulting with them to identify how the adults around them can successfully support them and meet their needs.

# 5.2.3 Sub-question 1b: What are YCs' reflections on their educational experiences?

The YCs reflections on their educational experiences vary, which may be expected due to the differences in age and year group. One thing that most of the YCs agree on is their enjoyment of school. George does not specifically state that he does not like school nor does he say that he does. The other three participants do clearly state that they like being at school and for different reasons. One of the reasons was to be in a space away from their caring role at home, almost as if school was a place of respite (Martin, 2006). Other participants spoke about their connections with adults in school and at YC projects and the importance of those relationships (Barry, 2011).

As part of the superordinate theme, 'support through education' there is the subordinate theme, 'missed opportunities'. It is in this section of the findings that the focus turns to areas of support that YCs feel have been missed within school. The YCs themselves had their own ideas of what kind of support they thought would be of benefit to them and to other YCs in their school. Hannah spoke about her experiences of support in school from teachers. For the most part Hannah speaks highly of the teachers in school and about the support she receives for her learning and her mental health. One point she did raise was around the consistency of teacher awareness and teacher response in school. She gave the example of different teacher responses to her not completing homework. She states that the teachers who know she is a YC accept that she has been unable to complete it, whereas teachers who are unaware of her being a YC are not as lenient. George also mentions that he

does not know who in school knows about him being a YC and assumes that it is only his class teachers who would know about his caring role.

These differing perceptions of teacher awareness are evident in different YC studies. According to Eley (2004) YCs were concerned about the lack of a formal support system in schools. Some of the YCs struggled to meet school deadlines and felt frustration when school staff did not recognise or acknowledge the difficulties in balancing a caring role alongside being a student. Others queried how school staff could not know that they were YCs and felt anger at their lack of awareness. Jessica reported that some of the staff in school were aware of her caring role but did not make any attempts to support her. When asked if she felt comfortable asking for support, she stated that she would prefer that teachers initiated the support. Research by Barry (2011) shows the contrasting experiences of YCs in schools, with some YCs reporting how supportive their teachers were and that they were fully aware of their caring role. Teachers were not considered to be supportive enough by other YCs and it was felt that teachers could have done more. The lack of concern and understanding from teachers is further emphasised by Hamilton and Adamson (2013). There are some YCs who regard teachers as a positive influence, although many YCs favour speaking to and sharing information with project workers. Teachers were seen as to not be trusted as it was thought that they did not understand the YC role and that they may escalate difficulties to other services without the knowledge of the YC (Barry, 2011).

It is already established that schools are a protective factor for many YCs (Gough & Gulliford, 2020) and that any support set up by schools would most likely be attended by many of the school's YCs (Lakman, et al. 2017). The participants, Jordan and Jessica, had their own ideas for school support. They both suggested having a group in school that they along with other YCs could attend together. Opportunities to spend time with other YCs was found to be beneficial by Choudhury and Williams (2020). Spending time with other YCs

ensured that YCs did not feel as isolated and reduced withdrawal from school. Friendships with YCs and non-YCs were important to the participants. Those who attended YC projects had both friends in school and separate YC friends at the YC projects. Jessica did not attend a project but had made a friend with another YC in school. Having reliable friendships with peers is another protective factor for YCs (Gough & Gulliford, 2020).

Friendships have shown to be valuable for YCs and attending school is an ideal time for YCs to meet with their friends. There are some YCs who choose not to tell their friends about their caring role as they may feel embarrassed or want to try and maintain some privacy. Friends are typically chosen because of shared interests and experiences (Barry, 2011). The YCs who discuss friendships in this study make the distinction between their YC friends and non-YC friends. Jessica and her YC friend at school connect about their home experiences. Hannah values all of her friends and feels supported by both sets but did state that her YC friends have a better understanding of what she experiences at home. Creating YC groups in schools adds to their educational experience. The groups allow YCs to gather and to share their own experiences in a safe environment. These social spaces create communities within schools which enable YCs to develop relationships and to feel a sense of belonging and of being included in the school (Choudhury & Williams, 2020).

When discussing the differences between being at primary and secondary school Hannah raised the point that she attended the same primary school as her brother, who she cared for. She explained that her caring role was not discussed at primary school and she did not receive any educational or emotional support. One of the reasons for this could be due to the 'disability rights paradigm'. It is indicated that for a number of years the primary focus for most professionals, particularly health and social care has been on valuing the rights of the care-receiver and not the needs of the YC. Instead YCs are viewed as children who hold no power and are overlooked by professionals (Bjorgvinsdottir & Halldorsdottir, 2014).

Although this appears to focus on health and social care professionals the same could also be said for school staff in that the focus is placed on the child with the difficulty and not the people around them.

School in general for the participants in this study is positive and they are able to identify what is enjoyable about their school experiences. It is evident from the YC's reflections that more support could be in place for YCs. The YCs themselves, even if they have received support through school, are able to provide suggestions of school support. The support from teachers provides a mixed response from the YCs. Friendships are valuable to all of the YCs and are also a protective factor. Finally, the focus on the care-receiver may impede rather than promote educational support for YCs.

## 5.2.4 Additional Key Findings

In addition to the findings which directly correspond to the central research question and sub-questions there are other findings which are relevant for educational professionals to be aware of when supporting and working with YCs. As has already been mentioned time with friends is of high importance to YCs as is respite and self-care. Included as part of the subordinate theme 'respite and self-care' are interests of the YCs and also friends. McDougall et al. (2018) found that YCs reported that they needed time to engage in fun activities away from their role of being a carer and described spending time with friends and playing video games. All of the YCs in this current study were able to name activities they liked to do on their own or with their friends. In research completed by Doutre et al. (2013), YCs who were able to have respite from their caring role were much better able to sustain their well-being. Although respite is, of its nature only temporary, having that opportunity to have time away was shown to help YCs when they then had to re-focus on their caring role. The well-being and mental health of YCs is addressed by Hannah. She spoke about how her mental health had been affected by perceived pressures from school and her caring role for her mum and brother. She stated how helpful she found it to have people in school to speak to. Jessica spoke about her worries during the school day when she would think about her sister and her mum. Low self-esteem and feeling anxious about family members are prevalent in YCs (Aldridge, 2006). A study which looked at YCs who supported family members with Huntington's Disease found that YCs had higher levels of anxiety and depression than those who were not YCs (Cohen et al., 2012). Jessica described how unsettled she found her home environment which could increase feelings of anxiety and low mood.

Responsibility and helping are two words the participants use in the current research to describe their view of caring and of what they do. George explained that becoming a YC for his brother seemed to be the right thing to do. All of the participants show commitment to their families and even when struggling with their YC role most of the participants want their family members to be happy. A consensus was found amongst YC participants in McDougall et al. 2018 study. The participants reported that they loved the person they cared for and that caring was done out of familial duty. The same study reports that YCs want to make family members happy and that caring is an extension of their role in their family. For many YCs their role is not considered to be exceptional in any way and referred to caring tasks as part of the everyday routine and perfectly normal to them. This shows how much responsibility and familial obligation are embedded within their families and their lives (Smyth et al., 2011). In addition, it would seem that being a YC can be a protective factor in itself as it provides a contributory role during times of family stress (Gough & Gulliford, 2020).

A number of YCs, in the research, greatly value their role and can identify the skills they are developing through caring. Not only do YCs feel that family relationships were strengthened through their role, but also, they reported feeling more independent, mature (Heyman & Heyman, 2013) and they felt good about themselves (Abraham & Aldridge, 2010). Some YCs report that the experience they gain from being a YC is only a benefit to them and it would help them in the future (McDougall et al., 2018). Jordan spoke about how much he enjoyed being a YC and spending time with his brother. He also expressed the idea of wanting to care and that it could be a possibility for him in the future. Ideas around wanting to care in the future and to incorporate it into careers seem to differ depending on the age of the YC. Younger YCs discussed the idea of becoming a doctor or other type of caring role. Older YCs considering their future identity wanted to make the transition away from caring and caring roles (Thomas et al., 2003).

# 5.2.5 Summary of Key Findings

These additional key findings such as respite and fun activities, the impact on mental health, responsibility and familial obligation and developing skills and interest in caring all apply indirectly to education and a YC's experiences of education. Some YCs rely on school in order to have time away from caring and to engage in fun activities with their friends (McDougall et al., 2018). Any YC who is in need of support and is struggling with their well-being and mental health will find accessing school and learning challenging (Doutre et al., 2013). The YCs who balance the demands of school and home caring may opt to follow their obligations as members of their family and prioritise their caring role (Rose & Cohen, 2010). Although there is a perception that all YCs only have negative experiences some do enjoy their role and see their future in some sort of caring role (Smyth et al., 2010). These findings along with the central research question findings are all relevant to educational professionals and the work they do with YCs.

#### **5.3 Psychological Theory**

As well as exploring the outcomes of different YC research in relation to the current study, there also needs to be an examination of the psychological theory which underpins the current research. The following section will focus on theories which informed the current research and discusses whether it supports or differs to the findings of the current study. The following theories, self-determination theory (Deci & Ryan, 2002), systems theory (von Bertalanffy, 1950). and the bioecological model (Bronfenbrenner, 2005) are discussed in relation to the current study's findings

## **5.3.1 Self- determination Theory**

According to self-determination theory (Deci & Ryan, 2002) people require three basic needs to develop healthily. These three needs are competence, autonomy and relatedness (Deci & Ryan, 2012). These needs can be met in social environments through social interactions which in turn promote intrinsic motivation. A lack of intrinsic motivation can impact on engagement and well-being. For those CYP who struggle to be motivated from within they can be supported by adults around them, including professionals, such as teachers and EPs and family members (Ryan & Deci, 2017). Support from adults around CYP can not only facilitate their intrinsic motivation but can also help to develop meeting the three basic needs. In essence the three basic needs focus on giving people choices, listening to and respecting people's views and supporting people's initiatives. These three areas are significant to YCs and to their experiences in education.

The three basic needs can be looked at with a direct focus on YCs and school and education. In order to promote autonomy in school YCs need to be listened to and they need to feel that their voices are being heard, as often they are excluded from decision making (Doutre et al., 2013). The YCs in this study gave suggestions of what they felt would support them well in school but they have not yet shared these views in school or with school staff. Is

this due to adults around the YCs making their own decisions and deciding what is best for them? Aldridge (2006) suggested that by listening to YCs and looking at ways to include them will empower them and will succeed in meeting some of their educational needs.

The second need, competence, can be met through school staff and professionals acknowledging the care that YCs provide and the difficulties there are in balancing this with school work. School staff can provide recognition through positive feedback to YCs (Lakman et al., 2017). Some of the participants, Jessica and George, thought that there may be some school staff who knew that they were YCs but were not sure as nobody had ever spoken to them about their caring roles. In situations such as when Jessica struggled to complete homework due to distractions from her sister, there is no acknowledgement of this and Jessica is left to struggle. Equally, Hannah spoke about the differences in the support she received from teachers, with those teachers who did not provide any leniency even when aware of her home situation. By having adults around a YC who take the time to listen and understand their life will positively affect their developing competence. Research shows the beneficial effects of the support and understanding of school staff (Hamilton & Adamson, 2013).

The third basic need, relatedness emphasises the importance of establishing connections and relationships. It is clear that connectedness with schools is important for YCs but so too are the relationships within the school environment (Gough & Gulliford, 2020). From the YC research it can be seen how important it is for YCs to develop positive and strong relationships with school staff and also their peers, through friendships. Friendships are built on sharing experiences and YCs enjoy spending time and befriending other YCs, something which can be developed and supported within schools (Barry, 2011). When Hannah spoke about school her main source of support came from teachers who are respectful of her home life and who listen to her when she needs them to. Jessica repeatedly

spoke about wanting to have an adult in school to speak to, something that she had not yet experienced but something which she felt would be helpful to her.

For YCs to develop their internal motivation, which is separate to external rewards they need to have their three basic needs met, according to self-determination theory. The three basic needs and ways in which to meet them are supported by YC research, including the current study. The recognition of the caring role they hold by school staff will help YCs who struggle balancing school with their role and provide them with options in completing school work (Kavanaugh, 2014). By listening to YCs and including them in decision making YCs are able to access resources, groups and people who will best meet their individual needs (McAndrew et al., 2012). Throughout YC research and this current study positive relationships with key adults and peers have been key. Jessica and Hannah both spoke about the importance of having somebody to speak to in school, away from their home environment and their caring role. An understanding and support for these three basic needs need to be understood and embedded to enable YCs to experience relatedness and to develop their competence and autonomy.

# 5.3.2 Systems Theory

As discussed in the introduction the systems theory moved away from looking at mechanistic systems and looked instead at how biological systems adapted to the demands in the environment (von Bertalanffy, 1950). This links to self–determination theory as the interactions a person has with the environment around them influences and determines the circumstances of that person's life. There are potentially many systems around a YC, such as school, YC projects, family, LA, health and social care professionals. A YC's life and circumstance are affected by how and in what way these systems interact with each other (Barry, 2011). Not only is it important to look at how these systems interact but to also consider the difference between having a wide and varied network and a social network

which is supportive and gratifying to a YC. Research indicates that YCs' needs are met through relationships which are supportive and understanding and do not depend on having a large network of people around them (Cassidy et al., 2013). This stresses the importance of key adults in the lives of YCs.

#### **5.3.3 Bioecological Model**

Within the bioecological model a child or YC is at the centre of many different systems and considers the interactions between the child and all of those different systems. The child will not interact directly with all of the systems around them but each system will have an impact on the life of that child or YC (Bronfenbrenner, 2005). Structural factors which are interconnected at familial, policy and service levels bear a significant impact on the restrictions YCs face in being able to exercise their views (Hamilton & Adamson, 2013).

Research carried out by Choudhury and Williams (2020) looked at each system level in the bioecological model and identified what YCs needed in order for them to be included in education. The authors found that having a key adult at either school or a YC project was imperative and was a prominent feature of the microsystem. Having a key person enabled a YC to access school and to see it as a safe space. At the mesosytem level interactions between YC's families and their schools were found to be crucial in helping a YC to engage with school. The worries held by families and YCs that they are somehow different (Kavanaugh et al., 2015) and that social care involvement will have a negative impact on them subsides, as the established trust between school and family helps the YC to engage with school and enables them and their family to access further support (Choudhury & Williams, 2020). Also, part of the mesosytem, according to Choudhury and Williams (2020) is the significance of YCs being able to connect with and spend time with YCs, which contributes towards lowering feelings of isolation. The study by Choudhury and Williams further suggests within the exosystem level the need for social spaces for YCs to interact with

each other, the need for professionals to work together including enabling YC project workers to share important information and YCs advocating and raising awareness of YCs within different organisations.

Bronfenbrenner's bioecological model (2005) focuses on the systems and interactions a child has with these different systems. Relating this to YCs shows the importance of those interactions and who and what are important in supporting YCs to access education successfully. The most pertinent findings by Choudhury and Williams (2020) indicate that YCs benefit from having access and time with a key adult who understands and supports them and for there to be a good relationship between school staff/key person and the YC's family. As already identified YCs value relationships with other YCs, which is further supported by the current study and research by Choudhury and Williams (2020).

#### **5.3.4 Summary of Psychological Theory**

All of these theories emphasise the interactions and systems around YCs. Most importantly theory supports YC research in recognising that key people and organisations have an impact on the lives of YCs and their ability to access and be supported in education. Comparing the theory to the current study it is apparent that some of the YCs wanted people to speak to and needed a key adult, however, only one of the participants had the security of knowing they had access to that level of support in school. Along with support in school the idea of sharing information and collaborative working is supported by theory and also the work of Choudhury and Williams (2020). Both of which appear to be lacking, according to the participants in the current study.

# 5.4 Critical Review

Upon completion of research, it is important to consider the challenges, strengths, limitations and unique contribution of the study. These areas will be discussed in the section and will conclude with suggestions for future research.

