

Young Carers' Experiences of Caring in an Inner London Borough – an Interpretative Phenomenological Analysis (IPA)

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A thesis submitted in partial fulfillment of the requirements of the University of East London for the Professional Doctorate in Educational and Child Psychology

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STUDENT DECLARATION

University of East London
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Declaration


This work has not previously been accepted for any degree and it is not being concurrently submitted for any degree.

The research is being submitted in partial fulfillment of the requirements of the Doctorate in Educational and Child Psychology.

The thesis is the result of my own work and exploration, except where otherwise stated. Other sources are acknowledged by explicit references in the text. A full reference list is included in the appendix.

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Karen Mary Wadey

Signature:  Date: 11th September 2015

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Abstract

Young Carers are children and young people (CYP) between the age of 5-18 years who provide care for a family member who has an illness or disability. The prevalence of Young Carers (YCs) in the UK is high and rising rapidly; the most recent census in England and Wales (2011) highlighted 177,918 YCs known to services, and an increase of almost 19% between 2001 and 2011. Local authorities have a legal responsibility to identify, assess and support YCs in their role.

Most research in this area has focused on the vulnerabilities and risk factors of YCs. This current research, using IPA, has set out to have a bottom-up exploration of the experiences of YCs, placing the CYPs' views at the centre of the study and looking at the meaning they make of the role as well as the support that they receive. The study took a positive psychological perspective by being open to the positive and the negative impact of the caring experience.

A sample of 8 YCs (4 female and 4 male) ranging from the age of 11 to 18 years took part in individual face-to-face semi-structured interviews. Participants were recruited from a multi-cultural inner London local authority YCs' project. The YCs cared for either parents, grandparents or siblings.

The findings of this study concurred with previous research, highlighting that YCs endure physical and psychological hardship; but this study demonstrated that they also identify benefits of the caregiving role and some YCs have adapted various ways to manage the impact of caring. The study also finds that YCs value support such as the YCs' group, but many expressed the need for more individual support, especially for the younger YCs.

The author outlines the implications of the findings for Educational Psychologists, referring to various skills of assessment and intervention which they could implement to identify and support YCs so that their wellbeing is promoted. The author suggests further longitudinal mixed methods research to explore the potential of this suggestion.

List of Tables and Figures

Table 1 Showing some demographic profile details of participants

Figure 1 Superordinate and subordinate themes

Figure 2 Hardship

Figure 3 Benefits of caring

Figure 4 Managing the impact of caring

Abbreviations

BPS	British Psychological Society
CYP	Children and young people
DfE	Department for Education
EP	Educational Psychologist
EPS	Educational Psychology Service
SEN	Special Educational Needs
EPiT	Educational Psychologist in Training
LA	Local Authority
SEND	Special Educational Needs and Disability
SEN	Special Educational Needs
PWB	Psychological Well-being
YC	Young Carer
YP	Young Person

List of Appendices

Appendix A. Literature Search Summary

Appendix B. Sample of researcher's reflective diary

Appendix C. Audit Trail Log

Appendix D. Timeline for Stages of Research

Appendix E. Information and Letter of consent to parents

Appendix F. Information and Letter of consent to YCs

Appendix G. Schedule of questions for semi-structured interview

Appendix H. Example of transcript

Appendix I. Example of table of coding and emergent themes

Appendix J. Photo showing example of clustering of participant themes

Appendix K. Photo of example of hand-drawn mind-map of participant's clustered themes

Appendix L. An example of a pupil's summary list of themes

Appendix M. Photo showing process of cross case clustering and analysis

Appendix N. Final summary of superordinate and subordinate themes

Appendix O Table of cross-case analysis of themes with evidence

CD - contains recordings of all interviews

TABLE OF CONTENTS

	Page number
Title Page.....	i
Declaration	ii
Acknowledgements.....	iii
Abstract	iv
List of Tables and Figures.....	v
List of Abbreviations	vi
List of Appendices.....	vii
Table of Contents	1
1. CHAPTER 1: INTRODUCTION	
1.1 Overview of chapter.....	4
1.2 The researcher’s position: personal and professional background	4
1.3 Background, aims and rationale for this research: Historical conditions and legislation.....	7
1.3.1 Prevalence of Young Carers.....	7
1.3.2 Legislation relevant to Young Carers.....	8
1.3.3 Support and safeguarding for Young Carers.....	9
1.4 The psychological underpinning of the research	11
1.5 Research aims and contribution to current knowledge	12
1.6 Summary and next steps.....	13
2. CHAPTER 2: LITERATURE REVIEW	
2.1 Overview of chapter	14
2.2 Research on Young Carers – an initial exploration.....	14
2.3 Details of systematic and critical literature review.....	18
2.4 Critical review of studies found in systematic search, including approaches and findings.....	19
2.5 Methodological challenges of research with Young Carers.....	42
2.6 Conclusions drawn from the literature review, leading to the author’s current research.....	44
2.7 Chapter summary	46
3. CHAPTER 3: METHODOLOGY & DATA COLLECTION	
3.1 Overview of chapter	47
3.2 Researcher’s position: Epistemological and ontological position	47
3.3 Research aims and purpose	49
3.4 Research questions.....	49
3.5 Research design.....	50
3.5.1 Rationale for using IPA, theoretical basis of IPA.....	51
3.5.1.1 Limitations of IPA methodology.....	52

3.5.2	Alternative approaches considered.....	53
3.5.2.1	Thematic Analysis.....	53
3.5.2.2	Grounded Theory.....	54
3.5.2.3	Narrative Approach.....	55
3.6	Data collection.....	56
3.6.1	Recruitment.....	56
3.6.2	Sampling framework and research participants.....	58
3.6.3	Data gathering.....	59
3.7	Data analysis.....	60
3.7.1	Stages of analysis.....	61
3.7.1.1	Reading and re-reading.....	61
3.7.1.2	Comments/coding on individual transcripts for each participant.....	62
3.7.1.3	Developing emergent themes.....	62
3.7.1.4	Search for connections across emergent themes.....	63
3.7.1.5	Repeat each stage with other participants.....	65
3.7.1.6	Compare and contrast themes across participants.....	65
3.8	Trustworthiness and reflexivity.....	66
3.8.1	Role of the researcher.....	66
3.8.2	Research quality control – trustworthiness.....	67
3.8.2.1	Sensitivity to context.....	68
3.8.2.2	Commitment and rigour.....	68
3.8.2.3	Transparency and coherence.....	69
3.8.2.4	Impact and importance.....	69
3.8.2.5	Credibility.....	69
3.8.2.6	Transferability.....	70
3.8.2.7	Dependability.....	71
3.8.3	Reflexivity.....	71
3.8.4	Audit trail.....	72
3.9	Ethical considerations (Axiology).....	73
3.10	Chapter summary.....	74
4.	CHAPTER 4: RESEARCH FINDINGS	
4.1	Overview of Chapter.....	75
4.2	Themes.....	75
4.3	Superordinate theme: Hardship.....	78
4.3.1	Lack of freedom.....	79
4.3.2	Accelerated childhood.....	85
4.3.3	Not fitting in.....	90
4.3.4	Reticence regarding hardship.....	93

4.4	Superordinate theme: Benefits of caring.....	97
4.4.1	Positive self-identity.....	98
4.4.2	Positive Feedback.....	99
4.4.3	Generalising skills.....	101
4.4.4	Preparation for future Life.....	103
4.5	Superordinate theme: Managing the impact of caring.....	105
4.5.1	Support from others.....	105
4.5.2	Normalising the caring role.....	109
4.5.3	Boundaries.....	112
4.5.4	Making sense through knowledge.....	113
4.5.5	Awareness of strengths	115
4.5.6	Focus on the future.....	116
4.6	Chapter Summary.....	117
5.	CHAPTER 5: DISCUSSION	
5.1	Overview of chapter.....	119
5.2	Major themes discussed in the light of research questions and previous research.....	119
5.2.1	Hardship.....	120
5.2.2	Benefits of caring.....	121
5.2.3	Managing the impact of caring.....	125
5.3	Relevant psychological theory.....	129
5.4	Implications of the research and relevance to EP practice	130
5.4.1	Helping other professionals to identify and understand YCs.....	130
5.4.2	Individual approach	133
5.4.3	Interventions EPs could use with YCs.....	135
5.4.4	Working with schools.....	137
5.5	Proposal for dissemination of the findings.....	140
5.6	Limitations of the study.....	140
5.6.1	The interviews.....	141
5.6.2	The sample.....	142
5.7	Future research opportunities.....	143
5.8	Reflections on the research journey.....	144
5.9	Research conclusions	144
	References.....	148
	Appendices.....	156

CHAPTER 1: INTRODUCTION

1.1 OVERVIEW OF CHAPTER

This chapter introduces the thesis in terms of its origins, intentions and justification for the research carried out. It outlines the position of the researcher within the research, her personal and professional interests and how the research came about. The national and local context of the research is also outlined along with any related legislative policies and definitions of terminology.

1.2 THE RESEARCHER'S POSITION

In this section the researcher outlines some personal and professional background information about herself which illuminates possible reasons for, and influences on, her choice of research in an area associated with the psychological aspects of education and development of those children considered to be disadvantaged. It positions the researcher in the research as a parent of two teenage girls, a previous teacher, Educational Psychologist in Training (EPiT), researcher, and adult carer, all of which is important, due to the choice of methodology, and the requirement and significance of reflexivity.

The researcher worked for 15 years as a teacher in both Primary and Secondary schools in London and South America, and throughout her career as a teacher has applied her knowledge of psychology to her teaching, having been inspired by her undergraduate degree in the subject. Like most teachers, she aimed to promote the love of learning and

the fulfillment of potential for all; but in particular she wanted to narrow the gap in children and young people's (CYP's) achievements in education. In her time as a teacher she became aware of the influence of the systems which surround CYPs, such as the classroom, school, family and the wider community in the CYP's education and development. During her experience in schools she noticed the effects of a CYP having a 'difficult background.' This was in terms of a child having greater risk factors and fewer protective factors in their lives, and the effects on cognitions about self in terms of, for example: self-esteem, self-efficacy, self-determination, locus of control, mindset, ability to pay attention, the ability to remain self-disciplined, hopeful or optimistic, and also the way CYPs saw themselves in relation to others who had relatively stable home lives. The researcher witnessed, albeit anecdotally, how these psychological responses, which appeared to correlate with environmental systemic experiences, could negatively impact the educational outcomes and wellbeing of some CYPs. In order to help those CYPs who exhibited negative self-beliefs, the researcher successfully prioritized her efforts to create a supportive classroom climate, by ensuring opportunities for active learning, good relationships within the classroom, as well as supportive pastoral care beyond.

Another aspect of the researcher's professional career which has influenced her position relates to her study and completion of a BA and an MA in English Literature, with a particular (inevitable) interest in the link between language and meaning. Her research within the MA was focused on the psychological realism in the Plays of Joanna Baillie (1762-1851), with a particular interest in the emotional regulation, the location of meaning in language, and the expression and interpretation of experience through close

analysis of language; this links to her choice and appreciation of IPA as an appropriate methodology to explore the experiences of YCs.

More recently the researcher's interest has been drawn to positive psychology with the completion of an MSc in Applied Positive Psychology, and a particular interest in the application of Positive Psychology to education and child/adolescent development. This has broadened her view of psychology to include the study of what helps people flourish, rather than applying the purely deficit-model approach of traditional psychology (e.g. Seligman & Csikszentmihalyi, 2000).

The researcher, who is now an EPiT, wanted to carry out research that focused, and ultimately helped in some way, those CYPs who are often considered disadvantaged in their education. The researcher also wanted to use in her exploration, the meaning created by language used to describe experience. In line with the new SEND Code of Practice 2014, she wanted the research to be person-centred and to elevate the status of the experiences, views and cognitions of CYPs, which relates to the sense made of their experiences, and the impact on their sense of self.

The researcher, who has herself been a part-time (adult) carer for her elderly parents for several years, became interested in YCs through her contact with a charity which supports adult and YCs. She learnt through incidental discussions that Educational Psychologists (EPs) do not tend to work directly with YCs, or the Carers' charity organisations which support them. As an adult carer she is aware of the impact that being a carer has upon one's life, so she decided that research which focused on the experience of YCs in the borough where she worked as an EPiT could be worthwhile in

terms of eliciting the views of these CYPs, in order to inform professional knowledge, understanding and ultimately future practice.

The researcher is also a mother of two teenage girls so is also aware of the importance of acknowledging her position and her personal views regarding the typical caring relationship between parents and children.

1.3 BACKGROUND, AIMS AND RATIONALE FOR THIS RESEARCH

YCs are CYPs who provide ‘care under the age of 18,’ (McAndrew, Warne, Fallon, & Moran, 2012, p.13). Dearden and Becker (2002) have suggested that ‘common factors in all definitions of YCs are that they are children, i.e. under the age of 18 and therefore considered to be the dependents of adults; that they undertake significant caring tasks; and that these tasks would usually be associated with, and performed by adults,’ (op cit, p. 1).

Over the last 30 years there has been a steady growth in the focus on the plight of YCs (e.g. Meredith, 1991). The continued concern expressed for YCs has no doubt been in response to both their prevalence, and the various areas of legislation relevant to addressing their vulnerability, as well as the continued tension between providing support and safeguarding for these CYPs, (e.g. Aldridge & Becker, 1999).

1.3.1 Prevalence of Young Carers

Whilst Young Caring is a global phenomenon (Becker, 2007; Smyth, Blaxland and Cass, 2011), in 2011, there were 177,918 young unpaid carers (5-17 years) in England

and Wales. This was an increase of almost 19% since the previous census in 2001 (Office for National Statistics, 2013).

At a local level, where this research has taken place, whilst The Young Carer's Strategy (London Borough of XX, 2008-11, full reference withheld to retain confidentiality) acknowledges that the caring 'responsibility can allow young people to grow and develop personal skills,' it also states that these individuals must have 'full access to education and leisure opportunities for personal development'. The strategy therefore aims to 'improve access to training and development opportunities and to provide advice to support them with the additional responsibilities they have as carers' (p. 3).

1.3.2 Legislation relevant to Young Carers

Refinements and changes in certain areas of legislation have also perpetuated the close attention paid to YCs, especially areas of legislation that gave local authorities (LAs) responsibilities for the safeguarding and welfare of all children, such as found in The Children Act (1989). In addition to this, and at about the same time, the importance of seeking the views of CYPs in matters that affect them has been promoted, for example in Article 12 of the UN Convention on the Rights of the Child (1989, in force 1990) (UN CRC) which 'allows for the wishes of children to be taken into account, depending on age and maturity'.

Relatively recently, legislation has promoted the assessment of YCs by social services departments. For example, firstly the 1995 Carers (Recognition and Services) Act (HM Government, 1995), and then the Carers (Equal Opportunities) Act (HM Government,

2004), placed a responsibility on Councils to be proactive in informing carers of all ages of their right to the assessment of their ability to provide care for the relevant person.

Most recently, the Children and Families Act 2014, states that:

a local authority in England must assess whether a young carer within their area has needs for support and, if so, what those needs are, (pg. 72, section 96, Children and Families Act 2014).

The YC's assessment 'must include an assessment of whether it is appropriate for the young carer to provide, or continue to provide, care for the person in question, in the light of the young carer's needs for support, other needs and wishes, (p.72).' In addition to this, 'the extent to which the YC is participating in or wishes to participate in education, training or recreation', and 'the extent to which the YC works or wishes to work,' must also be considered (p.72). As a result, YCs have been on the radar of children's social care departments and this has generated a lot of research interest in the area.