## 5.4.1 Strengths and Unique Contribution

The researcher is not aware of any other research which has been completed with YCs with a focus on their educational experiences in the UK using a qualitative IPA approach, at the time of writing. Much of the YC research looks to the adults around the YC to share their views, although this is beginning to change and may be a reflection of UK legislation and policy (Children and Families Act, 2014). This research explored the educational experiences of YCs whether positive or negative and highlighted the areas which were most important to the participants. The areas emphasised by the YC participants included support and connections with school staff and other YCs, support with learning, opportunities the YCs felt school staff had missed and enjoyment in attending school. The YCs spoke about having somebody to speak to in school which reflects the findings of other YC research.

The research included four YCs, ranging in age from 8 through to 17 years of age, with two males and two females, across a wide geographical area in England. This enabled the researcher to find out about experiences in primary and secondary and to compare the two, allowing the two secondary participants to reflect retrospectively on their primary experiences. The experiences of the YCs could have potentially been influenced by their age and stage of development and also the area in which they lived. The support for YCs across England differs which could affect which services were available and accessible to them.

One criticism which is often levelled at YC research is that participants are drawn only from YC projects and do not seek the views of those carers who may be considered to be 'hidden' (Choudhury & Williams, 2020). Three of the current participants were part of YC projects but were not identified directly through the projects. Two of the participants were identified through snowballing. The YC who does not attend any YC projects and has not been specifically identified as a YC in school could qualify as a 'hidden' YC.

There is some YC research which has focused on the needs of the care-receiver and the impact this has on the YC (Bjorgvinsdottir and Halldorsdottir, 2014 & Kavanaugh, 2014). This study has chosen not to focus on this and has instead kept the focus on YC views and experiences of education, instead of grouping them by care need. This was to ensure that the educational experiences of YCs remained the prominent focal point of the research.

## 5.4.2 Challenges of the Research

The greatest difficulty of this research was in finding and gaining access to YCs who showed interest in participating. This has been identified by other researchers when trying to locate YCs for their studies due to YCs not necessarily seeing themselves as carers or YCs remaining hidden due to possible implications for their families and themselves (Choudhury & Williams, 2020 & Smith et al., 2010) and so there was some awareness that the process may take time. Initially it was thought that approaching YC projects would be a good way to find YCs, as they had already been identified. Alongside this the researcher approached schools, primary and secondary, to see if participants could be identified this way. After repeated attempts to contact schools and YC projects with little response a snowballing method was implemented and families who were interested contacted the researcher directly. What had become apparent was that the difficulties in finding YCs was not necessarily in identifying them, it was being able to access this population which was dependent on gatekeepers.

In this research gatekeepers refers to school staff and YC project leads. Part of the role of these professionals is to safeguard the YCs they are working with and to provide consent for research to begin (Greig et al., 2007). When reaching out to schools and projects they were asked if they would be willing to complete a consent form stating that they were willing to work with me and to help identify YCs. In some cases, consent forms were

returned, whilst others were not. From this point progress was either very slow or nonexistent, hence the decision to look at alternative ways to identify participants.

At the start of the current study Covid-19 was identified resulting in changes to the way interviews would be completed. It had been intended that interviews would have taken place face to face at either the YCs school or project. Due to the Covid-19 restrictions implemented across the UK interviews had to be changed from face to face to remote meetings with all interviews taking place with YCs whilst they were in their own homes. It was thought that this could result in a positive in that YCs would be away from school and may be more willing and open to discuss their educational experiences.

The challenges which surfaced from remote interviews was having access to suitable IT equipment and being in a space in the home that would allow the YC to focus only on the interview. Along with suitable IT equipment was also the arrangement for confidentiality. All interviews were recorded and so to maintain confidentiality the YCs kept their camera off throughout, meaning the researcher was unable to see the YC throughout the interview. This proved difficult for the researcher to respond in response to any feelings the YC may have experienced and so the researcher felt it necessary to check in with the YC at several points during the interviews. In general IT equipment worked well and the YCs were able to hear the researcher and vice versa. However, one of the YCs did not have access to anything other than a mobile phone with a poor internet connection. This resulted in loud background noises and the interview having to be paused for twenty minutes when the connection was lost. On several occasions the researcher had to ask the YC to repeat their answers and some sections of the interview were difficult to hear on the recording.

## 5.4.3 Limitations

Firstly, due to the small number of participants it could be said that the findings may not reflect an extensive understanding of YCs' experiences of education. Whilst interesting

themes have been identified in this research, it is not guaranteed that the same or similar themes would be found with a different group of YCs, especially for those YCs who have a significant caring role. It would appear that the findings from this research would not be generalisable to the wider YC population, from a small group of participants and a phenomenological approach, although Yin (2013) would argue that the interpretations of findings should focus on connecting to prior research in order to account for any gaps or areas of weakness.

A further limitation is the inclusion of double hermeneutics within the interpretative process, in which the researcher aims to make sense of the participant's experience of the participant making sense of their own experience. In essence the same phenomena may be viewed differently by the YC participant and the researcher (Wagstaff et al., 2014). It should be acknowledged it is possible that the researcher's own beliefs and values can impact and influence the interpretation of the findings which could alter the meaning which had been implied by the participant. Findings from this research were not checked with the YC participants themselves, so they were unable to look through the outcomes of the analysis and provide any additional view-points or amend anything that they were not in agreement with. The analysis was, however, shared and discussed with the researcher's Director of Studies.

# 5.4.4 IPA Critique

As discussed in the methodology chapter there are some concerns that children will struggle to engage in IPA studies as they may have difficulties in detailing their experiences. It is recommended by Smith (2004) that researchers need to take the lead and have a substantial role in guiding CYP through interviews. The researcher reflects that all of the participants were able to answer all of the questions without any difficulties. There were some differences between the primary and secondary participants, with the primary participants at times needing some additional prompts. The eldest YC participant provided

the most detailed answers and required the fewest prompts. All of the participants had English as their first language, with none of them having any identified communication difficulties. The YCs appeared to understand what was asked which was evident in their responses.

# 5.4.5 Suggestions for Future Research

As the current study has sampled only YCs in the future careful sampling of the adults around the YC, such as a teacher, parent or YC project worker could be included to extend the robustness of the findings. These adults could provide an additional perspective on what support is already in place, regarding educational support, what has been tried, what has been considered and what they deem to be effective supports. Having these multiple perspectives may aid the development of more educational interventions and policies and would also act as a way in which to raise awareness about YCs in schools.

The use of IPA in this study has been effective in finding out more about the lived experiences of a small group of YCs. To better understand and to gain greater insights into the lives of YCs a participatory approach could be adopted. Through the use of this method YCs can have an active and influential role in the decision-making processes which can affect their lives. It may be possible for YCs to contribute their ideas and views towards school policies and to the interventions and support in schools.

# **5.5 Implications for Practice**

There needs to be consideration of the implications for EPs who are actively working in and with schools. This current research and its outcomes are relevant to all in the educational field and it is thought that EPs would be able to promote a strengths-based approach to working with YCs and their families.

#### **5.5.1 Implications for EP Practice**

As a profession EPs are well placed as they have an understanding of the education system and the LA, along with psychological perspectives of learning, development, wellbeing and mental health. EPs are able to support the needs of vulnerable children and it was in the former inspection handbook (Ofsted, 2015) that YCs were identified as being a vulnerable group. Not only are EPs able to support and work with individual YCs, they can work with groups of YCs, support schools and staff, support families and facilitate multi-agency working. These areas will be explored in the following section.

# 5.5.1.1 Supporting YCs

As part of the person-centred approach many EPs are adept at prioritising listening to the voices of CYP. All YCs have different experiences making it even more important that their individual stories are heard and listened to without judgement. Listening to YCs about their lives and to what they feel that they need with regards to support will help EPs and other professionals to gain a better understanding of the lives of YCs (Doutre et al., 2013). EPs can be the professional who brings the YC's views into prominence and also the professional who helps others to do so. Through understanding different YCs' experiences an EP has the ability to advocate for them as a vulnerable group (Gough & Gulliford, 2020).

Adopting a positive, strengths-based and solution focused approach EPs can help YCs and the adults around them to consider their different experiences. It is recognised that for many YCs their role is challenging but there are also benefits to being a YC, which have already been explored. Using these approaches with YCs may help them to have a positive outlook on their identity as a YC and their caregiving role (Gough & Gulliford, 2020).

By having an understanding and an ability to apply psychological perspectives EPs are positioned well to support YCs' well-being and mental health. The YC role can be a challenging one and can impact on mental health, particularly when there is limited support in place. EPs can provide therapeutic work or aid schools to develop their understanding of how to support YCs and their mental health (Choudhury & Williams, 2020).

#### 5.5.1.2 Supporting Schools

The focus on supporting schools may initially be in relation to identifying YCs. In order to do this EPs could support a school team through consultation or organisational change, perhaps with an appreciative inquiry approach, as an example. This kind of project would help schools to think about what they already have in place and have the time to discuss what they would like to implement and the practicalities of it. It would also be a time for school staff to reflect on their work with YCs to date (Choudhury & Williams, 2020). This in turn will foster a positive school climate, raise awareness of YCs in schools and of the possible hidden carers within schools.

Sharing the views of YCs with school professionals should encourage them to listen to YCs and their families to find out what support they need (Doutre et al., 2013). From this school staff can look at all of the suggestions, such as YC groups, a key adult and availability of resources, which can support school connectedness. As a follow-on EPs can then provide training, ideally to whole school teams to raise awareness, support mental health and the resilience of YCs. Work with individual key adults can focus on training and supervision (Gough & Gulliford, 2020).

Applying person-centred planning should emphasise existing strengths and should not automatically look at what is not working. School staff will need support in responding flexibly to the individual needs of YCs in respect of their needs and views. School staff may need the support of EPs to look at how they could work creatively and flexibly to ensure educational inclusion without lowering expectations (Doutre et al., 2013).

#### 5.5.1.3 Supporting Families

Much of the work with the families of YCs will likely be through schools. Family engagement with schools can be supported by EPs who can challenge any stigmatising attitudes which may present (Choudhury & Williams, 2020). Schools can be supported to recognise and support the needs of YC's families and EPs can signpost families to other organisations for additional support for themselves and for YCs (Gough & Gulliford, 2020).

## 5.5.1.4 Multi-agency Working

Multi-agency working is key when working with any vulnerable groups of children and EPs are able to co-facilitate this kind of work, including a team around the child approach, in which all professionals gather and share information. This is particularly pertinent for YC project workers who feel excluded from meetings with professionals (Choudhury & Williams, 2020). The work with different agencies can contribute to the engagement of YCs in school and for professionals to have a better understanding and awareness of YCs. Intervention through multi-agency working can provide and elevate good universal services for YCs and their families (Doutre et al., 2013).

#### **5.6 Plans for Dissemination**

It is important to the researcher that the YCs involved in this study are aware of the findings. A summary letter (Appendix AA) of the findings was sent out to parents of YC participants. Parents and YCs were encouraged to contact the researcher if they had any questions or wanted to discuss the findings further. The researcher has already spoken to a group of SENCos in the researcher's placement LA when recruiting participants and is due to speak to them again to disseminate the findings. Additionally, the researcher will present an overview of the current study and findings to the researcher's EPS. Finally, the researcher is currently working as part of a multi-agency team to roll out training about YCs across the LA and findings from the current research will be incorporated into this.

## 5.7 Reflections and Reflexivity

Due to the research design of the current study, it is accepted that the analysis is not fully objective. It is acknowledged that the researcher's own experiences, values and beliefs will have influenced and shaped the research process and the interpretation of the data. Although attempts were made to dampen prior assumptions it is recognised that analysis of each interview and, upon completion of further reading around YCs, additional knowledge would influence further analyses. To counter this and to 'bracket' ideas a research diary was kept in which the researcher's reflections on the analyses were included. At the end of each interview the researcher recorded key thoughts in the reflective diary, which were revisited and used to inform the data analysis. The data analysis was further checked by the research supervisor to ensure research credibility.

Throughout the current research the researcher has further developed their understanding of YCs through interviews, analysis and reading of general YC research. The researcher is aware that this developing knowledge gained through accessing YC research will have had an impact on the researcher's approach to interviews and analysis. The researcher is also aware of how reading one transcript could influence reading of further transcripts. To counteract this, as mentioned above, a diary was maintained and the researcher used this to write down thoughts and ideas which were raised through readings and analysis.

The researcher has had some carer experience as a young adult but was not a YC growing up. This information was not communicated to the YCs or to their families as the researcher was unsure if this would affect any of the YCs' responses during the interviews. With hindsight sharing this information may have helped to develop trust between the YCs and researcher, but at the time it was felt by the researcher that they did not want to move the focus away from the YCs and the importance of their own experiences.

Time was taken to try and establish some level of trust with the YCs and their families through meeting with them virtually prior to the interviews. Time was given for questions about the research process and the researcher. Through this the researcher had hoped that this and the fact that interviews were being carried out virtually and not in a school environment would have had a positive influence and lessened the power imbalance. However, most CYP see adults in a position of power, typically in a school environment and so it can be difficult for CYP to see adults in a different way. The researcher felt that they had put as much as they could in place to try and negate the power imbalance but it cannot be ignored that YCs likely felt the difference in power.

Prior to Covid-19 restrictions it had been the intention of the researcher that interviews would have taken place face-to-face with YCs in either their school or YC project. The researcher felt that if the YC was in a place that they felt comfortable then they may be more relaxed and willing to share information. All of the interviews took place virtually with each of the participants being in their own home at the time. Whilst this could be seen as a positive and a place they likely felt most comfortable, the researcher was aware that family members and sometimes the care-receiver was with the YC or nearby. Therefore, the researcher questions whether the YCs spoke as freely and as openly as they may have done at a YC project, for example.

Prior to the current study the researcher, in their placement LA, was involved with a YC project in which YCs attended a weekly online group. Two of the group's participants subsequently participated in the current study through the researcher discussing the future research and discussion with the YC group. The researcher accepts that the interviews with the two participants felt somewhat easier, due to the already established relationship, but this could also be due to the fact that those two participants were also the older out of the four and had been YCs for a longer period of time and had more information and knowledge to share.

This area of research has a particular interest for the researcher and they were keen to learn more from YCs themselves and from the existing literature, to incorporate learned information into work with schools, YCs and families. This area may be of interest to the researcher but it should also be recognised that this piece of research is part of a process which needs to be completed as part of a qualification and is not a standalone study.

# 5.7.1 Key Learning

Due to the content this section will be written in the first person. The current study has allowed me the time and the focus to explore a long-standing interest in work with YCs. I feel passionate about raising awareness of YCs, exploring and taking account of their views and the importance of multi-agency working to ensure YCs are being fully supported. The research has at times challenged my assumptions, which I held prior to my TEP training. Of particular note was the assumption that YC's experiences would be negative and I was enlightened to read and hear from YCs that although they may face many challenges, there are numerous positive factors which result from caring for family members. I am grateful to the YCs and their families who participated in the research and shared with me the reality of their world.

# 5.8 Final conclusions

As policy and legislation lean in favour of identifying and supporting YCs it is crucial that all professionals working with them are aware of their role in supporting them, particularly so for those in educational provision and schools who see CYP on a daily basis. Statistics may vary but it is clear that there are a high number of YCs, meaning there are several in each school and potentially in each class. In this study YCs knew what kind of support they needed and would like, highlighting a need for key adults in school and access to a YC group. Although a key worker or adult system is seldom put into place into primary

and secondary schools it is important to the YCs taking part in this research and deemed essential by other YC research. Though YCs may know what they want, they do not know who to go to and how to get that help. Therein lies the responsibility for professionals to engage with YCs and to provide the support they need.

For the most part YCs remain positive but can detail the challenges they encounter at home. In this study YCs spoke positively about their experiences at school and gave their thoughts on interventions which could only enhance their learning and connectedness with school. To facilitate support for YCs in school a person-centred and strengths-based approach needs to be adopted to ensure that individual needs are met and that YCs are fully included. It is acknowledged that EPs are in a prime position to raise awareness, to facilitate multiagency working and to support YCs, their families and school staff.