1.3.3 Support and safeguarding for Young Carers

Unless a YC has been referred for Special Educational Needs and Disability (SEND) concerns, EPs in the borough targeted are not directly involved with young people in this group. However, given that these CYPs are potentially vulnerable and the fact that local authority services are now becoming more integrated, this study aims to explore the experience of YCs in order to discuss the implications for the role EPs might play in working with other agencies to support this group of young people.

According to Dearden and Becker, who carried out a large-scale national quantitative study ‘the overall proportion (of YCs) experiencing educational problems is still high’ (Dearden & Becker, 2004, p. 11). More recently the Children’s Society’s report that ‘Young carers are 1.5 times more likely than their peers to have a special educational need or disability,’ (The Children’s Society, 2013, p.5). Therefore, the SEND Code of Practice (DfE, 2014) will be relevant to those YCs who have SEND, or who are vulnerable to developing SEN, and require preventative support. In this code of practice, CYPs are defined as having SEN if he/she has ‘a learning difficulty or disability which calls for a special education provision to be made for him or her,’ (p.16), or if he or she ‘has a significant greater difficulty in learning than the majority of others of the same age,’ (DfE, 2014, SEND Code of Practice, p.16).

This indicates that YCs are likely to need continued specific identification and support by education, health and social care services, which are required to work collaboratively according to the new Code of Practice, (DfE, 2014, p.24). It is therefore important that EPs, along with other professionals, further understand the lived experiences, strengths and needs of current YCs within their local authority. The development of a joint understanding of YCs’ local needs will lead to a more holistic planning approach which could include psychological as well as educational and social support where necessary.

As the literature review will explore, most of the research has been carried out by social scientists or social workers. The researcher/author of this research study has so far found only two studies that have used the in-depth qualitative method of Interpretative Phenomenological Analysis (IPA) to explore the lived experiences and views of YCs.

Only one of these has considered the experience from the perspective of Educational and Child psychology. This proposed piece of research takes an Educational Psychological perspective, involving the interpretation of YCs' everyday experience of caring using IPA. This is important since EPs need to continue to develop their understanding of the experience and views of YCs, and work more collaboratively with other professionals and services in their local borough to listen to and support them as individuals.

1.4 The psychological underpinning of the research.

Previous research has tended to focus on YCs from a sociological, behavioural, or social psychological perspective; or it has looked at the practical barriers YCs face concerning, for example, their education (Dearden, 1998; Moore, 2005).

This study explores the YC's experiences from a humanistic standpoint applying a positive psychological framework by exploring YCs' experiences and the impact of caring on their psychological wellbeing. Positive Psychology has its origins in humanistic psychology but officially began as a movement instigated by Seligman and Czikszentmihalyi (2000). The author draws on the definition of positive psychology as the...

‘study of the conditions and processes that contribute to the flourishing or optimal functioning of people, groups, and institutions’, (Gable and Haidt, 2005).

In order to explore YC's views and experience the researcher has used IPA. The aim of IPA is to explore in detail how participants are making sense of their personal, social,

psychological response to their world, and the main value of an IPA is the elicitation of the meaning that particular experiences, events and states hold for participants. IPA is an ideal methodology to combine with a positive psychological approach with its potential to explore thoughts, beliefs, feelings, emotions, perceptions, as expressed by individuals in relation to their experience and interpreted by the researcher in order to see how these might be effecting cognitive outcomes, such as self-determination, self-belief self-identity, resilience, optimism, hope (goals for the future), and mindset (fixed or growth).

IPA involves a two-stage interpretative process, called a double hermeneutic; the researcher analyses the participants trying to make sense of their experience (Smith and Osborn, 2008, p.53). Further explanation of the use of IPA will be outlined in the methodology section.

1.5 Research aims and contribution to current knowledge

The study aims to explore the experience of current YCs in a multi-cultural, inner London borough. This is taken from an Educational Child and Adolescent Psychologist's perspective in order to facilitate multi-agency professionals' understanding of young caring from the perspective of the YPs who are in this situation, and in the context of their particular lives. The research aims to understand the YCs' specific concerns and their experience of Young Caring as well as their views about support they receive or would like to receive. However, the emphasis is not solely on the possible risks associated with the young caring role but also the potential ways in which challenges are faced and skills, knowledge, resilience and personal strengths

might be developing. In this way the research takes an open and balanced positive psychological approach, offering further contribution to a new, recent approach to the research area.

1.6 Summary and next steps

This chapter has introduced background information related to the present research in terms of highlighting information about YCs in the UK, such as preferred definition, prevalence, relevant legislation, and concerns for support and safeguarding. This led to the psychological underpinning of the research being explored. Chapter 2 presents a critical and systematic review of current research related the experiences of YCs. The gaps in the research will be identified in order to further define the aims, purpose, research questions and methodology of this study outlined in Chapter 3. The findings from this research will then be analysed and reported in Chapter 4, and the knowledge gained is then discussed in Chapter 5, particularly in terms of what EPs might be able to offer to further support individual YCs or projects that exist for YCs.

CHAPTER 2: LITERATURE REVIEW

2.1 Overview of chapter

In this chapter the author will introduce some different approaches to research on YCs that she found in her initial reading of hand-searched early research focusing on YCs. A systematic literature review follows, highlighting the search criteria and studies which aim to specifically explore the experiences of YCs. The systematic literature search and screening of articles generated 12 articles. A critical review of these studies follows, emphasizing each study's key features of methodology, including strengths and limitations. Concluding observations and comments lead to the final part of the chapter, which identifies the gaps in the research, and a justification for the further research which the author presents.

2.2. Research on Young Carers – an initial exploration

In the early 90s, Aldridge and Becker highlighted that whilst there was 'a considerable research literature on the lives and needs of informal carers in the community,' there was little research relating 'in any depth, (to) the particular experiences and needs of children who care,' (Aldridge & Becker 1993, p.459). Since this time there has been a steady growth in research focusing on YCs. The approaches taken have included quantitative demographic surveys, and more recently qualitative phenomenological research looking at the experiences of YCs.

The most recent, and largest survey related to YCs in the UK, was carried out by Dearden and Becker (2004). This research collected data from 87 YCs' projects concerning 6,178 young carers, and compared findings with two previous national surveys carried out in 1995 and 1997 (Dearden and Becker, 1995, 1998). The studies highlighted important figures, for example about the prevalence of identified young carers, the impact on their education, the YCs relationship to the person with care needs, the nature of the illness/disability of the person with care needs and the type of caring role they undertake.

The findings in much of the previous research point to several areas of negative impact of caring in youth: physical impact (Hill, 1999); social impact (e.g. Aldridge & Becker, 1993); educational impact as a result of poor attendance and performance, (Dearden and Becker, 1998); negative emotional impact (Dearden and Becker 2000; Frank, 1995), and impact on the YCs' future (Dearden & Becker 2000). As a result the role of YCs has become somewhat 'problematised,' with the suggestion that YCs are at risk if they take on the caring role too young (Heyman & Heyman, 2013). Maybe because a developmental perspective has usually been taken, with the child development viewed as uniform, individual differences have been overlooked. As such, important aspects, such as the child's potential for personal growth, change and access to protective factors were not usually taken into holistic account.

In spite of the growing interest in listening to the voice of the child, with the emphasis on consideration being given to the child's views in all matters that affect him or her (Article 12 of the United Nations Convention and the Rights of the Child, 1989, in force in 1990), there is little research in general which presents children as the experts in their

own lives (Hogan, 2010). In line with this there was little research which focused on the individual lived experience of YCs.

Many studies have more recently, since the early 2000s, started to include elements of qualitative research using phenomenological methods, especially since it was beginning to be recognized that ‘a strong argument can be made that research which is directly relevant to the lives of children, should seek to capture the views of those children’, (Kennan, Fives, & Canavan, 2012, p. 275). ‘Phenomenological psychological research aims to clarify situations lived through by persons in everyday life’ (Giorgi and Giorgi, 2008), and for this reason, experiences of YCs have been explored using various qualitative methods. For example, much of the research concerned with educational outcomes of YCs has used focus groups (e.g. Moore, 2005).

In seeking to give a voice to YCs, some studies successfully used a participatory approach. For example, Moore & McArthur (2007) trained a group of YCs to be peer consultants who helped the researchers to construct questions and chose themes to be explored. They were also involved in interviewing. McAndrew, Warne, Fallon, & Moran (2012) report the outcome of a ‘World Café’ event, which was hosted in the UK in 2010 and 2011. It was led by service users, including YCs, and the participatory project approach gave two groups of YCs the opportunity to present to mental health professionals their ideas about what they needed to do in order to improve their mental health. It has to be pointed out that whilst this was an immensely empowering experience to the YCs involved, the self – selected samples may have been biased, being made up of YCs who were confident enough to present at such an event.

Phenomenological studies have also used in-depth individual interviews in order to elicit the experience of individual YCs. For example, in a mixed methods study, Svanberg, Stolt and Spector (2010) used grounded theory to explore the experiences of YCs. However, also included in this study were self-report measures of mood, burden, and resilience. Whilst this study can be applauded for including a homogenous sample of YCs (all caring for parents with early onset of dementia), there is the presumption, with the inclusion of these quantitative measures, that having parents with a condition like this will impact mood, burden and resilience. This is an example of the way that researchers often take a top down approach and preempt what might be relevant, and found, before carrying out the research, therefore creating the possibility of demand characteristics, experimenter bias and response bias.

As well as starting to treat children as the experts in their own lives, more recent research, with the advent of positive psychology (Seligman & Csikszentmihlyi, 2000), has begun to balance the focus on YCs by including the potential benefits and positive experiences of caring.

The author's research aims to be truly bottom-up, exploring the YCs experiences first hand, and through their voice using IPA methodology. So far only two other such explorations of YC's experiences using the IPA methodology have been found and these will be reviewed as part of the systematic literature review in the next section, so that the findings can be compared and research critiqued.

2.3 Details of systematic and critical literature review

In order to carry out a systematic literature review, articles were searched for in electronic databases. On 31st October 2014 a systematic literature search was carried out. Five databases (British Education Index, Child Development and Adolescent Studies, Education research Complete, PsychArticles, and PsychINFO) were searched using the search terms: “young people who care” or “young carer*” or “child carer” or “children caring” or “young caregiver*” or “young caring” or “children caregiving” were searched for in via ‘Title’; and “experience” or “phenomenolog*” or “view*” or “voice*” were searched for in ‘Abstracts,’ and qualitative or quantitative in ‘All Text.’ The parameters were set to include studies:

- 1) written in English
- 2) published in the last 20 years: 1993-2013.
- 3) related to the first-person experiences of young carers
- 4) which included participants up to the age of 18 years, according to the UK definition of YCs.
- 5) published in peer-reviewed journals.

The initial search yielded 26 studies.

Following the initial reading of all the abstracts of each article, some were excluded due to irrelevance. For example an article by Grant (2011) was excluded because it is a discussion paper, rather than a research paper. Other studies were excluded because they did not relate to experiences as described by YCs, but were the views of professionals or other members of the family (e.g. Gray, 2008). Studies which involved research carried out in countries of extreme poverty, disease or war were also excluded

because the researcher did not consider experiences of YCs who lived in a 3rd World country to be comparable to those of children in the UK or other western societies. Appendix A includes a full list of articles generated by the literature search and notes the inclusion/exclusion decisions made by the researcher.

When the inclusion and exclusion criteria were applied, 12 articles remained for a more detailed review, which took place after the author had completed the analysis of data gathered in this study. No further articles were found ‘by hand’. Research themes, methodology, and findings of previous studies were then identified and critically reviewed, with the research gaps highlighted and the context of this present study aligned.

2.4 Critical review of studies found in the systematic search including approaches and findings

This section presents the full critical review of the articles identified as described above. The review of findings was done after the author had analysed her own data so that the findings of the previous research would not ‘contaminate’ her own process of analysis and interpretation. The researcher felt that if she had read the detailed findings in previous research this might influence her interpretation and analysis of her own data by causing her to look (even unconsciously) for similar findings.

The review will focus on each research study in turn, but studies have been clustered according to similarity of methodology. Key features have been identified, such as the participants involved, purpose, methodology, where noted the theoretical perspectives,

and the findings. Strengths and limitations of each study are also highlighted leading to a clear justification of how this present research aims to compliment and build on the existing body of research.

Four of the studies found in the systematic literature search involved focus groups; three were mixed methods studies, and five involved individual interviews. Details of these studies are presented and evaluated in turn but within these methodological groupings:

1. Taking a social perspective and being concerned with how YCs experience, interpret and understand their social relationships, **Smyth, Blaxland and Cass (2011)** carried out a qualitative study involving 68 YCs between age of 11 and 25. 11 focus group sessions took place to capture the point of view of the YCs, allowing them to explore and express in their own words the issue of self-identification amongst YC. The focus groups took place in three YCs' 'Camps' in Sydney, Adelaide and Canberra. The 1-hour sessions involved discussions exploring: becoming a carer; support from family and level of responsibility; school; free time and health; usage of services; hopes and plans for the future; jobs, education, and training. The study also involved individual interviews and two focus groups with 16 YC policy makers and service providers.

Many participants reported that for a long while they did not identify themselves as being a YC, which corroborates previous research (Moore, 2005; Becker, 2007). Most regarded their caring tasks as normal family duties. The researchers linked this with participants' strong intra-familial bonds of love and reciprocity, and perhaps encouragement to view the caring relationship as normal. Smyth, Blaxland and Cass

concluded that reluctance to identify as carer is to a certain extent shaped by the social norms surrounding the caregiving.

The data also showed that being given the label of 'Young Carer' was empowering for some of the young people providing care to others in their family. Some said it also helped them to feel valued. The YCs said that services were very important to them in order to help them meet other young people and achieve a sense of belonging. It was concluded that there is a need for awareness to be realised in order to identify hidden carers.

This study had several strengths. For example, the data collection took place during the YC 'camps' which not only made it easier to access the large sample of YCs in familiar surroundings, but also meant that a counsellor could be on hand if needed. Also, the focus groups were organised according to age, which meant that younger carers were not intimidated by older participants being present in the same group.

An issue related to this study, and many other studies featuring YCs, is the bias in the sample, since it is not possible to include YCs who, for various reasons have not been formally identified as YCs. It would be interesting to see how these 'hidden' YCs see themselves before they officially join the social policy category and have been identified as YCs. This is a difficulty in the research which cannot be overcome.

The use of focus groups as a methodology has the advantage of exploring views of several participants at a time, particularly for uncovering general initial issues which can then be explored in more depth individually. However, the appropriateness of

exploring sensitive issues in a focus group is questionable since the format is not sufficient in eliciting individual subjective experiences because there is the danger that divergent experiences can be diffused by the majority views within the focus group, and responses can be therefore biased. In addition, focus groups are not ideal situations for discussions about more in-depth sensitive issues related to YCs.

2. Nichols, Fam, Cook, Pearce, Elliot, Baago, Rockwood, Chow (2013) explored the needs and experiences of YCs caring for patients with frontotemporal dementia (FTD) in order to create a relevant website. Participants were invited to take part in one of two focus groups. The semi-structured focus group interviews were carried out over telephone or skype and facilitated by a medical journalist who had prior experience as a caregiver to a patient with FTD.

The participants were made up of 14 YCs (10 girls and 4 boys) from the US or Canada. They were aged between 11 and 18 years old. On average they had 3 years living in a household with someone diagnosed with FTD, however, it was not made clear if all the participants were carers or how much caring they do.

Seven overlapping theme areas were identified using Thematic Analysis: emotional impact of living with a parent with FTD (positive emotions – especially linked to diagnosis - as well as negative emotions of guilt and self-blame if they felt their patience wore thin), caregiving (specific tasks as well as rewards and challenges), coping (increasing knowledge, relationships) symptoms, diagnosis (knowing helped),

relationships and support (others supported – especially friends who understood because they were willing to listen).