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# Appendices

# Appendix A

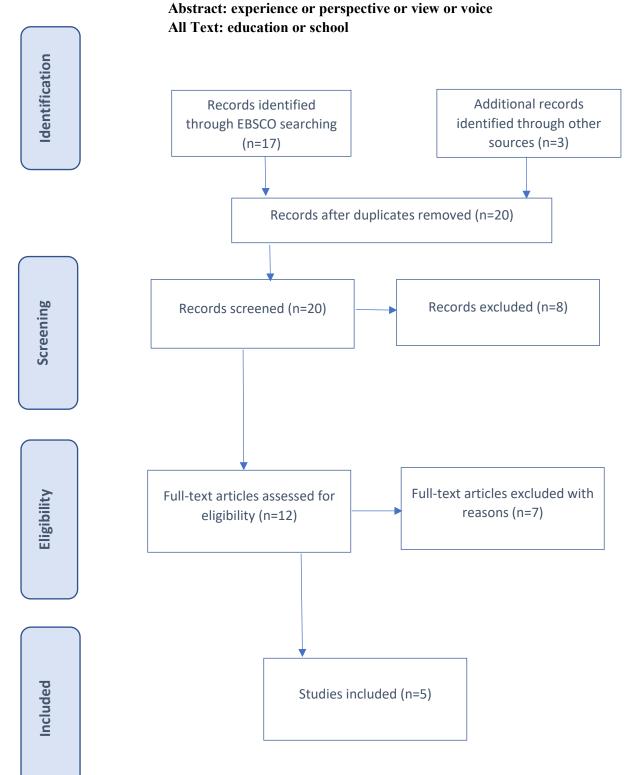
# Inclusion/Exclusion Criteria for literature review

Inclusion criteria	Exclusion criteria	Rationale	
Study primarily focuses on the views of young carers	Study only includes views of adults	Relevance to area of research	
Research within the last 10 years	Research older than 10 years	Up to date research which closely reflects legislation and policy	
School age 6-12yrs & Adolescence 13-17yrs	Young adults over the age of 18, adults and children below the age of 6 years	Age most relevant to the study – school age (primary and /or secondary)	
Inclusion of views around school and education	Main focus of the study does not relate to educational experiences	Study to be relevant to the research	
Peer reviewed	Non peer reviewed	Credible, peer reviewed research	
Article in English	Non-English text	Accessibility	

# Appendix **B**

# PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) Flow Diagram – Search One

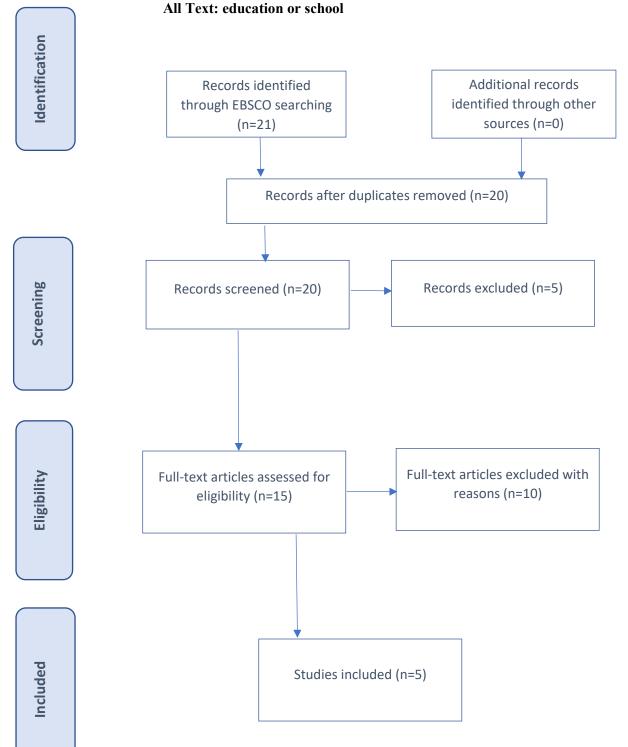
- Search carried out June 2020, through the EBSCO platform.
- ERIC, PsycINFO & PsycARTICLES, Education Research Complete, Child Development and Adolescent Studies were the chosen databases
- Search terms Title: young carer or young caregivers or hidden young carers



# Appendix C

# PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) Flow Diagram – Search Two

- Search carried out March 2021, through the EBSCO platform.
- ERIC, PsycINFO & PsycARTICLES, Education Research Complete, Child Development and Adolescent Studies were the chosen databases
- Search terms Title: young carer or young caregivers or hidden young carers Abstract: experience or perspective or view or voice



Author, date & location	Participants/Sample	Methodology	Summary/Findings
Lakman, Chalmers & Sexton,	145 Young Carers, aged between	Quantitative	The study explored the educational experiences of
2017 - Canada	8 and 18 years	Surveys with ratings were	young carers and to find out, if any, which school
		completed by the Young Carers	supports were preferred.
			The study found there to be a correlation between
			the amount of time caring and increased risk
			factors for academic success. Most young carers
			valued their education and would access support in
			school if it was available to them.
Doutre, Green & Knight-Elliott,	6 Young Carers, aged between 11	Qualitative	The study aimed to listen to young carers using a
2013 - UK	and 13 years old. The Young	Sem-structured interviews (IPA)	strengths-based perspective to learn more about
	Carers supported parents with		their resiliency.
	mental health difficulties		The study found that services tend to work in a
			fragmented way, with schools having little
			awareness of young carers' needs. Young carers
			found it hard to manage maintaining relationships
			outside of the caring role, but found respite aided
			their well-being. Young carers utilised their
			strengths to carry out their role within their family.
Hamilton & Adamson, 2013 -	23 YCs, aged 7-17yrs and 13	Mixed methods	Bounded agency – A young carer's aspirations and
Australia	young adult carers, aged 18-25yrs	Semi-structured interviews &	decisions are based on the contexts in which they
		questionnaires	find themselves. Past experiences, the chances
			they believe are available to them in the present
			and their perception for the future all impact on
			young carers.

# Appendix D: Table of included studies – Databases EBSCO

			Caring is found to affect health, well-being and social relationships. Young carers who had been caring from a younger age were more likely to feel more positive about the future. They felt that caring was their priority and school systems lacked flexibility and understanding.
Kavanaugh, 2014 - USA	40 CYP, aged 12–20yrs. YCs who cared for a parent with Huntington's Disease	Mixed methods Semi-structured interviews Descriptive and correlational statistics	<ul> <li>The exploratory study used the stress process model, in order to describe CYPs caregiving experiences, by focusing on relationships between caregiving, parent/child conflict, school difficulties, and the psychological well-being of young carers.</li> <li>CYP who have a higher number of caring tasks experience greater difficulties with school.</li> <li>Schools play an important role in reducing the negative impact on CYP.</li> </ul>
Barry, 2011 - UK	20 YCs, aged 12-23yrs	Qualitative Semi-structured interviews	<ul> <li>Young carers tend to be ambivalent about school.</li> <li>Research shows that young carers find more opportunities through groups for young carers.</li> <li>Some young carers only left home to go to school.</li> <li>Young carers more likely to be taken into care.</li> <li>Projects for young carers proved to have a positive impact. Majority of young carers felt negative towards school and experienced bullying, negative attitudes from teachers and little support. Young carers preferred to keep their caring role secret from school staff.</li> </ul>

CASP Question	& Sexton (2017)Was there a clear atement of the ms of theYes – the aims of the research are clearly stated and the		Kavanaugh (2014)	Hamilton & Adamson (2013)	Barry (2011)	
1.Was there a clear statement of the aims of the research?			Yes – the aims of the research are clearly stated and the relevance of the research is made clear	Yes – the aims of the research are clearly stated and the relevance of the research is made clear	Yes – the aims of the research are clearly stated and the relevance of the research is made clear	
2. Is qualitative methodology appropriate?	Yes – research aims to explore the experiences of YCs	Yes – research aims to explore the subjective experiences of YCs	Yes - research aims to explore the subjective experiences of YCs	Yes – research aims to explore the views and experiences of YCs	Yes – research aims to explore the views and experiences of YCs	
3. Was the research design appropriate to address the aims of the research?	Yes – quantitative design addresses the research aims	Yes – qualitative design addresses the research aims	<b>Can't tell</b> – mixed methods design addresses the research aims but it is not clear why those methods were chosen	<b>Can't tell</b> – mixed methods design addresses the research aims but it is not clear why those methods were chosen	Yes – qualitative design addresses the research aims	
4. Was the recruitment strategy appropriate to the aims of the research?	Yes – clear explanation of recruitment and selection of participants, including who and	Yes – clear explanation of recruitment and selection of participants	Yes – clear explanation of recruitment and selection of participants, including who and	Yes – clear explanation of recruitment and selection of participants	Yes – clear explanation of recruitment and selection of participants	

Appendix E: Summary critique for each study using the CASP Qualitative Checklist (CASP, 2018)

	why they were selected		why they were selected		
5. Was the data collected in a way that addressed the research issue?	Yes – clear description of how data was collected. Researchers did not justify the chosen methods	Yes – clear description of how data was collected. Researchers justified the chosen methods	Yes – clear description of how data was collected. Researchers did not justify the chosen methods	Can't tell – description of data collection. Interview schedule design unclear	Yes – clear description of data collection. Researchers justified the chosen methods. Interview schedule design unclear
6. Has the relationship between researcher and participants been adequately considered?	No – no consideration of the researchers' own role, any potential bias or influence	No – no consideration of the researchers' own role, any potential bias or influence	No – no consideration of the researchers' own role, any potential bias or influence	No – no consideration of the researchers' own role, any potential bias or influence	No – no consideration of the researchers' own role, any potential bias or influence
7. Have ethical issues been taken into consideration?	<b>Can't tell</b> – information provided about ethical approval but no further information relating to informed consent and how ethical standards were maintained	<b>No</b> – no information regarding ethical approval or clarity around how ethical standards were maintained	<b>Can't tell</b> – information regarding ethical approval and consent. No further information relating to how ethical standards were maintained	<b>No</b> – no information regarding ethical approval or clarity around how ethical standards were maintained	Yes – detail is provided relating to consent, support for participants and description of how ethical standards were maintained
8. Was the data analysis sufficiently rigorous?	<b>Yes</b> – description of data analysis process and data is presented	<b>Can't tell</b> – description of IPA process with sufficient data to	Yes – description of data analysis process and data is presented	<b>Can't tell</b> – there is no description of the data analysis process and how themes were	<b>Can't tell</b> – there is no description of the data analysis process and how themes were

	to support the findings	support findings. Not clear how the themes were derived from the data	to support the findings	derived from the data. Some of the data was presented to support the findings	derived from the data. Some of the data was presented to support the findings
9. Is there a clear statement of findings?	Yes – the findings are explicit and discussed in relation to research aims. There is no discussion of credibility	Yes – the findings are explicit and discussed in relation to research aims. There is no discussion of credibility	Yes – the findings are explicit and discussed in relation to research aims. There is no discussion of credibility	Yes – the findings are explicit and discussed in relation to research aims. There is no discussion of credibility	Yes – the findings are explicit and discussed in relation to research aims. There is no discussion of credibility
10. How valuable is the research?	Contribution to research is discussed along with implications for practice and future research	Contribution to research is discussed along with implications for practice	Contribution to research is discussed along with implications for practice and future research	Contribution to research is discussed along with implications for practice and future research	Contribution to research is discussed along with implications for practice and future research

# Appendix F: Synthesis Matrix

	Education and the	<b>Relationships and</b>	Identity	Impact of caring
	future	support		
Lakman, Chalmers & Sexton, 2017	Link between the amount of time spent caring and the impact on a YC's education. Many YCs set a goal for post-secondary education.	YCs did not reveal their caring role to school staff as they did not think that they would receive support.	Worries that idetifying as a YC will bring judgement from others. YCs reported that they felt self- sufficient and saw professionals as a threat.	
Doutre, Green & Knight- Elliott, 2013			YCs look for another identity away from their caring role. Most of the YCs accepted that caring was something that they neded to do.	A YC's respnse to situations can be dependent on factors including the different types of caring tasks, who is being cared for and the age and gender of the YC.
Hamilton & Adamson, 2013	Education as a priority is dependent on possible opportuities and future goals. Education is valued.			YCs did not feel that their caring role had a harmful effect on their we-being or health. Although young adult carers struggled with their mental health.
Kavanaugh, 2014		YCs felt that there was little support from adults in school. Link between difficulties in relationships at home and at school.		YCs may receive more social support and be more resilient due to being a YC. The practicalities of the caring role impacts on

			school activities such as homework and on school attendance.
Barry, 2011	Friendships are important to YCs. Friends bring a sense of normality to the lives of YCs. YCs have to work hard to maintain friendships due to their caring role. Friendships easier to maintain in school. YC project workers are important adults for YCs. School staff are not trusted by all YCs.	YCs were worried about possible consequnecs if they revealed their roel to school staff. They wanted to be treated in the same way as all other students at school. Difficulties in merging together two identities – child and parental child.	Caring tasks and low school attendance for YCs can become a barrier to educational success.

## Appendix G



ТЕР

Educational Psychologist in Training Email:

# PARTICIPANT INVITATION LETTER (Parent/Carer)

# Exploring Young Carers' Experiences of Education

Your child is being invited to participate in a research study. Before you agree it is important that you understand what their participation would involve. Please take time to read the following information carefully.

#### Who am I?

My name is xxxx and I am currently an Educational Psychologist in training in the School of Psychology at the University of East London. I work with children and young people in schools in Redbridge. As part of my training, I am conducting a piece of research which will focus on the educational experiences of young carers.

#### What is the research?

I am conducting research into young carers' experiences of education. There is limited research in this area, particularly in gaining the views of young carers themselves. It is important to understand their views so that they can be better supported in educational settings and by professionals in the future. I will ask questions related to the young carers' experiences of education and what/who they have found to be supportive.

My research has been approved by the School of Psychology Research Ethics Committee. This means that my research follows the standard of research ethics set by the British Psychological Society.

# Why has your child been asked to participate?

Your child has been invited to participate as they have been identified as a young carer, either by their school or the local authority. These factors and their participation will help me to explore my research questions.

You are quite free to decide whether or not your child participates and should not feel coerced.

# What will your participation involve?

If you agree to your child participating, they will be invited to an online meeting through Microsoft Teams. I can explain the research to them and ask if they would like to take part. Due to the COVID19 pandemic I will be arranging interviews through Microsoft Teams. I will meet with them on no more than four occasions to gain their views. Each session should not be any longer than an hour. I will carry out semi-structured interviews which will be audio recorded, to ensure that I capture their thoughts accurately. Interviews will be as informal as possible so that your child feels at ease.

I will not be able to pay you for participating in my research, but your participation would be very valuable in helping to develop knowledge and understanding of the educational experiences of young carers.

# Your taking part will be safe and confidential

Your child's privacy and safety will be respected at all times. Any information that I collect through the interviews will be confidential. Your child will be asked to choose a pseudonym (a different name) which will be used throughout the research, so that they cannot be identified. Their information will remain confidential to me and to those supervising my research. Your child's information will not be shared unless there are concerns for their safety. Whilst being interviewed your child can choose whether to answer the questions or not and can stop at any time. If your child chooses to withdraw from the study, they can do so up to four weeks after the interview, as this will be when the study is written up.

# What will happen to the information that you provide?

All of the information will be stored securely and stored for an additional 5 years after the study has been completed. Your child's details will be kept confidential as will any data collected.

# What if you want to withdraw?

You are free to withdraw from the research study at any time without explanation, disadvantage or consequence. Separately, you may also request to withdraw your data even after you have participated, provided that this request is made within two weeks of the interview, after which point the data analysis will begin, and withdrawal will not be possible.

# **Contact Details**

If you would like further information about my research or have any questions or concerns, please do not hesitate to contact me.

If you have any questions or concerns about how the research has been conducted please contact the research supervisor –

Chair of the School of Psychology Research Ethics Sub-committee:

# Appendix H



# UNIVERSITY OF EAST LONDON (Parent/Carer)

Consent to participate in a research study

**Doctoral Research – Exploring the Educational Experiences of Young Carers** 

# Parent/Carer Consent Form

I have the read the information sheet relating to the above research study and have been given a copy to keep. The nature and purposes of the research have been explained to me, and I have had the opportunity to discuss the details and ask questions about this information. I understand what is being proposed and the procedures in which my child will be involved have been explained to me.

I understand that my child's involvement in this study, and particular data from this research, will remain strictly confidential. Only the researcher(s) involved in the study will have access to identifying data. It has been explained to me what will happen once the research study has been completed.