It was concluded that the ‘YCs saw the experience of caring for a parent or grandparent with early onset dementia as positive overall, but identified opportunities for professionals to assist them in overcoming stigma and the challenge of balancing childhood and adolescent development within this context,’ (p. 21).

A strength of this study was that the YCs’ views were obtained in order to share their coping strategies. A strong outcome of the study was that their responses and suggestions of the participants were used to create a website. The study also focused on the positive rewards of caring as well as the challenges with the result that the participants communicated that they found the talking process helpful.

The authors point out that one of the limitations of this study included the fact that the interviewer was not a psychologist, but a medical journalist who is not trained in methods of qualitative research and who perhaps had a different approach to interviewing. In addition to this, whilst the interviewer did not run the thematic analysis of the focus group transcripts herself, the fact that her experience as a caregiver to parent with FTD may have influenced her input to the focus groups interviews. Whilst this has been mentioned by the co-authors, and part of the interview was cut from transcript during review and prior to thematic analysis because the interviewer had included shared information about her own experiences, it has not been fully acknowledged in terms of acknowledging and allowing reflexivity. Also two of the

interviewees were her own children, which could have influenced the dynamics and direction of the focus group discussions.

The focus group sessions took place over the phone and whilst this made it easier to access participants, the extent to which trust could be built up over the phone is questionable, although it could be argued that this method made it easier for participants to talk about sensitive issues in a group situation. The size of the focus groups and whether or not the participants were separated into age groups is unclear. If the younger participants were interviewed in the same focus group as older participants this could have made it difficult for them to express their views if they felt intimidated by older participants who were likely to be more confident to speak out.

3. Thomas, Stainton, Jackson, Cheung, Doubtfire, & Webb (2003) set out to explore the characteristics of YCs in Wales: who they are, their life experiences, perspectives on their situation and role as a YC, as well as their hopes and expectations for the future. 21 YCs in Wales (13 girls and 8 boys) aged between 9-18 years took part. A series of voluntary focus group discussions were initially held to develop questions for individual interviews. A carer's quality of life index (Williams et al. 1999) was used to explore the participants' ability to elicit both positive and negative impacts of caring. The interviews and group discussions were recorded and then analysed using data analysis software.

Taking a social political perspective the researchers had intended to obtain a sample, which was representative in terms of language, culture, community locality (rural and

urban) ethnicity, age, gender, and types and degrees of illness disability of person being cared for. Nonetheless the sample was poorly represented by ethnic minorities and overly represented by low income families dependent on welfare, with none being described as middle class. Therefore, like many of the studies on YCs the sample was biased socio-economically. Another issue with the sample was the fact that all but three participants were recruited from YCs project. Therefore only 3 participants were not receiving support from YC services.

This study concludes that YCs' needs often go unrecognized due to lack of awareness, especially in schools. The research also found that YCs had different experiences of school, with half struggling, and only one having a key adult at school they could talk to regularly, whilst others seeing schools as too intrusive. Most participants, however, said that their caring took precedence over homework. Few of the YCs had contact with a community nurse or family doctor, and YCs had negative views of social services. It was repeatedly said by the YCs that their involvement was often unrecognized, with only one having been assessed. The YCs explained that they were less able to go out due to time and money and this inhibited them making friends. The YCs in this study indicated a severe emotional impact of caring, including sadness, and, for some, depression. The participants welcomed support at the YCs' projects, as they felt recognized, valued and understood when attending the sessions, which offered a place where you could talk to someone. Some of the participants observed positive aspects of their caring experience, valuing it as part of family life which brought members closer. Most of the YCs did not see themselves as the parent; in only two cases was there the suggestion of adult-child role reversal.

In this study, ethical considerations were made explicit. For example, consent to take part was obtained from both the YCs and their parents. Participants were also told that they could withdraw at any time and were able to influence how the interviews were conducted and recorded. For example they were allowed to have family members with them. Another strength of this study was the fact that the researchers visited the YCs project so that the YCs would become familiar with them.

4. Moore and McArthur (2009) carried out a mixed method exploratory research project in Canberra Australia, which gathered YCs' views of school, and the challenges they face in engaging with education and their peers. It also considered how the Education system might improve support for YCs. 51 YCs (22 females and 29 males aged 12 to 21, with 80% under age of 18) were recruited, again from existing YC projects. 44 participants were interviewed by phone, and the rest were given the opportunity to voice their opinions during a group interview.

Quantitative data analysis produced percentages related to demographic descriptive data, whilst the open-ended questions were analysed for their emergent themes. A YC was employed as a project consultant to work with researchers to explore themes.

The study found that the YCs in the sample valued schooling, but identified challenges to attending school and achieving educationally. Challenges included getting to school; poverty; lack of time to socialise with friends after school; bullying and harassment; feeling uncomfortable in situations for example where teachers or peers speak about people with illness and disabilities in a derogatory way; expressing anger and other negative emotions.

A strength of this study was that the YCs were asked to identify ways that they thought schools could support them and their families. Participants believed that schools had a responsibility to identify YCs in a sensitive way, by tackling anti-disability cultures, giving additional training for teachers, and flexibility in how education provided and assessed. They also highlighted the importance of acknowledging the skills developed in their home lives and to allow opportunities to be recognized for positive contributions they make to their families and community. The participants also suggested in-home support and respite as well as support for families in financial difficulties

A limitation of this study was the use of an interview schedule which was informed by previous research, so whilst open-ended questions were used, these could have come with presumptions prompting responses lacking in depth and balance. For example, the participants were asked to respond to barriers to access and participation to school with no explicit questioning about what YCs learned from their caring role.

Another limitation of this study was that for a mixed methodology, the sample was small therefore without the opportunity of making any definitive claims beyond reporting emerging themes. Whilst the sample included YCs giving varied levels of care and type of caregiving (28% cared for their mother, 20% for a sister and 20% cared for more than one person), the sample was biased because participants were recruited from a metropolitan area and consisted of non-indigenous YCs, so backgrounds were not culturally or linguistically diverse. Moore and McArthur point out that further research

should include YCs who are not engaged with services and have varying backgrounds to understand the broad caring experience.

5. Shifren and Kachorek (2003) carried out a mixed methods, retrospective correlational study in the USA. It aimed to examine the effects of caregiving in youth on mental health in adulthood.

Recruitment was carried out via advertisements in local and national caregivers newsletters, so to a great extent participants were self-selected which could have biased the sample – perhaps those with more severe mental health issues would be less likely to volunteer for the research. It was only when prospective participants contacted the experimenters they were told the purpose of the experiment, which may have been daunting for some. 24 mostly female participants (between 21 and 58 years old) who were primary carers for a parent or adult relative when they were under 21yrs old took part. Semi-structured screening interviews with open-ended questions were carried by phone or email. If the research criteria were met the prospective participants were asked if they would be willing to answer questionnaires on their early caregiving experiences, mental health, and early parent-child relations. 28 agreed but only 24 returned the completed questionnaires, which again could have biased the sample.

The quantitative analysis found that more positive mental health than negative mental health was reported in this sample, although 42% had high depression scores on the total CES-D questionnaire (Hertzog, Van Alstine, Usala, Hultsch, & Dixon, 1990). Interestingly the age of beginning caring was not associated with current adult mental health, and those who described fathers as too protective reported less current positive

mental health. These findings suggested that early caregiving is not associated with poor mental health in adulthood, but some individuals (10/24) appear at risk of depression later in life.

This study had a biased sample, not only in terms of self-selection but also in terms of gender and ethnic origins of the participants. The sample mainly consisted of females, and 19 were European descent Americans, and only 1 was Asian, 2 were African Americans and 2 were Latino America. Many of the open-ended questions were factual questions rather than those eliciting psychological depth, so not only did the research provide findings which could not be generalised to a wider population but it failed to reach subjective depth.