I hereby freely and fully consent to my child participating in the study which has been fully explained to me. Having given this consent I understand that I have the right to withdraw my child from the study at any time without disadvantage to myself and without being obliged to give any reason. I also understand that should I withdraw my child; the researcher reserves the right to use the anonymous data after analysis of the data has begun.

#### **Child's** Details

Name of Child: \_\_\_\_\_

Address: \_\_\_\_\_

Date of Birth:

Parent/Carer Details

Signed:\_\_\_\_\_\_

Name of parent/ carer:\_\_\_\_\_\_

Relationship to the child:\_\_\_\_\_

Contact telephone number:\_\_\_\_\_

Date: \_\_\_\_\_

### Appendix I



#### PARTICIPANT INVITATION LETTER (Child Version)

#### **Exploring Young Carers' Experiences of Education**

#### Who am I?

My name is xxxx and I work with children and young people in xxxx. I am training to be an Educational Psychologist and as part of my training I am doing a study which will look at young carers' experiences of education. I would like to hear your views so that I can have a better understanding of how you like to be in supported in school. The information you share with me could help to support other children in the future.

If you would like to take part in my study, I will arrange a date and time to speak to you online or on the phone, to tell you more about what I'm doing which will give you the chance to ask me any questions you may have.

If you do agree to be a part of my study, I will arrange a time to meet with you on Microsoft Teams, there are no right or wrong answers. I will record what you say to make sure I remember everything you say.

Anything you say will be kept between us, unless you tell me something that means you or someone else is in danger. When I have spoken to you and some other children. I will type it all up. Your real name won't be used so nobody will know what you have said. You will be able to choose a name for yourself and I will use that during the study.

It is your choice if you would like to speak to me and it is fine if you choose not to. If you would like to speak to me circle YES and circle No if you don't want to.

TEP

My name is \_\_\_\_\_\_ and I am happy to talk to xxxx about her project

YES/NO

# Appendix J



## **Child Consent Form**

Please read the statements and tick either yes or no. Underneath there is a space for you to sign your name.

	Yes	
		No
Have you read the information sheet or had it read to you?		
If you have any questions have, they all been answered?		
Would you like to take part in the study?		
I know that nobody will be able to identify me because I will be given a different name		
I know that (researcher's name) will only share what I have told her if she is worried about me or somebody else		

# Signature: \_\_\_\_\_

Name in capitals: \_\_\_\_\_\_

Date	•	
Date	٠	

#### Appendix K



# **UNIVERSITY OF EAST LONDON**

#### Young Carers' Group Lead Information letter

Dear (insert name)

I am a Trainee Educational Psychologist at the University of East London. As part of my training, I am carrying out a study looking at how young carers view their experience of education. My hope would be that this study and the findings will help to look at ways that schools can support young carers in education.

I am writing to enquire whether you would give me permission to recruit participants from among the children and young people who attend the young carers' group. I would need help to identify a group of children and young people who meet my criteria.

In addition to this, I would need help to send parental consent and information letters in order to gain parental permission to interview the identified carers. Interviews will be conducted through Microsoft Teams and should take between 30 minutes to 1 hour.

If you have any comments or questions about this research please could you contact my supervisor, Dr xxxx, using the contact details provided overleaf.

This research has been approved by the University of East London (UEL) Ethics Committee. If you wish you can contact the UEL ethics committee by email researchethics@uel.ac.uk if you have any complaints or questions about this research.

If you would be willing to give me permission, I would appreciate it if you could sign the enclosed form and return it in the envelope provided. Many thanks in advance for your consideration of this project. Please let me know if you require further information.

Regards,

TEP

#### Appendix L



# UNIVERSITY OF EAST LONDON

#### Young Carers' Group Lead Consent form

#### Consent Form

I understand that the group's participation in this project will involve:

- Assisting the Researcher to identify a group of young carers to take part in this study.
- My assisting the Researcher by my sending a consent letter to the parent or guardian of young people selected in order to obtain parental consent for their child to take part in this study.
- Ensuring the young carer has the use of a suitable location in which to participate in the interviews.
- Allowing the Researcher to conduct interviews with students during group hours. These interviews should take between 30 minutes and 1 hour.

I understand that the group's participation in this study is entirely voluntary. I understand that the children and young people the Researcher interviews will also be free to withdraw themselves from this study at any time and without giving a reason.

I understand that I must keep the identity of all young carers who participate confidential.

I understand that that the identity of children and young people will be treated confidentially by the Researcher and that all information will be stored anonymously and securely. All information appearing in the final report will be anonymous. All children and young people will have the option of withdrawing their data from the study, up until their transcript has been anonymised.

I understand that I am free to discuss any questions or comments I might have with Dr xxxx (research supervisor).

I understand that I am free to contact the University of East London Ethics Committee to discuss any complaints I might have.

I also understand that at the end of the study I will be provided with additional information and feedback about the purpose of the study.

I, \_\_\_\_\_\_(NAME) consent to the Researcher proceeding with this study with the supervision of Dr xxxx (research supervisor).

Signature of Group Lead .....

Date:

#### Appendix M



## UNIVERSITY OF EAST LONDON

#### **Headteacher Information letter**

Dear (insert name)

I am a Trainee Educational Psychologist at the University of East London. As part of my training, I am carrying out a study looking at how young carers view their experience of education. My hope would be that this study and the findings will help to look at ways that schools can support young carers in education.

I am writing to enquire whether you would give me permission to recruit participants from the students currently enrolled at your school. I would need help to identify a group of students who meet my criteria. I would like to select students who are currently young carers.

In addition to this, I would need help to send parental consent and information letters in order to gain parental permission to interview the identified students. Permission would also be needed in order to complete the interviews during school hours as would access to an appropriate space in which to conduct the interviews through Microsoft Teams, if the child is in school. These interviews should take between 30 minutes to 1 hour. I will endeavour to work with the school to ensure that there is minimum disruption to the child's learning, as interviews would take place during the school day.

If you have any comments or questions about this research please could you contact my supervisor, Dr Janet Rowley, using the contact details provided overleaf.

This research has been approved by the University of East London (UEL) Ethics Committee. If you wish you can contact the UEL ethics committee by email researchethics@uel.ac.uk if you have any complaints or questions about this research.

If you would be willing to give me permission, I would appreciate it if you could sign the enclosed form and return it in the envelope provided. Many thanks in advance for your consideration of this project. Please let me know if you require further information.

Regards,

TEP

#### Appendix N



#### UNIVERSITY OF EAST LONDON

#### Headteacher consent form

#### **Consent Form**

I understand that my school's participation in this project will involve:

- Assisting the Researcher to identify a group of students to take part in his study.
- My assisting the Researcher by my sending a consent letter to the parent or guardian of young people selected in order to obtain parental consent for their child to take part in this study.
- The use of a suitable location in which to conduct the interviews.
- Allowing the Researcher to conduct interviews with students during school hours. These interviews should take up between 30 minutes and 1 hour.

I understand that my school's participation in this study is entirely voluntary. I understand that the students the Researcher interviews will also be free to withdraw themselves from this study up to the point of data analysis and without giving a reason.

I understand that I must keep the identity of all students who participate confidential.

I understand that that the identity of students will be treated confidentially by the Researcher and that all information will be stored anonymously and securely. All information appearing in the final report will be anonymous. All students will have the option of withdrawing their data from the study, up until their transcript has been anonymised.

I understand that I am free to discuss any questions or comments I might have with Dr Janet Rowley (research supervisor).

I understand that I am free to contact the University of East London Ethics Committee to discuss any complaints I might have.

I also understand that at the end of the study I will be provided with additional information and feedback about the purpose of the study.

I, \_\_\_\_\_\_(NAME) consent to the Researcher proceeding with this study with the supervision of Dr xxxx (research supervisor).

Signature of Headteacher: .....

Date: .....

#### Appendix O

#### Interview schedule for Young Carers (YC)

Introduction - I am here today because I want to find out about your experiences of being a YC in school. I will ask you some questions about being a YC and about school. Please only share what you feel comfortable sharing. You can pass on any questions you do not want to answer. If you do not understand a question please let me know so that I can be clearer. I will be recording the interview so that I can transcribe it but I will make sure that I do not use your name or any other information that could identify you. Do you have any questions? Are you happy to continue?

#### 1) Tell me about yourself.

Prompt: I don't know you very well and would like to learn about what is important to you and what you like to do.

#### 2) Can you tell me how you became a YC?

a) Do you see yourself as a YC?

#### 3) Can you tell me what kind of care you provide?

Prompt: Personal care, housework, giving medication, going to medical appointments, translating, emotional support, looking after siblings.

#### 4) Do you think your life would be different if you weren't a YC?

Prompt: In what way? What would your life look like - home, school, friendships, social life

#### 5) Who in your life do you feel you have key relationships with?

- a) Do they know that you are a YC?
- b) Do you have key relationships in school?
- c) Could you describe those relationships to me?

#### 6) Do you talk about being a YC in school?

Prompt: If so, who with? If not, why? Do adults in school know that you are a YC? Do they know what you do as a YC?

#### 7) Do you know if any adults in school speak to the support workers at the YCs' group?

Prompt: If not, would you like them to? If they do how do you feel about that?

#### 8) How do you feel about school? Tell me about your experience of school?

Prompt: Lessons, different subjects, people in school – adults and children, homework, after school clubs, attendance.

#### 9) Is there anything else you would like to share with me about your school experience?

# 10) Imagine that tomorrow morning you wake up and it is a miracle day, everything is going to be perfect and you're going to feel happy all day.

Prompt: What would the day look like? Who would you see? Where would you go? What would you do?

# Appendix P



ТЕР

Educational Psychologist in Training

Email:

#### PARENT DEBRIEF LETTER

Thank you for allowing your child to participate in my research study on exploring the educational experiences of young carers. This letter offers information that may be relevant in light of your child having now taken part.

I have met with your child on three occasions to seek their views of their educational experiences. I asked them questions through semi-structured interviews. (Child's name) was extremely helpful and provided me with lots of useful information for my research.

# What happens now?

I am now in the process of going through all of the information I have collected from your child and other children who participated in the study. Once this has been completed, I am able to send you an anonymous summary of what I have found, should you wish. Your child had a different name throughout the research process so that they cannot be identified. I would also like to share the findings with your child as part of a group which will include other children who participated in the research.

If you have any questions or concerns about how the research has been conducted please contact the research supervisor –

or

Chair of the School of Psychology Research Ethics Sub-committee:

#### Appendix Q



# **DEBRIEF LETTER - Child**

Thank you for taking part in my study on the educational experiences of young carers. This letter will give you some information about what will happen next.

# What happened during the research?

I really enjoyed working with you and hearing about your experiences. We have now finished working together but I want to thank you for your help.

## What happens now?

I am now writing up all of the information that I got from you and some other children. When it is written I will send you a summary of what I found out from everybody. I won't use your name but you might see the made-up name you chose for yourself.

If you have any questions about the study and what I will do next, you can ask your school SENCo (name) / young carer project lead (name) to contact me. If there is anything that is worrying you and you would like to speak to somebody you could speak to your SENCo/project lead, speak to your doctor or contact Childline on 0800 1111.

Many thanks for your help and time,

TEP

# Appendix R Young Carer Flyer – Schools



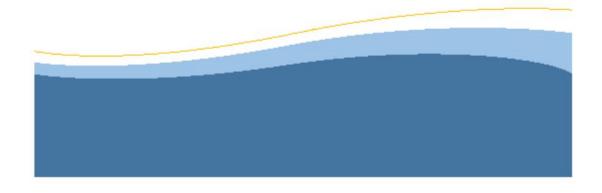
# Research – Young Carers and their Experiences of Education

I am a Trainee Educational Psychologist at the University of East London. As part of my training I am carrying out a study looking at how young carers view their experiences of education.

I need the help of schools to find young carers who might be interested in participating in my research.

If you are aware of any young carers in your school aged between 8 and 18 years old please contact me and I will provide additional information.

Contact details: xxxxx@uel.ac.uk



# Appendix S Young Carer Flyer – Young Carer Project



# Research – Young Carers and their Experiences of Education

I am a Trainee Educational Psychologist at the University of East London. As part of my training I am carrying out a study looking at how young carers view their experiences of education.

I need the help of schools and young carer projects to find young carers who might be interested in participating in my research.

If any young carers in your project aged between 8 and 18 years old would be interested please contact me and I will provide additional information.

Contact details:

xxxxx@uel.ac.uk

# Appendix T

# Example analysis for one participant – Jordan (Participant 1)

Stage 1- Reading and re-reading

The transcript was read several times before pertinent information was underlined. Below are the initial impressions of the interview and the information Jordan provided.

The interview took place in Jordan's home and he was in the same room as his mum and younger brother. Jordan seemed quite reserved through the interview. His brother could be heard throughout singing and shouting words. It was not clear if this was slightly distracting for Jordan. I wondered if Jordan provided answers which he thought he should as he was with his family, who could hear everything he said, none the less I did not check this with Jordan. Perhaps his answers would have been different had Jordan been in school for the interview. Jordan spoke positively about school and seems to really enjoy learning and getting to see his friends. He suggested an idea for a YCs club at school for other YCs. Jordan did not apply the idea to himself rather to other YCs. Overall as he was so positive about school it made me think consider if the idea was his or he felt the need to do some sort of prep before the interview. He attends a YC group outside of school and did not seem to want any additional support in school. It made me think that perhaps Jordan might not want any additional support in school as he is already doing well and enjoys school.

Stage 2 - Initial noting (exploratory comments) & Stage 3 - Emergent themes

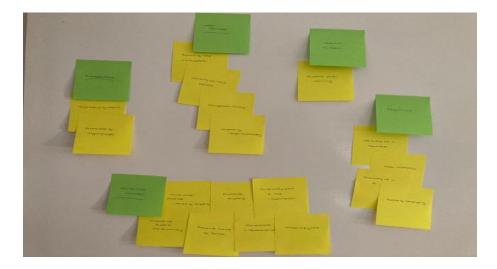
Initial noting can be seen in the right-hand column. The initial noting focused on descriptive comments (black pen), linguistic comments (blue pen) and conceptual comments (red pen).

Toorecon	251 252	J: I think they would uhm, I think they should acknowledge the fact that there are young carers in their school a bit more.	"Activatedge" - be acore
	253	I: Mhm.	boes he cont then just to
Identican source of support	254 255 256	J: Like maybe do something, I don't really have any examples of what but like do something to help them maybe to make that support group for example or-	"Help then rockely ne
- wisched	257	1: Mhm.	verole inscrool others
	258	J: Something like that.	doesn't identing hursele Provides example
	259 260	1: Ok. And would that he something that you'd be interested in joining if there was a support group in the school?	
	261	J: Yeah.	manager and and
	262 263 264	1: Yeah (background noise, six second pause). Is there anything else you'd like to share with me about your school experience?	
some of	265 266	J: Uhm, no I think that uhm (background noise) I do enjoy school quite a lot to be fair.	Non positule about som
	267	I: Mhm.	responsibilities that he
serve q belonging	268 269	J: I enjoy my lessons and I'm able to concentrate well and I'm able to learn well.	conducie enconnent
	270 271	I: Do you do you feel like there's a difference between primary and secondary school, kind of in, when as a young carer do	Freedong being a Babuch

Emergent themes were noted in the left-hand column. Examples included sense of belonging, identity and support in school.

Stage 4 - Looking for connections across themes

Emergent themes (yellow sticky labels) for Jordan were grouped and labelled with a superordinate theme. The superordinate themes (green sticky labels) for Jordan were, learning support, protective factors, care provider, identity and differences.



#### Appendix U: Transcript example and analysis for one participant

- Descriptive connerts

- Liquietic convertes
- -conceptud connents

#### Hannah Analysis – Stages 2 & 3

Before the interview began the interview process was explained to the participant, as was anonymity, confidentiality and data security. The participant was encouraged to ask questions and it was explained that the participant could choose not to answer questions and ask for clarification if they were unsure at any point. It was made clear to the participant that their voice was being recorded for the purpose of transcription. Once the participant stated that they were happy to continue the interview began. Each participant chose their own pseudonym.

Emergent themes	Line number	Original transcript	Exploratory comments (initial noting)
	1	I: Hi Hannah, thank you for meeting me- (sound cuts) today.	
	23	I'm here today because I want to find out about your	
	3	experiences of being a young carer and specifically in school.	
	4	So, I'm going to ask you some questions about being a young	
	4 5 6	carer and about school. Please only share what you feel	
	6	comfortable sharing, you can pass on any questions that you	
	7	don't want to answer, and if you don't understand the question	
	8	please let me know so that I can be a little bit clearer. Uhm	
	9	I'm going to be recording the interview as you can see on the	
	10	screen. So that I can transcribe it and write it all down, uhm so	
	11	I'll make sure that I don't use your name uhm or any other	
	12	information that could identify you. Just wanted to check have	
	13	you got any questions?	
	14	H: Uhm no.	
	15	I: No ok. And are you happy to continue and to participate?	
	16	H: Yeah.	
	17	I: Brilliant ok so let's start with the first question then, uhm so	
	18	I don't know very much about you Hannah so it would be	
	19	really useful if you could tell me a little bit about yourself so,	
	20	should we start with how old you are?	

			Y
	21	H: I'm 17.	
	22	I: 17 ok and what year are you in?	
	23	H: Year 13.	
	24 25 26	I: Year 13. Ok fantastic, uhm what can you tell me about yourself what kind of things do you like to do outside of school.	
an interests	27	H: Uhm, I'm into music and drama.	Honohs an interests
	28	I: Ok.	
	29	H: The creative subjects.	
	30	I: Uh-hm.	
time for herset	31 32	H: Uhm, because, not only are they the subjects that I study at school but is, hobbies that I enjoy outside of school as well.	herests Laked between home od school
ne set	33	I: Ok. And do you play music as well as listen to music?	where school subjects
	34 35	H: I- (sounds cuts for 9 seconds, unintelligible) -so voice is my main instrument.	
	36	I: Ok. And what-what kind of music do you like?	
	37 38 39	H: Uhm I'm open to like a range of genres, cause I've listened to, all types of music which I mean you study at school so you have to but also I'm into it as well.	

			The second s
	40	I: Ok.	
	41	H: Cause of the older generations as well.	
	42 43	I: Ok. And you said that you like drama as well what do you like about drama?	
Enjoyeent	44 45 46	H: Uhm- (static interrupts, H continues muffled) -as an art form, uhm, and uhm, learning from it. Uhm, it's a huge part of entertainment and everybody enjoys it. So, I enjoy it doing it.	enjoye drana-sees it es entertainent ord enjoyeble for all
	47	I: Uhm H, are you still there?	-
	48	H: Yeah.	
	49 50	I: Yeah. I'm getting a lot of feedback I don't know if you're able to hear me clearly?	
	51	H: I can hear you clearly, I can't hear any feedback.	
	52 53	I: Ok (three second pause) let's go with the next question. Sorry I'm getting lots and lots of feedback.	
	54	H: Oh.	
	55 56	I: Can you hear me now? (Static pauses, then starts again, 8 second pause) Can you hear me?	
	57 58 59	H: Yeah. I: Yeah. Ok I can just about hear you so let's keep going. Is there anything else that you like apart from music and drama?	

	60	H: Uhm, I'm quite boring actually so not that much. Uhm-	
	61	I: -I'm sure you're not.	
	62	H: Uh, just doing nothing just relaxing, I guess.	
	63 64	I: Ok that sounds like a good thing to do. Is there anything you like watching on TV or Netflix?	
Some coopers	65 66 67	H: Uhm, a lot of dramas and TV shows I like to binge so, quite a lot of the popular ones right now. (Background noise, 8 second pause).	votching to - binge votchog programmes
	68 69 70	I: And I'm going to ask you a little bit about being a young carer H if that's ok. Can you tell me a little bit about your family-(unintelligible)?	
	71 72	H: So uhm I live with my mum and my dad and my two older brothers.	
	73	I: (4 second pause) Sorry did you say two older brothers?	
	74	H: Yeah.	
stoting facts Reason for K role	75 76 77	I: (4 second pause) Who are you a young carer for Hannah? H: Uhm my second oldest brother. He's autistic. And my mom is an amputee.	Receip Honothis a YC Description for each peson Autostic - brother
role	78 79	I: Ok. (12 second pause – continued static). And what can you tell me about your family? What do you like doing together?	states the person before rooming their difficulty

Togetheries	80 81 82 83	H: Uhm, we, uh, we do like, just this thing at home and then watching stuff together. But then we also enjoy having family outings and, like going on holiday going travelling, swimming, barbecues.	foncing activities
	84	I: (5 second pause) So lots of things.	
	85	H: Yeah.	
	86 87	I: What, did you have anything in particular that you really enjoyed during lockdown?	
	88 89	H: Uhm, barbecues I guess because we hadn't had one in a while.	
	90 91	I: Ok (4 second pause). Ok can you tell me how you became a young carer?	
	92 93	H: Uhm, when I was, uh I can't really remember the age now, 13, 14 when-	
	94	I: -Ok-	
Role response	95 96 97 98 99	H: Uhm, my mum became an amputee that was when I mainly became a young carer, I've always been a young carer for my older brother, but then obviously I was a lot younger and my mum was a lot more able-bodied then, so she did a lot more than I did.	Resons por becoming a K inchy become a Kichah mus become a public shags a K but a chage in responsibility with own doing more than predid
	100 101 102	I: And, do you see yourself (static ends) as a young carer, when you hear the term 'young carer' do you feel that it applies to you?	doing more than she did

	103	H: Yes.	
	104	I: Yeah. And-and do you like the term young carer?	
	105	H: Yeah.	
	106 107 108	I: Ok. (2 second pause) Is there anything else that you would prefer to young carer or do you think young carer is fine as it is?	
ve as a lovel Identifier gae	109 110	H: I think young carer is fine as it is, but, I'm sure other people might have opinions about it.	That the term
	111 112	I: Ok. And-and can you tell me about the kind of care and support that you, you first of all provide for your brother?	
	113 114 115	H: Uhm, just making sure he's ok uhm, if I'm honest. Uhm, making sure he's happy. And organising everything when my parents aren't able to.	
	116 117	I: Yeah. And what kind of things do you do for him how do you make sure he's happy and or (static).	
incluster dung needs	118 119 120	H: So, in terms of, cause, with autism you have to have a daily routine in order to function so you have to make sure his routine is going the way it should be going.	clear pous on meeting botho's needs undestanding herbrothe's needs ord the difficulties he has compared to prove how how has undestanding what actusmis excless diregood's before saying both
	121	I: Uh-hm.	contraction of knowing bother and indestanding what autiens is
understock of needs -1	122 123	H: So, uhm (2 second pause) making sure he has food at certain times making sure, that he's just happy and there's	excles diagoes before saying bothe orners knows what to do por brother

knows bother cell ord the routines

			has at there isn't anything
Helperg rate	140	rearry the best I could do.	best ' she condo - as long as
Renture responsibilities Helping role	145 146	as long as you can see and observe that he's ok, then that's really the best I could do.	focus o- procluced activities
Rautice	144	H: So, uh I would leave him alone but in a good way, uhm. So	Erang bother us of
	143	I: Ok.	
	142	reserved and introverted so he likes to stay to himself.	
N N	141	H: Uhm, he likes music. A lot. Uh he mainly, he is quite	
	139 140	I: Yeah ok. Anything else that you do with your brother to just help him or make sure he's happy?	
	138	H: Yeah.	
	137	laundry is that right?	
	135 136	Uhm, but also helping the uh other carers who are around and also making sure that he's got the clothes that he needs in his	
	133 134	saying, Hannah is that you kind of help out with food so you make sure that he's eating and getting his food prepared.	Earging in prostical tasks for brother not doing organize would
	132	I: Ok. So, from what I understand, uhm, from what you're	Enging in practical tasks
Hapigole Precisical	131	I would be there to help them.	and have routines
Haping of	130	with stuff like finding clothes or laundry or anything like that,	brother knackedepoble abt brother
	128 129	H: Uhm, not as much now that I'm older and he has other professional adult carers, but then, I guess, if they need help	Helping others not just
	127	activities with your brother?	'helping' role with bother
	126	I: Yeah. (2 second pause) And do you do any specific	stating reportibilities
theiping ole	125	there's something, uh you're there to help.	stating responsibilities
	124	nothing wrong, and knowing that if there is something wrong	There to provide help

nore shalen do

	1.47		
	147	I: So, do you feel you-you kind of need to watch what he's	
	148	doing when you're at home to make sure he's ok?	
	149	H: Yeah.	
	150	I: Yeah. Ok. And it sounds like you know him really well so	
	151	you know when to give him space and when to spend more	
	152	time with him?	
	153	H: Yeah.	
	154	I: Yeah, ok and can we move on to your mum you said your	
	155	mum is an amputee what-what do you do to help your mum at	
	156	home? (8 second pause) Hello Hannah, can you hear me? (7	
	157	second pause) Hello? (5 second pause) H can you hear me? (8	
	158	second pause - recording cuts out - recording ends)	
		-Second recording begins-	
		(Static in background)	
	159	I: Ok, so we were just talking about the kind of care and	
	160	support (static ends) that you provide for your brother and I	
	161	was asking you uhm, what-what kind of things do you do to	
	162	support your mom cause you're a carer for your mum as well?	
		support your mom outpoy you to a outor for your main as went	
Conn	163	H: (Static in background) Uhm yeah so, I do similar things	commente testes de similar con
respectation	164	that I do with my brother.	covery note tooks ore explicitly for brother and muss
C marcal car		and the first my brother.	provene and mucan
Crossever of	165	I: Ok.	
	166	H: But then, like uh she can't really get around so she can't	Prectucal activities she does
freeticel	167	leave the house without me pushing her or my brother or	
LISTS	168	anyone. Whenever we go out someone has to be with her.	forhermer.
		any oner whenever we go out someone has to be with her.	some has to be with her
			- read Bital i ta

-responsibility

Side office	189 190	a lot easier, uh I had more time to do stuff, there was less chores less jobs for me to do, less stressful over time.	changes at home - Roles changing - replecting on time when she was the child ond was the one being water apper. Now she has the
Rele reversal	188	H: Uhm, it was me being the one who was looked after, it was	changes de home-
	183 184 185 186 187	I: (2 second pause, unintelligible - static) Ok, so thinking about the times before you were a young carer, I know you've been a young carer for your brother for quite some time, do you remember what it was like before you were a young carer for your mum?	when other or the responsibility when others or and there. Should responsibility with family members.
Adulte Recte responsibilité Recte responsibilité	180 181 182	H: Uhm yeah so, I tend to cook a lot in my house and do shop runs. And then chores around the house. Uhm, whenever, like, my dad is working. Or no one else is home so.	cooking, chores and pood shapping. Empresis - 'cook a lok' Toking on the responsibility when others or and there
	178 179	I: Ok. And do you have to help with things like food shopping or cooking-	
	176 177	H: Uhm no she (unintelligible) uhm juts reminding her I guess, but she tends to do it her-herself.	x
	175	I: I'm sorry do you have to help her with her insulin?	
	173 174	H: And uhm in terms of food as well, uhm so she's diabetic (unintelligible - static) the insulin.	oppointments
	172	I: Ok.	Prochical - hospital
Helping role	170 171	H: Uh, helping, go with her to hospital appointments, and helping her out in that way.	Repetition of helping' Horon is helping de romand helping her relatives preatical - hospital
	169	I: Ok.	

Repeats 'Less' - at a time when she didn't have the responsibility of being all

	T			
	191 192	I: (4 second pause) Can you tell me what life looked like when you weren't a young carer, what-what (voice cuts out - static).		
Acroality Replecting on the past	193 194 195 196 197	<ul><li>H: Uh I was just a normal kid really, just like went to school, and came back home and played, I guess.</li><li>I: And did you get to spend more time with your friends before you were a young carer (unintelligible) or the same amount of time?</li></ul>	"Norsed Kid" - bees she consider her Lipe robite be norsed roothot she has ye responsibilities. Norsed Life second to be	
conceptors with piros	198 199 200 201 202	H: Uh, the same amount of time I've been lucky in that sense. There are times where I have to cancel cause I'm too busy. But uhm, cause I'm older now and more independent, you don't have to ask permission every 5 seconds or have an adult with you.	simple - cost to school - plaged. spending time with priords - cost as she's got older Feels 'Lucty' that staget	>
	203 204	I: Yeah (2 second pause - static). So, you were saying that it was a little bit different maybe because (unintelligible - static).	Feels 'lucty' that steget tone with her prices independence - she as do not her as ad have benearay. her parting	6 con
	205	H: Yeah.	+	
	206 207	I: And I think you said that it was a little bit less stressful before you were a young carer is that right?		
	208	H: Yeah.		
	209 210	(Continued static) I: Yeah, ok. So uhm, who is in your life that you feel like you have key relationships with at the moment, so something,		

	230 231 232	I: Ok. What-what do you feel is the difference between your friends at school and your friends at the young carer project at Barnardo's.	bacquise she's accept other yes a different subjections who might not have supportive provide Friends or notstanding
supporture.	228 229	H: Uh yes because they are very understanding and I'm lucky to have friends like that.	feels 'hecty' to have her priords boos she feel hicky
	226 227	I: And do you feel like you could speak to them about being a young carer?	
	224 225	H: Uh most of them the ones that I hang out with on a daily basis know.	
to all intesterd	222 223	I: (2 second pause) Thinking about your friends do they all know that you're a young carer?	Relating more to Vis as they share scalar experiences. Dorienced to explain situation to Victoriends
concentrations concentrations being wistorial to all	219 220 221	H: Uhm, well there's Barnardo's, I talked to the workers there and also my friends there, uhm unlike my friends from school they can relate cause they're also young carers.	Frienderip grps - school and Ve project Relating more to Yes as
	217 218	I: And is there anybody outside of (unintelligible - static) or your friends that you would speak to.	sees teacher as being able to provide contice - trutting relationships
support from friess ord teachers	213 214 215 216	H: Uh my friends, a lot, cause they're the same age. And, uhm, that they'll understand to an extent. Uh, teachers in my school, cause then I'll get advice from someone who is professional, and older.	Friends one important and Hanch con share information with these Friends independ to a except
	211 212	challenging or something big happening in your life outside of your family is there anybody that you would speak to?	