This study was not a longitudinal or experimental study, therefore cause and effect relations between early caregiving experiences and current adult mental health cannot be assumed. Mental health is a complex issue, being influenced by many factors and perhaps the best approach would be a more in-depth qualitative longitudinal study. As the authors accept, it could be that current mental health influenced the participants' individual retrospective recall of their relation with their parents, rather than poor parent-child relations affecting current mental health scores among caregivers, (p. 344). In retrospective studies many factors, including current mental state, life stressors, and social support system play a role in the reports of early caregiving.

Shifren and Kachorek also suggest that replication is necessary with other American samples examining the same variables. They also acknowledge that their study does not control for type of mental or physical health problem of the care recipient and type of

problem may play an important role in the early caregiving experience. There is a need for longitudinal research assessing the caregiving experience from the beginning to end of the caregiving situation as it could lead to a better understanding of the dynamic relationship between the early caregiver and the adult care recipient; assessment of caregivers' mental and physical health over time, and allow the comparison of different care recipient problems on YC adult mental health. The authors therefore advocate a comparison group of age-matched adults from rural and urban communities located in the states as the early caregiving sample to give a comparison group for current mental health and recall of parent-child relations.

6. Lackey and Gates (2001) also conducted a retrospective study looking at adults' recollections of their experiences as young caregivers of family members with chronic physical illnesses. The aim of the research was to describe the number, type and intensity of caregiving activities carried out by individuals who had caregiving responsibilities in their youth for adults with chronic physical illnesses, and to explore the effects of the caregiving experiences, examining positive and negative effects on them in the present and in the past. A convenience sample of 51 adults (age range 19-68 now and 3-19yrs then) who cared for a family member diagnosed with various chronic physical illnesses was used. 20 participants were from rural and 31 from urban areas, with 63% caring for their parents.

Three methods were used to collect data including a demographic data form, a Caregiving Activities Checklist (Gates and Lackey 1998), and semi-structured interview. Content analysis (Krippendorff, 1980) was used to analyse the data, looking at meanings of caring then and now, patterns of caring, and positive and negative

consequences of caring. Demographic data and caregiving data were analysed using descriptive statistics.

The study found that personal care was the most difficult of the care tasks performed and household tasks were the most time consuming. 'Family life, school, and time with friends were areas most likely to be affected by caregiving,' (p. 320). The participants reported that they would allow their own child to look after a family member so long as they were not the sole caregiver. They also said that youngsters need to know information about the illness and the task, and have support systems as well as time to be a child. Whilst the participants said they had less time for homework, and 4 dropped out of school and identified caregiving responsibilities as the cause, positive consequences were also reported such as caregiving teaching them responsibility (learning new skills such as paying bills), and allowing them to feel part of a closer and stronger family. A sense of pride was also expressed. Regarding friendships, some said that friends understood and supported them, whereas others said they had limited friends as less time to go out, or were reluctant to tell friends about their situation. 'Participants believed the caregiving experience helped them become more caring and nurturing' p. 325, and several entered careers involved with helping others. The study concludes with advice for caregivers.

The limitations of this research relate to the fact that it is a retrospective study and relies on the accuracy of memory recall, and is influenced by the participant's present situation. Also, there was little homogeneity in the sample in terms of who the participants cared for which meant that it was difficult to compare their experiences. Also, using a check-list for caring responsibilities does give the impression that the

study was particularly bottom up or open, but instead could have led to response bias.

It was a good idea to collect demographic data using a form, rather than incorporating the questions in the interview, which may seem to be intrusive. Other strengths include the large sample and the fact that participants were asked to review findings and interpretations following final analysis.

7. In a study which aimed to compare the impact of caring on younger and older YCs in terms of participants' education, employment, health and social life, **Hamilton & Adamsom, (2012)** set out to hear from YCs about their circumstances, experiences and needs and how these needs may be met by service infrastructure.

This was a qualitative study which included semi-structured interviews, and a short online questionnaire after the interview to obtain socio-economic and demographic information about family circumstances and the needs of person being cared for. The questionnaire also obtained qualitative information about satisfaction with education employment health and future and use of services.

The perspective taken drew on 'the concept of bounded agency to understand the way in which young people (aged 25 years and under) who provide care interpret and inhabit the constraints associated with their caring institutions, make decisions and develop aspirations' p. 103. Bounded agency is a concept which explains how barriers and contexts a person finds themselves in effects their expression of agency, (Evans, 2002).

36 participants of two cohorts took part. 23 YCs (7-17years) and 13 Young adult carers (18-25) were compared. Almost all were in some form of education. The study concluded that 'age and life-course stage were important factors that shaped young people's experience of care,' (p. 104). 'Younger carers had a greater sense of possibility about the future whereas young adult carers described real constraints on their capacity to make decisions about their future, particularly those concerning tertiary education, their career and moving out of family home,' (p. 115). Participants expressed that caring was their priority, but they were not happy about the lack of understanding, support and flexibility in school system.

The study compared two groups but there were fewer Young adult carers than YCs – nearly half. It is unclear how the data were analysed, in particular how the themes emerged. The online questionnaire appeared to collect demographic data only, plus information about the participants' caring situation, but it is unclear how open these questions were. The research tends to focus on constraints of the caring role and not the benefits. Therefore the findings could be subject to experimenter bias.

A strength of this study was that the participants were recruited via different partner organisations, such as government departments from four different states in Australia; however, the fact that these participants were self-selected would also mean that there was some element of sample bias.

8. Heyman & Heyman's (2013) study aimed to challenge the developmental perspective applied to looking at the caring impact on YCs. This was done by

comparing the accounts given by adult YCs and specialist support worker about the riskiness of becoming a carer relatively early in life.

Individual interviews with the YCs (13 young adult carers 16-29 yrs. 7 who were 20-25 years old and one who was 29 years old) were carried out at locations of participants' choice. 10 staff (three managers and 7 YC workers for different locations) were interviewed individually or in pairs. The participants were from a range of socio-economic backgrounds and locations in urban and quasi-rural areas. They received various types of support from specialist YC workers and 5 had not received any formal assistance.

This study took a realist biographical approach (Henderson, 2007), aiming to compare the risk-averse social scientists' views with the actual voice of the YP. An open interviewing style was used, with questions related to family structure, the needs of the person with disabilities and how these were met, adequacy of any support service, and perception of wider public attitudes.

The findings suggest that whereas support workers mostly see young caring in terms of risks to future prospects. Only one saw possible benefits and another 'problematised service inflexibility' rather than the YCs,' p. 569. The YCs, however, identified with not just the current stresses but also personal gains from their experiences. The YCs did not categorise their caring role as a risk but critiqued the services on offer to support their relatives, and also the insensitivity experienced in the education system.

A strength of the study is that the data analysis focused on the perceptions of both risks and benefits of a caring responsibility when young. The views of the YCs were elicited as well as those of the practitioners. A limitation of this study was that the sample was small, and not homogenous in terms of caring roles.

9. Taking a social capital perspective, **Barry (2011)** carried out semi-structured interviews with 20 participants (10 young men and 10 young women aged 12-23), asking questions about various aspects of their lives, exploring their views, experiences about their social networks and experiences of relationship with others, such as the family, friends, and teachers.

The 1:1 interviews, which took place in YCs project in Scotland, were recorded and transcribed with permission.

It was found that the YCs tended to keep their friends, family and community networks separate from each other, which the researchers concluded may lead to reduced social capital. Close family members and friends were important to them, but often they were torn between friends and home. School was regarded as place which was good for meeting friends and for learning. Comments about teachers were generally more negative than positive. The female participants were more like to be negative about school and teachers, and reported to be more affected by bullying. It was felt that the attitude of teachers was too authoritative, rather than supportive. However, some saw school as a safe haven and others saw it as separate from their caring role. Some YCs said that they did not want school to know about their caring role in case they received preferential treatment, which they did not want. Some singled out specific teachers who

knew their situation and were supportive, but the majority were wary about confiding in teachers about their problems because they lacked trust. The YCs' projects were seen by the participants as crucial practical and emotional support. The overall conclusion of the study was that in spite of responsibilities at home, the YCs:

‘tend to demonstrate a high degree of resilience and build coping mechanisms to protect themselves, their families and their close friendship. Whilst vast majority rarely seek formal support from outside world, instead negotiating their family, school and social lives by themselves, they do have, and invariably acknowledge, the support of close friends, family cohesion and young carers projects in particular, all of which are a valuable source of social capital’, (p. 538).

The sample was small and the method of analysis was not made clear. The age range of the YCs was wide and the types of illnesses or disabilities that their relatives had varied, so the sample was not homogenous.

Barry acknowledged herself that strengths of this study included the use of 1:1 interviews which she saw as more appropriate for exploring such a sensitive issue and were more explorative than self-administered questionnaires. The interview also elicited retrospective as well as projective views of experiences of caring, support and social networks, perceptions of self and significant others and aspirations for the future. Rigorous ethical considerations were outlined in the study such as the researcher ensured that support was on hand during the interview and afterwards and the interviews took part at the YCs' premises for the safety and comfort of the participants.

10. Bjorgvinsdottir & Halldorsdottir (2014) explored the personal experiences (lives and needs) of being a YC of a chronically ill parent diagnosed with multiple sclerosis (MS).

A specific phenomenological approach (the Vancouver School), which ‘involves the hermeneutic circle of grasping the meaning of a phenomenon by understanding the parts and the whole’ (Halldorsdottir, 2000, p. 47), was used. It involved 1-3 unstructured interviews with each participant, with questions based on the main interview question: ‘Can you tell me about your personal experience of being a YC of a chronically ill parent diagnosed with MS?’

This was a purposive sample, with recruitment involving healthcare professionals asking permission of 20 MS sufferers if their grown up children would take part. 11 YC took part, yielding 21 interviews. Emerging themes were analysed case by case, with the YC as co-researcher. Then a cross case analysis was carried out.

The findings suggested that participants felt silent, invisible and unacknowledged as caregivers, and received limited professional support. They said they were often left to give parents physical and emotional care, which was demanding, embarrassing and difficult. At the same time they felt unsupported, excluded and abandoned. They saw caring as restricting, as if they were living ‘without true childhood,’ because they were left to manage lots of responsibilities on their own and at young age. They reported often needing to release tension, anger and sorrow but support from family helped. To move from feeling abandoned towards being independent, they learned that breaking their silence was important.

The purposive sampling meant that the participants were chosen and whilst this created a homogenous sample, there could have been bias in terms of who the professionals chose to recruit. The authors do not say how they chose the 11 participants out of the 20 parents who gave consent.

The phenomenological approach taken appeared similar to IPA, although there was no mention of reflexivity. This method, however, involved both researcher triangulation and participant checking.

Whilst the perspective taken created an opportunity for the voice of the YC to be heard, the focus seemed to be on the negative aspects of caring, the positives and YCs' strengths developed were not referred to. The study did not pick up on the more positive findings, which are mentioned in the table of 'Lessons learnt by participants', but not featured in the findings.

Strengths of this study lie in the focus on the lived experience of the YCs. Ethical considerations were outlined fully and were sensitive to the participants. For example, informed consent was obtained and participant identity was protected with the use of a pseudonym. This method involves a 'reverence for the participant as a truth-telling individual and fellow researcher of the lived experience under study and the dialogue becomes a bridge the researcher uses to visit the world of the participant to gain understanding,' (Bjorgvinsdottir & Halldorsdottir, 2014, p. 40). Lessons learnt by participants were compiled and these suggested useful for implications for professionals and as a starting point for developing intervention and strategies for schools.

11. Bolas, Van Wersch & Flynn (2007) used IPA methodology to investigate the wellbeing of young people who care for a dependent relative. Five YCs (2 boys 3 girls) who attend a YCs group in the North East of England took part in individual semi-structured interviews. The YCs were between 14-18 years of age, and had been caring for a family relative for over two years. The caring needs and impairments of the relative varied (ADHD, alcoholism, stroke, lymphedema).

A psychological perspective was taken, looking at the psychological processes that determine and maintain the relationship between the young person's role as carer and their well-being.

The YCs in this small self-selected sample found caring a struggle, relentless, overwhelming, taking them away from social life and social support. Integrated caring in their emerging sense of self and identity – sense of pride and this helped with feelings of uncertainty and isolation. The authors of this study concluded that the implication for 'health psychology is that clinicians must be aware of the negative psychological consequences that young carers experience,' (p. 841).

Limitations include the fact that homogeneity of sample was not sustained since the participants were not caring for relatives with comparable disabilities and caring needs. The author openly states that she was herself a YC but does not state how this may have influenced her expectations and interpretations. There may have been a presumption that YCs in UK are at increased risk of physical and psychological ill health, and experimenter bias could have influenced the YCs responses and researcher

interpretations. As the YCs were all receiving support outside the family unit the findings cannot be generalized to those YCs who have had no support from professionals.

One particular strength of this study was that participants were asked for feedback on the preliminary lists of themes and interpretation, in order to carry out respondent validation. Also, the author did acknowledge that the interpretations were not fixed and that the reader could form their own conclusions. Bolas was transparent and included plenty of examples of the YCs responses so their voices were heard, and the readers could also form interpretations for themselves.

12. A study by Doutre, Green, & Knight-Elliott, (2013) also used IPA and interviewed six YCs who were between the ages of 11 and 13 years to give their views on being a YC. The sample of participants was homogeneous as they were all caring for parents with mental health illness. They were accessed and recruited through a rural Young Carer's project. A strengths-based perspective was taken by the author, an Educational Psychologist, to see if this exploration could add to an understanding of YC's resilience. As the researcher viewed caring as socially constructed, with multiple realities it was felt that a qualitative research design was appropriate. Three separate semi-structured interviews (in school setting) were carried out, and participants were given a disposable camera so that a photo elicitation technique could be used to gain deeper insight into the participants lived experiences.

It was found that these YCs had complex and disadvantaged lives, but the caregiving role was seen in a positive light. Tensions in their lives existed, but the YCs found ways of managing and adapting to their situations.

This study had a number of strengths. Firstly, it focused on the lived experiences of the YCs and was open to findings that emerged. It was a good idea to generate exploration of experiences using a camera, with the YC choosing photos to take and bring in to the interview. Initial reflections and preliminary interpretations were shared with YCs, which meant that meaning was co-constructed.

The sample in the study was fairly homogeneous since all the participants were caring for a parent with mental health illness. The suitably small sample for this IPA study allowed for in-depth exploration which was truly bottom-up.

There was a useful discussion about the difficulty with defining YCs, since they are a broad and diverse population whose needs vary on an individual basis; the study also acknowledged the difficulty of isolating the impact of caregiving in the context of YP's complex lives. It was acknowledged that not all carers experience negative effects associated with caregiving (Gladstone, Boydella & McKeever, 2006), that there are mediating factors, such as the nature of care receivers illness, type of caring responsibilities age, gender and social context. All these issues are important to bear in mind as implications for professionals and policy makers.

Whilst it was done so for the purpose of keeping the sample homogenous, a limitation of the study was that it only took account of YCs in a rural area. Perhaps cultural context might add another layer of mediating factors. For this reason the current study which focuses on YCs in an inner London, multi cultural area, might add to the

emerging body of research which aims to explore the experience of YCs through the voice of the individual.

The study found that participants identified positives associated with caring role. 'their perceptions of their lives was growth orientated. These YC could see challenges as opportunities to grow,' (p. 37). This was in spite of having a lot going on for them such as experiences of disadvantage.