support frompers ficturing gips	233 234 235 236 237 238 239 240 241 241 242 243	<ul> <li>H: Uhm, the I-I guess the only difference is our backgrounds in terms of, Barnardo's my friends are young carers and at school my friends aren't young carers.</li> <li>I: Ok.</li> <li>H: But they are both supportive in (two second pause) the same way.</li> <li>I: Ok. You also mentioned that there are teachers that you would speak to as well in school.</li> <li>H: Yeah.</li> <li>I: Are they people that you just feel like you can approach or do they put time aside to speak to you?</li> </ul>	Different friendship gifts categorising prierds is to Vas ord non-Vas sees the only difference is the Va role friendship gps supportive sees both as supportive sees both as supportive but pergo supportive in different rang -prierds who indestand herrole as a Va as they at disposed
Identified Export Accorencesory Climes	244 245 246 247 248 249 250 251 252 253	<ul> <li>H: Uh both? So, there are professional ones who are in inclusion whose job it is for you to talk to if there are problems at home, but then there are also the teachers who are very nice who you just want to talk to who you might see, as a friend as well as a teacher.</li> <li>I: Ok. And you've been at the secondary school for quite a number of years is that right?</li> <li>H: Yeah.</li> <li>I: You joined there at Year 7 so has it always been the same teachers that you've gone to?</li> </ul>	Adults is school who Hands on spect to, traces which adults she con spect to. Identifies some teaches as possible priceds Viacos prieds and concer adults a school as supportive, speces the difference between adults whose is it is to support and planes who touch sees as nice. Spects positively at some staff a school
	254	H: Uhm, pretty much yeah.	Spects to the some teaches

thoughout secondary school

r		T	
	255 256 257 258	I: Yeah. Ok. So obviously there are people in your school who know you're a young carer, how did they come to find out that you were a young carer, did you tell them, was that something that your family did, how did that happen?	
Septerate Pravel Aukoneness	259 260 261 262 263 264 265	H: Uh with my closest friends I told them, uhm that I was. And uhm, for some of my other friends that I don't hang out with that much or the rest of my year group that just know me, like I've done work with Barnardo's before and quite a lot of it has been put in the papers, so some of them have seen that and ask questions about it. Uhm so then, that's how they found out.	Told priords directly the is a.X. othes pard out chant the concerned does with the charity. congregout work for the YC charity - cetting as an and concerned for the YC charity - cetting as an and concerned for YCS. Prove of the cork she has dore?
stagging	266 267 268 269	I: Ok, and what about the teachers at school? How did they find out that you were a young carer? H: Uhm, so when my mum was in hospital, uhm it was during a time when I was doing exams and it was very stressful.	Teaches knowing obther ye
	270	I: Ok.	stressput time - exceps and mum is hospital
	280	H: And it wasn't good, for my mental health.	Not apod for her mental health Aucheness of her all mental health and other needs
	281	I: Right.	health and other needs
seeking help	282 283	H: So, I guess teachers could tell that there was something wrong. And I was crying and I was upset.	Becare uppet in school Teaches becare accore of
Accorects of others Active supple	284 285 286	I: Yeah. H: Uhm, so they, uhm they helped me with that. They would like take time aside and talk to me and be like "are you ok?"	Teachers became above of something stressputtime-esotion of school Teachers checking in tomate site she's of

indestanting

[			T
	287	I: Yeah. And that's continued throughout secondary school?	
	288	H: Yeah.	
	289 290 291 292	I: Yeah. Ok. And so, it sounds like you've got people that you speak to in school, I mean, is it-it more that you go to them or do they sometimes come and speak to you as well, just to kind of check in and see how you are?	
Thist of othes at school	293 294 295	H: Uh they do tend to check in. I do see quite a lot of the same teachers on a daily basis, ok, but even if I don't have them, I'll still see them.	Teachers checking in consistency of some teachers consistency allacing trust to develop - knows that they are
	296 297 298 299 300	I: Ok. Any-and is there anything else that you would like from school cause you're obviously getting to have a chat with people that you-you feel you know quite well and that you trust, but is there anything else that you feel school could be doing to support you?	develop-knows that she goe three
septor in sector	301 302 303	H: Well, I'm quite lucky in that my school's always been very supportive, I know how a lot of schools aren't like that, but, uhm I would say, understanding, that uh, that children, have	Feels "Lucky". Repeated again from earlier in interview
bences bort	304 305	life at home as well as in school. Some teachers don't understand that.	Sees School as supportive Very positive intilatis point - not all teaches ore supportive or
and server	306	I: Yeah.	not all teaches are supportive or is it that they don't that Honor's subjection - had is inportation shored in school?
	307	H: So, so if I've been so busy and haven't had time to do my	shodo in struct.
C III	308	homework, uh there was a teacher who knew my mum was in	himsenes is the you Hanch is
accord a	309	hospital, and I said "I haven't done it for you today but can I	ufformer hetercher -
apported understanding	310	give it in tomorrow?" And she said "Ok." But then there are	Differences in the way Handh is tracted in school by teaches - some supporture, some not
Verseuvera	311	teachers who didn't know, yelled at me and gave me	some suppo enve, some not

misseri support misseri opportunities Acc-auctorigene impact on severel	312 313 314 315 316 317 318 319	<ul> <li>detention, so I guess some teachers to have that understanding, uhm or ask why instead of just making the assumption that uh a child wasn't bothered to do the work.</li> <li>I: Yeah, and so would you like it if everybody in school knew so that they all knew that you were a young carer and everybody was treating you the in same way or?</li> <li>H: Uhm, yeah but then I feel like not everyone would like that, some people like to keep their home life private.</li> </ul>	wonto teached to notestand Hanch wonto to shore what's oping on to her life so that she is sufforted. Facting like the's hazy when she wonto other to see that she has responsibilities wonto other to know she's
others norestancing accorrest of others openness	320 321 322 323 324 325 326 327 328	<ul> <li>I: Yeah.</li> <li>H: I've always been open about it. But then uhm, some uhm, people just need to understand that, you don't have to tell them the full details about what's going on at home, uh but understanding that it's difficult, so. Uhm. Give them the support if they need it.</li> <li>I: Yeah, ok. And you're obviously part of Barnardo's projects as well the young carers project. Is there any kind of communication between Barnardo's and your school?</li> </ul>	a YC Accords of how other YCS feel open dot being a YC scats others to undestand what it is to be a YCord the inflact it conhouse
storigation	329 330 331	<ul><li>H: Uh yeah so, they're the ones who set me up with Barnardo's.</li><li>I: Ok.</li><li>U. G. L. I'L is the second set it with Levels to an inclusion.</li></ul>	connections between school and VC project workers
identified support uncostoniting soral as	332 333	H: So, I didn't know about it until I spoke to an inclusion teacher in my school.	school mitticted the support for Handh to access

Support

	334 335	I: Ok. And do-and do they still talk to each other now and once that had been set up did school kind of move away and?			
continued commiccetion storing information	336 337 338 339	H: Uhm, they've spoken to each other now and then, whenever they were concerned about me. But uh yeah, they started that communication cause they also refer other students apart from myself and others.	A concress of commutation between propessionals no emotional response but doesn't stern to feel regative		
	340 341 342	I: How do you feel about Barnardo's in your school, sharing that information about you? Is that something that you want them to do?	abe the commutertion		
schooles	343	H: Uhm, yes, because it spreads more awareness.	Fouson acomess		
support shore	344	I: Uh-hm.	Honon vonts other to be avere quiner vic role. They can monitor had she is tagether.		
considente	345 346	H: Uhm, like I said not many people would like that, they're more private.	had she is togethe.		
	347	I: Uh-hm.			
openness	348	H: But I'm ok with it.			
	349 350	I: And what-what kind of information are you happy for them to share.			
moting others	351 352	H: That I am a young carer and that I do have to do stuff at home, but a lot of kids my age have to do.	what Hanch voorts her teached to		
when the same	353 354	I: Ok. And-and going back to school how do you feel about school, obviously you're in secondary school now, do you feel	teles abe herely but speaks on behap of other yes.		
be					

Preserve prom	355 356 357 358 359	<ul><li>differently about being a young carer in secondary school than you did as a young carer in primary school?</li><li>H: Uhm, yeah because, yeah there's a lot more responsibility in secondary school cause you have to think about GCSEs, A levels qualifications, the future, your career.</li></ul>	Responsibility that cores which being in second and school. Responsibilities increasing with age at horse and school
	360	I: Yeah.	Responsibilities according with age at home and school
Pressic from	361 362 363 364 365 366	H: The teachers put a lot more pressure on you in that way, and then the way they teach you as well the teaching styles are different. Everything is sort of handed to you, so you wanna play when you're in primary but in secondary, especially in sixth form, there's a lot of independent learning that you do so that's, that's the main difference.	Feeling present from teaches Horry to adopt to different teaches when she works them to adopt to her
	367 368 369 370 371	I: Did you receive any support? I mean it was before you started being a carer for your mum wasn't it when you were in primary school but obviously you were still participating making sure your older brother was ok. So, was anything put in place in primary school to support you?	
and of poors	372 373 374 375	H: Uhm not really. Uhm, so well we, me and my brothers went to the same primary school, so then they knew what was going on. But I guess at the time when my brother was at school, they did focus on him.	Focus on brother at promong school. Lacking accordess of Handris needs and what support she
	376	I: Ok.	might need
	377	H: So, I didn't really have to and I was a lot younger then.	

fositive seveci concorrect correction responsibilite	378 379 380 381 382 383 384 385 	<ul> <li>I: Yeah. So, thinking about hear and now how do you feel about school? Do you feel, you know quite positively about it, is there anything that you're not sure about? You know in relation to you being a young carer?</li> <li>H: Uh I mean, I enjoy school, uh not many people do but I enjoy it. But then there's always that pressure of exams and stuff that I always get stressed out about. And I know a lot of teens do. And the way, the education system just messes with your mental health in that way, uhm</li> </ul>	Enjoys school and is positive about school. Feeling pressure from school and ispect or montal health
	387 388	I: Do you-do you feel that school staff that the staff at school the teachers are able to support your mental health?	
	389 390 391 392	H: Uh they do what they can but some of the stuff is out of their hands cause there's a whole political thing that's involved with it, but they do the best that they can. Or in my school anyway, not all schools are like that.	
	393 394	I: (Two second pause) Is there anything in particular that they do to support your mental health?	
terches Helpful Support	395 396 397 398 399	H: Uh just making sure that you're ok, and taking the time to sit with you and then get you through whatever you need to get through, whether that be a mental health or if you're behind in work, or if you just want something to be explained to you, but slower.	Not cheor up Homon worts this support as a VC or as a student in general
	400 401 402 403	I: Yeah. Ok. And is there anything else that you can think of, uhm. You know about being a young carer in school you mentioned about homework and that you know sometimes there might be some difficulty in making sure you get	

	404	homeory and in an diverse Te there are this at a start of the	
	404 405	homework in on time. Is there anything else that you find difficult in school?	
	403		
Faire	400	H: Uhm, just, uhm the pressure of it, if I'm honest. Uh the foiled avome I'm not really the best when it ensures to avoid	vomies at exans
· · · · · · · · · · · · · · · · · · ·	407	failed exams I'm not really the best when it comes to exams.	-no specific detail
	408	I: Ok.	
Falle	409	H: Uhm, so like if you ask me a question about anything, I	
tutte	410	could answer it, but if you told me to write out that answer in	
	411	a 12-mark essay I'd fail, when it'd look like I don't know it.	
	412	I: Ok, so you worry about your exams, do you think being a	
	413	young carer contributes to your worrying about exams? Or do	
	414	you think you would just worry about exams anyway?	
auside			
support	415	H: I think it does contribute to it in a way, where I do, uhm	conacting verole to
Childonce	416	but my home environment isn't the best place to work in	connecting verole to
	417	cause you can't concentrate as much, so I mainly rely on	Relience on clubs of school
Leene s	418 419	Barnardo's homework clubs. Clubs at school, libraries, uhm	reluceos cues de avec
acres 2	419	stuff like that.	and ve project struggling to concentrate
	420	I: Yeah. Ok. And so, they've got clubs at school that you can	struggling to concercite
1962	421	attend as well?	
	422	H: Uh sometimes yeah, I mean cause of Covid we're not	
	423	really allowed to hang out after school, but yeah.	
	40.4		
loopact co	424	I: Ok. And has Covid had an impact on school and you being	
	425	a young carer?	ELEPPHS CO isolation
Lerneg	426	H: Uhm yes, because I wasn't allowed in school, and that's	when a way from school
"techted	427 428	the way you learn the most so I wasn't able to concentrate at	- Lackon the conection
	428	home, and learn by myself.	elements of isolation when along from school - lacking the convection usuth others who provide
in need q help			with other who police

in need queep

help and support

Contraction of the second s	T		
Freeds as a protect	429 430 431 432 433 434 435 436 437 438 439 440 441	<ul> <li>I: Ok. (2 second pause) Thanks Hannah that's good, that's really great information. Ok so I want you to think about uhm, your-your kind of perfect day, so what you're going to think about is imagine that you wake up tomorrow morning and it's going to be absolutely perfect everything is going to be the way you want it to be and uhm you're going to feel happy all day. So, thinking about that, what do you think that day would look like. (Background noise) So who would you be with? Where would you go? What would you do?</li> <li>H: Uh I'd probably be, with my friends.</li> <li>I: Ok.</li> <li>H: If I'm honest.</li> <li>I: Yeah.</li> </ul>	charce of friends
Friends Cennectory Normal day	442 443	H: Just taking a day out with my friends and spending all day with them.	wonts to be with friends did day
Masser and	444	I: Yeah.	
helpendence Beng mersek	445 446 447	H: So, uhm, that's probably my perfect day. Where I'm away from home, away from school and just with them where I can be myself.	feels most like heself along from home and school
	448 449	I: Ok and anything in particular that you'd want to do with your friends?	- Kraun co Vc de horrence school

nometity	450	H: Uh just, shopping or going to restaurants, or going to the	Activities with
-normalden	451	cinema just having a whole day to ourselves. (Background noise)	monde activities
Ture for herself Heraus	150		with prices
·	452	I: Ok. Fantastic. Ok, so H you've answered lots of questions I	c .
Hears	453	just want to make sure was there anything else that you	
CARE ESTS	454	wanted to share with me about being a young carer or about	
	455	school that I haven't asked you about?	
	456	H: Uh I don't think so I think you got the majority of it, yeah-	
	457	I: -Yeah. You've given me a really good overview of how	
	458	things are at school for you, what kind of support is in place,	
	459	your role as a young (voice cuts out), you've told me lots	
	460	about the things that you do with your older brother, uhm but	
	461	also the things that you do with your mum. Uhm you talked a	
	462	little bit about what things were like before you were a young	
	463	carer and I think you said it was less stressful and you had less	
	464	chores to do. Uhm it sounds like your friends are quite	
	465	important because you mentioned your friends quite a lot	
	466	during this interview. Is that right?	
	467	H: Yeah.	
	468	I: Yeah, ok fantastic. So uhm, what we're going to do now H	
	469	uhm we're going to come to the end of the interview so I want	
	470	to say a big-big thankyou uhm for letting me interview you	
	471	today. It's been brilliant to hear all about you know the things	
	472	that you're doing the things that happen at school, about your	
	473	life as a young carer. It's going to really contribute a lot	
	474	towards the research that I'm doing, uhm have you got any	
	475	questions for me?	

476 477 478	<ul><li>H: Uh none, not in particular no, I-</li><li>I: -Ok-</li><li>H: -I understand everything so thank you.</li></ul>	
479 480 481 482 483 484 485 486 487 488 489	I: Uhm so what I will do now I'm going to type everything up so obviously we've recorded this. Uhm I will type everything uhm and then I will look at the information that you've provided today, alongside other information that's been provided by other young carers. Uhm just to see what everybody is saying, what kind of support is happening in school, uhm if there's anything different that young carers would like to be getting, uhm and what I'd like to do is once I've done all of that is make a short report and send that short report to you, uhm and maybe have a chat with you again just to see if you agree with everything that's in that report?	
490 491 492 493 494 495	<ul> <li>H: Ok.</li> <li>I: Yeah, does that sound alright with you? (Two second pause) Yeah?</li> <li>H: Yeah.</li> <li>I: Ok fantastic so I'm going to stop the recording now just let me stop the recording.</li> </ul>	
I – Interviewer H – H	nnah (participant)	

A debrief letter was sent to each participant and their family following the interview. Reminders were given regarding timescales for withdrawing from the study and signposted to organisations and charities should they need any additional support.

Superordinate Themes	Emergent Themes	Line numbers (transcript)	Key words/phrases		
Differences	Identifying needs of the care	37	my little brother has autism		
	receiver	92	there's a lot of things he can't do on his own		
	Awareness of differences	86-88	my brother would probably go to the same school as me and he'd be capable of a lot more things		
Care provider	Providing help and support	79	give support to those who are in that situation		
	Wanting to help others	74-75	Well, I sort of enjoy being a young carer, so even if I wasn't, I think I would like to even, even if I wasn't, I'd like to help in that situation in a way		
	Obligation/duty	48-49	when I hear young carer I think of like, of-of like a huge responsibility that you have to take really seriously		
	Increasing responsibility / capability to be a YC	99	the older I get the more I'm able to do		
Learning support	Support with learning	120-21	it helps me to concentrate and because my brother loves like to play with me and stuff like that and it just helps me to concentrate a lot more		
Identity	Identity as a student	154-55	Despite being a young carer, I do manage to uhm, get good grades while I'm at school		
	Self-identity	45-46	I picture myself as that but I wouldn't really call it that in a way		
	Identity as a YC	17	I'm a YC of my little brother		
	Self-belonging as a YC	129-30	going there shows us like there are other people in similar situations to you and it does help quite a lot actually		
Protective factors	Time with friends	133	Yeah, I've made a lot of friends		
	Friends as support	180-81	they understand uhm, they're really good at showing it as well		
	Outside support	129-30	going there shows us like there are other people in similar situations to you and it does help quite a lot actually		
	Positive views about school	200	I do enjoy school quite a lot to be fair		
		202	I enjoy my lessons and I'm able to concentrate well and I'm able to learn well		

Appendix '	V: Summary	table for	Jordan (	(Particip	ant 1)

	Connections and	211-12	I'd be with my family, so my mum, my brother, my cousins, my
1	relationships		aunts and uncles and my grandma everyone basically
,	Time away from YC role -		I like playing piano, uhm and I like basketball
	separation	25	I do basketball at school
	Shared enjoyment	31-32	I like uhm, jumping with him on the trampoline. We like doing that
			and uhm we like playing with our dog
		69	I just I like spending time with him

Superordinate	Emergent Themes	Line numbers	Key words/phrases
Themes		(transcript)	
Environment	School as a positive	229	otherwise yeah, it's good
	School support	168-69	at school uhm I did a thing called draw and talk and I went out of
			with the teacher every afternoon on Tuesday – more like support
		177	I'd had enough when they finished
Me as a YC	Reasons for YC role	95	became a young carer because my brother got ill
	Start of YC role		then my mum said do you wanna be a young carer and I said yeah
		97-98	sure
	Doing what is right / Duty	71	Well, it just makes me feel, like I'm doing the right thing
	Practical care	105	sometimes turn on the fan when he wants it
		107	open the door for some, some lighting not too much
	Stating facts	57	Started when I was nine
		100	I started being a young carer
<b>Connections and</b>	Shared time	113	watching films
relationships			
	Friends as support	142	Yeah, just tell my friends
	Family connections	278	my family
		282	well, maybe my grandparents
	Family support	139	Then my mum and dad, then. See my cousin, then just further out
	Connecting with sibling	111	play games, uhm I'll go in goal for him so he can take shots
			against me
		137	Probably my brother
<b>Positive aspects</b>	Benefits	126-27	we've gotten multiple different things. Such as like uhm, now
			have a new PS4.
		129	a new back garden
	Time to play	22	football, playing video games

# Appendix W: Summary table for George (Participant 2)

Superordinate Themes	Emergent Themes	Line numbers (transcript)	Key words/phrases
School support	Teachers as support	173-174	teachers in my school, cause then I'll get advice from someone who is professional, and older
	Active school support	195-196	So, there are professional ones who are in inclusion whose job it is for you to talk to if there are problems at home
	Teacher awareness	220-221	They would like take time aside and talk to me and be like "are you ok?"
	Trust in teachers	196-197	but then there are also the teachers who are very nice who you just want to talk to who you might see, as a friend as well as a teacher
	Sharing information	257-259	they've spoken to each other now and then, whenever they were concerned about me. But uh yeah, they started that communication cause they also refer other students apart from myself and others
	Shared understanding	268	That I am a young carer and that I do have to do stuff at home
School stress	Missed opportunities	239-241	I guess some teachers to have that understanding, uhm or ask why instead of just making the assumption that uh a child wasn't bothered to do the work
	Worries – school performance	310-311 292-295	Uh the failed exams I'm not really the best when it comes to exams But then there's always that pressure of exams and stuff that I always get stressed out about. And I know a lot of teens do. And the way, the education system just messes with your mental health in that way, uhm
	Perceived pressure from school	276-277	The teachers put a lot more pressure on you in that way, and then the way they teach you as well the teaching styles are different
	Seeking help	217-218	So, I guess teachers could tell that there was something wrong. And I was crying and I was upset
Practicalities of caring	Practical tasks	135-136	she can't really get around so she can't leave the house without me pushing her or my brother or anyone
	Understanding needs	63 94-95	my second oldest brother. He's autistic. And my mum is an amputee with autism you have to have a daily routine in order to function so you have to make sure his routine is going the way it should be going

# Appendix X: Summary table for Hannah (Participant 3)

	Routines	97-99	making sure he has food at certain times making sure, that he's just
			happy and there's nothing wrong, and knowing that if there is
			something wrong there's something, uh you're there to help
	Helping role	103	I would be there to help them
Parental role	Role reversal – doing parent	76	my mum became an amputee that was when I mainly became a
	like tasks		young carer
		146-147	I tend to cook a lot in my house and do shop runs. And then chores
			around the house
	Shift in responsibility	77-78	I've always been a young carer for my older brother, but then
			obviously I was a lot younger and my mum was a lot more able-bodied
			then, so she did a lot more than I did
	Crossover of care	133	I do similar things that I do with my brother
	Shared care	147	whenever, like, my dad is working. Or no one else is home so
Self-care	Time for self	25-26	not only are they the subjects that I study at school but is, hobbies that
			I enjoy outside of school as well
		55-56	a lot of dramas and TV shows I like to binge so, quite a lot of the
			popular ones right now
		339-340	Where I'm away from home, away from school and just with them
			where I can be myself
	Connections and support from	178	unlike my friends from school, they can relate cause they're also young
	friends		carers
		183	because they are very understanding and I'm lucky to have friends like
			that
		337	Just taking a day out with my friends and spending all day with them
	Independence and assumed	160-161	I'm older now and more independent, you don't have to ask permission
	maturity		every 5 seconds or have an adult with you
	Together	67-68	But then we also enjoy having family outings and, like going on
			holiday going travelling, swimming, barbecues
Identity	Proud	207-208	I've done work with Barnardo's before and quite a lot of it has been
			put in the papers
	Identity as a YC	86	I think young carer is fine as it is

	A normal life	155-156	I was just a normal kid really, just like went to school, and came back
			home and played, I guess
Impact of caring	Burden/stress	151-152	it was me being the one who was looked after, it was a lot easier, uh I
			had more time to do stuff, there was less chores less jobs for me to do,
			less stressful over time
	Impact on learning	318-320	I think it does contribute to it in a way, where I do, uhm but my home
			environment isn't the best place to work in cause you can't concentrate
			as much, so I mainly rely on Barnardo's homework clubs. Clubs at
			school, libraries, uhm stuff like that

Superordinate Themes	Emergent Themes	Line number (transcript)	Key words/phrases
<b>Connections with</b>	Relationship with	92	We usually, I like to play dolls with her and that
others	sibling	305	I just like the peace from my sister
	Friends as support	213-214	there is like this girl in my school who also has somebody who's like autistic
		225	She's a friend of mine we still play together
		353-354	I feel ok cause my friends usually have something to talk about so it'll take my mind off it
	Seeking school support	242-243	I usually talk to my teaching assistant cause she's there all week 'cause I get a teacher different half way through the week
		273-274	Well, they don't really do anything but I'd like for them to actually, have somebody for me to sit down and talk to
	Connections with	200-201	definitely my mum and I like to spend time with my dad and my brother as well
	family members	416	probably like baking with my mum 'cause I really like doing that
Adult	Duty/obligation	108	I gotta try take her mind off it
responsibilities			
	Protector	112-113	take her away from whoever she's hurting
	Minimising discomfort	124	I like hug her or I stroke her
	Acting as a parent	121	Well, I just try to make her happy when she's a bit down
	Role as helper	95-96	I started to just like help out with her cause she started like acting up and that
	Worrying	363-364	I'm just wondering if she's ok cause usually she's a bit better if not, like, if
			everybody's home she's a bit overwhelmed
		368	I hope she's ok and hopefully it's not that bad
Maintaining	Hopes for the future	412	I'd like to go out maybe cinemas or something, or like go somewhere we all
positive outlook			enjoy
	Carefree	147	We could go out more and we could like play
	Hobbies and own	24	I like to play football
	interests	28	I usually train on a Thursday and play a match on Saturday
	Same as others	103	I'm just a normal person to myself
Life is difficult	Difficult feelings	177	Just a bit down

Appendix	<b>Y</b> :	<b>Summary</b>	table	for	Jessica	(Partici	pant 4)
repending		Summary	unit	101	ocosica	(1 41 1101	pane i)

	386	Sometime I just get a bit sad about it but sometimes I just think its life
Disruption to home life	162	Well especially with my sister. She uh makes the place a bit more, uncalm and
		that
	188	Cause if they leave or if they do something wrong my sister will just, meltdown
	378	Mmm and we can't go out as a family
	380-381	Cause she'll have a meltdown. And we can't even hum or sing or dance unless
		she allows it
Disruption to school	175	I just kept getting things thrown at me and taken away from me
work		

# Appendix Z: Superordinate themes for all participants

Jordan Participant 1	George Participant 2	Hannah Participant 3	Jessica Participant 4
Differences	Environment	School support	Connections with others
Care provider	Me as a YC	School stress	Adult responsibilities
Learning support	Connections and relationships	Practicalities	Maintaining positive outlook
Identity	Positive aspects	Identity	Life is difficult
Protective factors		Self-care	
		Parental role	
		Impact of caring	

### Appendix AA: Letter to participants about the findings



# **Research - Exploring Young Carers' Experiences of Education**

Trainee Educational Psychologist

To all participants,

Having read through all of the young carer interviews I wanted to let you know the key points I have identified as being very important to you, as young carers.

Friends & family

All of you said how important family and friends are to you. In particular many of you said that your friends helped you and were very supportive to you.

Young carer role

It was clear that all of you know the people you are caring for really well. You know what their needs are and how to support them effectively. You are all important members of your family and can be relied upon when help is needed.

Some of you mentioned challenges you face at home and the changes you've experienced since becoming a young carer. You've all manged these changes well due to your mature attitude and resilience.

#### School

All of you spoke positively about school and could identify different aspects you enjoy at school. Your experiences of the support you receive in school vary. Some of you have identified teachers in school who help you. Most of you stated that you would like to have someone in school to speak to regularly and that you would find this helpful. A few of you suggested a young carer club in school so that you could meet and share your experiences with other young carers.

In the interviews some of you reported that some school staff knew that you were a young carer and others didn't. Some of you wanted all school staff across school to know that you were a young carer, whilst others wanted only certain school staff to know. It was clear that most of you wanted to be asked first before this information was shared across the school.

Many of you said that even though some of your teachers knew that you were a young carer they didn't consider the impact caring could have on your learning. Homework was highlighted by some of you and you often find it difficult to complete work at home due to your caring role or finding time and space to complete it.

### Suggestions

With the schools I'm working with and through my research I will suggest that schools have a key person in school who will ensure that information is shared across school and between staff. As some of you have said I think it is important that school staff speak directly to young carers to find out what support you would like and need instead of deciding for you. It's also really important that school staff keep in contact with parents so that not only can information be shared but parents can provide their own suggestions and be included in support in schools.

Thank you for taking the time to speak to me and for being so open and honest. I've learnt a lot about young carers all from you participating in this research.

Thank you,

TEP

### Appendix BB: Research diary extracts

#### 27<sup>th</sup> July 2020

I interviewed my first participant today, which I was quite nervous about. It was quite an unusual experience as the participant kept their camera off, during the video call so that I only recorded the audio. I was only able to see myself and it was difficult to gauge the participant's interest and to know how long to leave after and between questions. I wonder if the interview would have been different had we both been face to face or at least had been able to see each other on screen.

The participant answered all of the questions but I'm not sure if the questions elicited enough information. The whole interview felt as though it was very much at surface level and didn't really allow for the participant to really reflect on their role as a YC. I stuck quite rigidly to the interview questions for two main reasons, my lack of interviewing experience and how nervous I felt. Going into the interview I worried that I would do or say something wrong but looking back on it I need to go through my interview questions again to see what I can adapt and turn it into more of a conversation. It will be interesting to read through the transcript and see if I feel any differently.

There are definitely aspects of today's interview that I have learned from which I hope will better guide the next interview.

#### 23<sup>rd</sup> September 2020

I had hoped to recruit participants from schools in the LA where I am currently on placement but have had no interest to date. I have created flyers and emailed all SENCOs and DSLs in primary and secondary schools and asked EPs in the service to speak to their link schools. The EPs have been incredibly supportive and have spoken to their schools. I have arranged to carry out a presentation about YCs to the SENCo forums, but that will be in November. I'm getting worried that it has been two months since my one and only interview and there's still no sign of any more. Having spoken to other TEPs I have decided to reach out to as many YC organisations as I can to see if I can find participants that way. I have spent time today researching charities and organisations who support YCs and have emailed several. Now that I have done that, I'm feeling a little more hopeful that I will get participants, I'll just have to wait and see.

#### 24th September 2020

I received a response from one of the YC projects I emailed yesterday. I'm feeling much more positive and I'm so grateful that the project worker is going to help me with this. Fingers crossed I'll have some more participants in the next few weeks.

### 16<sup>th</sup> October 2020

The project worker who emailed me on the 24<sup>th</sup> September has been in contact after I sent a follow up email. She will reach out to parents on my behalf and share the flyer I created. I'm not feeling quite as positive as it feels as though time is ticking and I still only have one participant. This whole process has taken a month and it doesn't seem to have progressed. I need to think about some other ways to find participants. Another possible option is word of mouth and see if any other TEPs, EPs or professionals know of any YCs who may be interested in participating.

## 18th October 2020

Word of mouth seems to have worked. I have been in contact with one family and have the contact details for a second. I have my second interview in two days. Again, I'm feeling nervous as it's been three months since the last interview. I really hope it goes well.

### 20th October 2020

It was my second interview today. The family were lovely and definitely put me at ease. I hope I manged to put the participant at ease as well! I spoke to the mum beforehand and suggested that the child be in the room on their own for the interview so that I could get just their views. The participant and parent decided against this and mum sat next to the participant throughout. It makes me wonder how differently the interviews would be if I was meeting each participant in their school. Would they say something different if their parent wasn't next to them?

I'm happy that the interview went ahead and I hope that some good information was gathered. I am in the process of following up with two other families who I may be able to interview.

### 2<sup>nd</sup> November 2020

I interviewed my third participant today. This interview felt much less stressful, probably because I've met the YC before virtually through work I have completed in the LA and the participant is older than the others. It was much more of a conversation and I felt like I got a real insight into their world. The participant gave their opinion and had their own views on what they thought should be happening in schools. It was easier to have a conversation instead of feeling like I was just working through a set of questions.

Working virtually proved to be quite hard for this interview. The family have got limited IT equipment and the internet connection was not stable. There was interference for most of the interview and the connection was lost completely after the first ten minutes. It then took thirty minutes to re-establish the connection and to start again. The participant didn't seem phased by this and carried on as normal. I wasn't always able to hear the participant and I worried that most of the interview would not be recorded. Having played it back I can hear the participant, which is a relief.

#### 8<sup>th</sup> November 2020

Today I interviewed the fourth participant. This participant was younger than the third and I felt as though I had to think more carefully about the questions and work on helping them to feel at ease. I can imagine it must be really hard for children to open up and talk about their experiences to someone who is a virtual stranger. All of the participants, in this respect, have done so well and have been quite open about their lives and their thoughts. Would I have gained more or less information by meeting participants in school, it's difficult to say, but I do think some of the responses may have been different. In some cases, the participants have been in the same room as the family member they help to care for and/or have been with their parent for the interview. Will participants give their full view when family are listening to them?

Participant four was great. Their mum stayed with them and I think it helped to reassure them. I spoke to mum at the end of the interview and it was during this conversation that the participant began to get upset. Both mum and myself decided it was best to end the call. I sent a follow up email along with a debrief letter detailing organisations who may be able to support them. I also sent information about their local YC group. Mum emailed me and said that she'd spoken to the participant. It seemed that the participant hadn't really thought about how changes in her family and her role of being a YC had affected her. Mum reported that they had a long chat and the participant spoke openly to her. I mentioned the organisations again and mum said that she would look into them. At first, I felt terrible for upsetting the participant but after speaking to their mum I realised that this was probably the first time the participant had spoken openly and I thought that this was probably a good thing.

#### 1<sup>st</sup> December 2020

I have not been able to find anymore participants so have decided to stop looking and to concentrate on the four interviews I have been able to do. I'm happy that I have four interviews and, having started to read through them whilst transcribing I feel much better about the content of them all.

Appendix CC

# School of Psychology Research Ethics Committee

# NOTICE OF ETHICS REVIEW DECISION

For research involving human participants

BSc/MSc/MA/Professional Doctorates in Clinical, Counselling and Educational Psychology

#### **REVIEWER:** Mark Harwood

SUPERVISOR: Janet Rowley

STUDENT: Gemma Hebden

**Course**: Professional Doctorate in Child and Educational Psychology

Title of proposed study: Exploring Young Carers' Experiences of Education

#### **DECISION OPTIONS:**

- 1. APPROVED: Ethics approval for the above named research study has been granted from the date of approval (see end of this notice) to the date it is submitted for assessment/examination.
- 2. APPROVED, BUT MINOR AMENDMENTS ARE REQUIRED BEFORE THE RESEARCH COMMENCES (see Minor Amendments box below): In this circumstance, re-submission of an ethics application is <u>not</u> required but the student must confirm with their supervisor that all minor amendments have been made <u>before</u> the research commences. Students are to do this by filling in the confirmation box below when all amendments have been attended to and emailing a copy of this decision notice to her/his supervisor for their records. The supervisor will then forward the student's confirmation to the School for its records.
- 3. NOT APPROVED, MAJOR AMENDMENTS AND RE-SUBMISSION REQUIRED (see Major Amendments box below): In this circumstance, a revised ethics application must be submitted and approved before any research takes place. The revised application will be reviewed by the same reviewer. If in doubt, students should ask their supervisor for support in revising their ethics application.

#### DECISION ON THE ABOVE-NAMED PROPOSED RESEARCH STUDY

(Please indicate the decision according to one of the 3 options above)

Currently, of course, this research would have to be done via video meeting software (e.g. UEL's MS Teams can be used to host mulitple external people in video conferencing). Althought this might change between now and this project's April 2021 deadline, I would recommend implementing this remotely regardless of any lockdown changes in the months ahead. Online sessions reduces the ethical impact (safeguarding etc), as well as ensuring the viral protection of all involved. With that critical caveat, the study can go ahead- 2.

Minor amendments required (for reviewer):

#### Major amendments required (for reviewer):

#### **Confirmation of making the above minor amendments** (for students):

I have noted and made all the required minor amendments, as stated above, before starting my research and collecting data.

Student's name Gemma Rothery Hebden Student number: u0838974

Date: 15.05.2020

(Please submit a copy of this decision letter to your supervisor with this box completed, if minor amendments to your ethics application are required)

#### ASSESSMENT OF RISK TO RESEACHER (for reviewer)

Has an adequate risk assessment been offered in the application form?

YES /

Please request resubmission with an adequate risk assessment

If the proposed research could expose the <u>researcher</u> to any of kind of emotional, physical or health and safety hazard? Please rate the degree of risk:



HIGH

Please do not approve a high risk application and refer to the Chair of Ethics. Travel to countries/provinces/areas deemed to be high risk should not be permitted and an application not approved on this basis. If unsure please refer to the Chair of Ethics.



MEDIUM (Please approve but with appropriate recommendations)

LOW

Reviewer comments in relation to researcher risk (if any).

**Reviewer** (Typed name to act as signature): Mark Harwood

Date: 01/05/20

This reviewer has assessed the ethics application for the named research study on behalf of the School of Psychology Research Ethics Committee

#### **RESEARCHER PLEASE NOTE:**

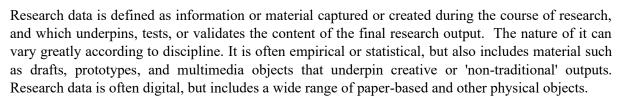
For the researcher and participants involved in the above named study to be covered by UEL's Insurance, prior ethics approval from the School of Psychology (acting on behalf of the UEL Research Ethics Committee), and confirmation from students where minor amendments were required, must be obtained before any research takes place.

## Appendix DD

# **UEL Data Management Plan: Full**

For review and feedback please send to: researchdata@uel.ac.uk

#### If you are bidding for funding from an external body, complete the Data Management Plan required by the funder (if specified).



Administrative Data	
PI/Researcher	Gemma Rothery Hebden
PI/Researcher ID (e.g. ORCiD)	0000-0003-3633-6035
PI/Researcher email	
Research Title	Exploring Young Carers' Experiences of Education
Project ID	N/A
Research Duration	Proposed end date of April 2021
Research Description	The proposed study seeks to find out and explore the educational experiences of young carers (YCs). It is the intention of the researcher to use an inductive approach, utilising semi-structured interviews and Interpretative Phenomenological to explore the meanings and understandings of YCs' views of their own educational experiences. It is anticipated that six YCs will participate and will be recruited through the LA project for YCs and local schools. The main research question is: What are YCs' lived experiences of education?

Funder	Part of professional doctorate
Grant Reference Number (Post-award)	N/A
Date of first version (of DMP)	17.01.20
Date of last update (of DMP)	17.07.2020 - updated research methodology in light of Covid-19
Related Policies	UEL's <u>Research Data Management Policy</u>
Does this research follow on from previous research? If so, provide details	N/A
Data Collection	
What data will you collect or create?	Six young carers will be interviewed by the researcher, via Microsoft Teams. Interviews will be 40 – 60 minutes long and semi-structured. All interviews will be audio-recorded and transcribed by the researcher. In order to record only the audio, the participant's camera will be turned off so that they are not identifiable. Data will be anonymised at the point of transcription. Each participant will be given a pseudonym and all identifiable information (e.g. names, schools, locations, identifiable scenarios) anonymised in the transcripts. Personal data will be collected on consent forms (names and date of birth) and prior to the interview (email address and/or telephone number for purposes of arranging the interview, via the researcher's UEL email address). If participants choose to disclose sensitive data it will not be collected intentionally to be analysed but may form discussion points led by them in the interviews. No further data will be created in the process of analysing the transcripts. No software will be used to analyse data or for the transcriptions. Interviews (mp3) and transcripts (word documents) will be created with an estimated volume of 0.675GB

How will the data be collected or created?	Interviews will be recorded via Microsoft Teams. Audio files of interviews will be transcribed onto a computer as a Word document.			
Documentation and Metadata				
What documentation and metadata will accompany the data?	Participant information sheets, consent forms, list of guide interview questions, debrief sheet, audio files and transcripts of interviews.			
Ethics and Intellectual Property				
How will you manage any ethical issues?	<ul> <li>Written consent will be obtained for all participant interviews.</li> <li>Participants will be advised of their right to withdraw from the research study at any time without being obliged to provide a reason. This will be made clear to participants on the information sheets and consent forms. If a participant decides to withdraw from the study, they will be informed their contribution (e.g. any audio recordings and interview transcripts) will be removed and confidentially destroyed, up until the point where the data has been analysed. I will notify participants that this will not be possible more than 4 weeks after the interview due to the data having already been analysed</li> <li>In case of emotional distress during or following the interview, contact details of a relevant support organisation will be made available in a debrief letter. If participants appear distressed during the interview, they will be offered a break or the option to end the interview.</li> <li>Participants will also be informed that any issues relating to their safety or the safety of others will be referred to the safeguarding lead at the school or young carers' organisation.</li> <li>Transcription will be anonymised and given a pseudonym during transcription to protect confidentiality. Agreement will be made that no names will be used or any other identifiable information including schools or local</li> </ul>			

now will you manage copyright	There are no copyright or Intellectual Property Rights issues.
Storage and Backup	
How will the data be stored and backed up during the research?	Transcriptions will be saved on the researcher's password protected laptop and will have individual password protection. The laptop is a personal, non- networked, laptop with a password only known to the researcher. Audio files will be stored in a separate location from transcripts in the UEL Microsoft Stream Library. Each audio file will be named with the participants' initials and the date of the interview. Each participant will be attributed a pseudonym and Transcription files will be named as the pseudonym. The list linking the pseudonyms to the participants will be destroyed after the interviews when analysis starts. Prior to this it will stored separately to the rest of the data, this will be on a separate external hard drive, which is encrypted and will be held in lockable storage. Audio files of interviews will be uploaded and stored to the UEL Microsoft Stream Library. Consent forms will be saved to the researcher's laptop immediately after the interview. They will then be transferred to an encrypted storage device and erased from the laptop. The encrypted storage device will be stored in a locked cabinet on the researcher's private property. Paper versions will then be destroyed and electronic versions will be transferred from the encrypted storage device onto the researcher's personal space on the UEL server (OneDrive for Business) that can only be accessed by the researcher (using the researcher's password). Consent forms will then be erased from the encrypted storage device.

	<ul> <li>addition to the area being password protected they will be encrypted and each file will be password protected.</li> <li>Scanned consent forms and audio files will be saved in a separate location to other research data. Consent forms will be stored in a separate folder on UEL</li> <li>OneDrive for Business. Once data has been saved to UEL servers it will be deleted from the encrypted storage device. Audio files of interviews will be uploaded and stored to the UEL Microsoft Stream Library.</li> <li>All study data on the researcher's personal laptop will be erased once the thesis has been examined and passed.</li> </ul>
How will you manage access and security?	The researcher will transcribe all interviews (removing identifiable information in the process) and only the researcher, supervisor and examiners will have access to the transcripts. Audio files will be saved in the UEL Microsoft Stream Library in an encrypted folder and titled as follows: 'Participant initials: Date of interview.'
Data Sharing	
How will you share the data?	Anonymised transcripts will be shared with the research supervisor via UEL email. File names will be participant pseudonyms and will be encrypted and password protected. Extracts of transcripts will be provided in the final research and any subsequent publications. Identifiable information will not be included in these extracts.
Are any restrictions on data sharing required?	Anonymised transcripts, which could potentially include sensitive and identifying data will not be deposited via the UEL repository.
Selection and Preservation	

Which data are of long-term value and should be retained, shared, and/or preserved?	Audio recordings and electronic copies of consent forms will be kept until the thesis has been examined and passed. They will then be erased from the UEL OneDrive for Business and UEL Microsoft stream library. The researcher will erase the transcripts from UEL servers once the thesis has been examined and the course completed. Data will be deleted from the researcher's laptop after five years in case of publication or future research.
What is the long-term preservation plan for the data?	As above.
Responsibilities and Resources	
Who will be responsible for data management?	Gemma Rothery Hebden
What resources will you require to deliver your plan?	Portable encrypted storage device and lockable cabinet
Review	
This DMP has been reviewed by:	Penny Jackson Research Data Management Officer
Date: 29/01/2020 v.1 17/07/2020 v.2	Signature: Penny Jackson

Appendix	EE
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UE Universi East Lor	UEL Risk Assessment Fo	orm							
Name of Assessor:	Gemma Rothery Hebden	Date of Assessment	08.05.2020						
Event title:	Exploring Young Carers' Experiences of Education	Date, time and location of activity:	Summer term 2020 – Spring term 2021 Schools within Redbridge and Young Carers' groups						
Signed off by Manager (Print Name)	Janet Rowley								
Please describe the activity in as much detail as possible (include nature of activity, estimated number of participants, etc) If the activity to be assessed is part of a fieldtrip or event please add an overview of this below: The focus of my research for my thesis will be to interview young carers aged between 8 and 18 years to find out their experiences of education. I will recruit participants through local schools and a young carers' group. I will have a maximum of six participants. School staff and professionals working with the young carers will be asked to help me to identify young carers who I could interview. Due to Covid-19 interviews will take place through Microsoft Teams, following guidance from the British Psychological Society (BPS), Health and Care Professions Council (HCPC) and Association of Educational Psychologists (AEP). There will be audio recordings of all interviews. Participants will receive an invite to join Teams at a pre-agreed time and date for the interviews. Children and parents will be asked to find a room in their home which would be suitable for the interview, with a recommendation that it does not take place in the child's bedroom. Children can decide if they would like their parent/carer present during the interview. If the parent/carer is not present in the room they need to agree to remain in the family home for the									
duration of the maximum of fiv children who h									

need to be gained before the interviews take place and I will only interview those children who have parental consent and have agreed to participate. When all children have been interviewed, they will be given information about the data collected. All data will be confidential and none of the children will be identifiable through the data. All of the children will be asked how they would like the findings to be disseminated to schools and the young carers' group. Children can decide to withdraw from the research up to the point of data analysis. All recordings and data will be stored securely in accordance with UEL guidelines.

### Overview of FIELD TRIP or EVENT:

I am currently a trainee on the Prof Doc Educational and Child Psychology course at UEL and the research is for my thesis.

#### Guide to risk ratings:

a) Likelihood of Risk	b) Hazard Severity	c) Risk Rating (a x b = c)
1 = Low (Unlikely)	1 = Slight (Minor / less than 3 days off work)	1-2 = Minor (No further action required)
2 = Moderate (Quite likely)	2= Serious (Over 3 days off work)	3-5 = Medium (May require further control measures)
3 = High (Very likely or certain)	3 = Major (Over 7 days off work, specified injury or death)	6-9 = High (Further control measures essential)

Which Activities Carry Risk?								
Activity / Task Involved	Describe the potential hazard?	Who is at risk?	Likelih ood of risk	Seve rity of risk	Risk Rating (Likeli hood x	What precautions have been taken to reduce the risk?	State what further action is needed to reduce risk (if any)	Rev iew Dat e

					Severi ty)		and state final risk level	
1) Interviews to be carried out remotely through Microsoft Teams	People outside of the interviews may be able to access the meetings	Participants – children & Researcher	1	2	1	All interviews will be carried out securely through Microsoft Teams and only participants who have received an invite will be able to	Participants will be informed of the procedures which will be followed to ensure their online safety - 1	08.0 5.20
						access the meeting. Online interviews will follow guidance from the British Psychological Society (BPS), Health and Care Professions Council (HCPC) and Association of Educational Psychologists (AEP).		

Participants having access to equipment to access the interviews and know how to use it safely and appropriately.	Participants – children & Researcher	1	1	1	Ensure that parents and children have access to suitable equipment in advance of interviews. Children who do not have access to equipment will be unable to participate in the interviews. Children will be given time to familiarise themselves with the equipment and Microsoft teams before the interviews begin. Children will be encouraged to ask any questions if they are unsure about anything.	Children and parents will be given time before, during and after the interviews to ask further questions if they have any. Online interviews will follow guidance from the British Psychological Society (BPS), Health and Care Professions Council (HCPC) and Association of Educational Psychologists (AEP) – 1	08.0
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2) Children will be asked to discuss their role as a young carer and talk about their experiences of education	Discussion of sensitive subjects may cause the participant to become distressed	Participants – children & Researcher	2	1	2	Questions to be checked and agreed by Director of Studies. Interview questions to be discussed in the focus group. Children will have received information letters and consent forms in advance of the interviews. Discussions held with participants prior to interviews.	Offer to stop the interview. Signpost the participant to relevant professionals & organisations. Researcher to inform parents/carers should the participant agree – 2	08.0 5.20
3) Concerns may be raised whilst speaking to the participants	Disclosures and safeguarding concerns may be raised during the research process	Participants – children & researcher	1	3	3	Researcher aware of LA safeguarding policy. Researcher aware of safeguarding lead in settings. Researcher to make participants aware of safeguarding and confidentiality procedures at the start of each session including the possibility of referring to safeguarding leads.	Any disclosures or concerns to be raised with safeguarding leads. Researcher to follow all safeguarding procedures - 3	08.0 5.20

4) Increasing the age range for participants from 8-12 years to 8-18 years of age	Ensuring safeguarding procedures, consent forms and information letters and any other information given (verbal or written) is suitable to the age range of participants	Participants – children & researcher	1	1	1	Consent forms and information letters include relevant information to the research which are suitable for children and young people aged between 8 and 18 years. See information above in relation to safeguarding.	Information letters and consent forms are provided before interviews take place. Researcher to check participant's understanding before proceeding with any interviews	02.1 0.20

A comprehensive guide to risk assessments and health and safety in general can be found in UEL's Health & Safety handbook at <a href="http://www.uel.ac.uk/hrservices/hs/handbook/">http://www.uel.ac.uk/hrservices/hs/handbook/</a> and a comprehensive guide to risk assessment is available on the Health & Safety Executive's web site at <a href="http://www.hse.gov.uk/risk/casestudies/index.htm">http://www.uel.ac.uk/hrservices/hs/handbook/</a> and a comprehensive guide to risk assessment is available on the Health & Safety Executive's web site at <a href="http://www.hse.gov.uk/risk/casestudies/index.htm">http://www.hse.gov.uk/risk/casestudies/index.htm</a>. An example risk assessment is also included below.