2.5 Methodological challenges of research with Young Carers

Several key methodological issues emerged from the literature review, as explored below:

- In aiming to explore the experience of caring for YCs most studies in the systematic literature review used either qualitative methodology or mixed methods. Three studies specifically explored retrospective views of adults who were YCs in their youth. Others, which were ostensibly snapshot studies, also allowed the YCs to give retrospective and projective consideration to their experience, drawing on their experiences in the past and present, as well as their desires and hopes for the future. Ideally, with time permitting, longitudinal studies could be more informative about the experience of caring for YCs.
- Whilst some studies claimed to be exploring the experiences of the YCs, their use of self-report measures of particular constructs suggested top down exploration rather than starting with the lived experiences of the individual YCs.

- Several studies used focus group discussions in their procedure to elicit views of YCs. Focus groups can offer some key insights to participants' views, however it might be that for individually sensitive topics such as caring for an ill or disabled family member, one-to-one interviews are more appropriate, especially with respect to safeguarding confidentiality.
- Except those focusing on the social perspective, few of the studies explicitly stated their theoretical position. However, given that most aimed to elicit the views of YCs drawing on their experience it can be assumed that a social constructionist stance was taken for most. The study presented in this thesis aims to take a positive psychological perspective.
- Sampling was a difficult element of the research design since YCs are hard to reach, and many are 'hidden.' Being children they are also potentially vulnerable, so ethical rigor is paramount, however, only a few studies made ethical considerations explicit.
- Most of the studies were conducted in YCs project settings, although some were carried out by telephone or emailed questionnaires. Whilst both have obvious advantages each have disadvantages too, particularly in relation to the response bias.
- Sample size was an issue for all studies. Some samples consisted of too many participants to carry out individual in-depth interviews whilst others had too few to carry out quantitative analysis to reveal trends which could be generalized to wider populations.
- Sample bias was unavoidable, as it is in most research. For example some studies included participants from only rural areas, or YCs accessed via young carers' projects who already receive support from professional services,

therefore not taking account for example YCs who are ‘hidden’ or who live in urban areas. Nevertheless, as part of the body of research on YCs these studies are collectively useful especially when compared to other homogeneous samples.

- In those studies which drew upon researcher interpretation of transcriptions, only 2 referred to reflexivity in terms of transparent acknowledgement of what the interviewer/researcher carrying out analysis brought of themselves to the research. Other modes of data collection and analysis which for example used remote telecommunications may potentially have missed subtleties in expression or nonverbal communication

2.6 Conclusions drawn from the literature review, leading to the author’s current research

The conclusions arrived at as a result of the systematic literature search and review follow:

- Many studies conclude explicitly or implicitly that parents and healthcare providers need to pay attention to the effects that caregiving has on particular areas of youngsters’ lives, particularly school life. However, the research could have more of a balanced, solution-focused approach – looking for when things are going well and why this might be, in order to encourage similar strategies or approaches for other YCs.
- Several studies have set out to explore the problems associated with YPs’ experiences of caregiving. Others, however, have either discovered the positive aspects of the YCs’ experience, or the focus of the research was more open to

the possible benefits as well as the risk factors associated with YC that could emerge. The current research is therefore open to whatever findings emerge as a result of the research, whether they are positive or negative.

- In many of these studies there is a lack of depth which truly allows the child to be seen as the experts in their own lives. Apart from the IPA studies the researchers are not seen as suspending or at least acknowledging the ideas and constructs that they bring to the research. For example, the acknowledgement of their own cultural views of what childhood is like, or their personal views and experiences of the parent child relationship, and how this might influence their research. This study aims to take a completely bottom up approach so as to empower the YCs to be the experts in their own lives and the author has chosen IPA as the methodology as she believes that this is the most bottom up method of study which also includes the process of reflexivity.
- One study focused on the social context related to YC identity but none has focused on the cultural context in which the identity of being a YC has evolved. As an EP working in a multi-ethnic inner city, the author has decided to take the opportunity to look at the experience of YCs in this culturally diverse community in order to compliment the body of research by exploring experiences of YCs in an inner city context.
- The current research has aimed where possible to explore in depth, the lived experiences of YCs drawing on a sample which is as homogenous as possible to recruit without losing ethical consideration and rigor.
- Lack of psychological theory applied to or used to interpret the strengths and needs of YCs. To address the research gaps, this current research aims to explore

form a psychological perspective the experiences of YCs in an urban, inner city area with a sample which is culturally homogenous.

As previously stated, the researcher is an EPiT working in an inner London borough where a high proportion of the population live in poverty and are of ethnic minority origin. Therefore, the author's study aimed to use IPA, and to recruit a homogeneous sample specific to the particular local urban area. In this way the study aims to compliment and go beyond previous qualitative research, in particular, the two other IPA research studies, in order to answer the following research questions:

- What are the current lived experiences of YCs in this multi-cultural inner London borough?
- How do they make sense of their experiences?
- What are their experiences of support?

2.7 Chapter summary

This chapter has given a brief historical overview of the type of research which has focused on YCs. The systematic literature search is described along with a critical review of each relevant study, leading to a justification for the current research.

CHAPTER 3: METHODOLOGY & DATA COLLECTION

3.1 Overview of chapter

In this chapter the aims, purpose, choice of methodology and research design are described and justified. The researcher's position, in terms of ontological and epistemological stance, is explained. The research design is detailed, alongside an explanation of the evaluative criteria and processes used to create the IPA in the attempt to build a trustworthy, credible and rigorous study. The process of reflexivity and the presentation of an audit trail have also been described. The chapter concludes with an outline of the ethical considerations adhered to throughout the study.

3.2 Researcher's position: Epistemological and ontological position

A researcher needs to be aware of, and to acknowledge, the paradigm that she/he holds because this influences the choice of research design. A paradigm is 'a way of looking at the world' and 'is composed of certain philosophical assumptions that guide and direct our thinking and actions' (Mertens, 2010, p.7). Guba and Lincoln, (2005) identify four basic beliefs associated with the major paradigms in research: ontological, reflecting the beliefs about the nature of reality or truth; axiological, which is the nature of and adherence to ethical behavior; epistemological referring to the nature of knowledge (objectivism/subjectivism), and methodological, which is the approach taken for systematic inquiry. By stating the ontological and epistemological position the researcher demonstrates that she can be reflective about the way in which her position

impacts the methodology, data analysis, interpretation and what she presents as the research 'findings'.

In this study, the researcher adopted a constructivist paradigm. This has its origins in the philosophy of Edmund Husserl's phenomenology (Husserl, 1936/1970), and the study of interpretive understanding called 'hermeneutics,' (Eichelberger, 1989). 'Hermeneutics is the study of the interpretive understanding of meaning,' 'a way to interpret the meaning of something from a certain standpoint or situation, (Mertens, 2010, p.16). The ontological belief associated with constructivism assumes that there is no singular truth, but multiple truths, each constructed by the individual's subjective response to their experience and the sense made of that experience. The epistemological assumption is that 'data, interpretation, and outcomes are rooted in contexts and persons apart from the researchers', (Mertens, 2010, p.19).

The researcher believes that reality is based on multiple perceptions of truth and for this reason the author explored the views of YCs, using a truly bottom-up approach focusing on individual experiences of young caring, and taking a qualitative phenomenological stance. This treats participants as the experts in their own lives and as those who are best placed to inform professionals about their experience of being a YC, and the meaning they make of this experience. The researcher was interested in the participants' own interpretation of this particular experience which some CYPs are exposed to. The researcher was aware that her own experiences and knowledge would affect her interpretation so she was mindful of this as part of the process.

The study also took a humanistic, cognitive perspective, using a qualitative method, (i.e. IPA) which aims to generate accounts of self-understanding and self-described relationships with the young caring role. Specific to the IPA approach, the subjective experience of the participant and understanding of this experience is at the heart of the exploration. IPA is open to the participant's experience and the researcher does not aim to predict possible findings.

3.3 Research aims and purpose

This research is an explorative study aiming to gain some psychological insights into what it is like to be a YC in an inner London multicultural borough, and the meaning made of these experiences in terms of the individual CYP's lives. In addition to being an explorative study this study also aimed to be emancipatory, because the study also hopes to be empowering, since the views of the YCs were being heard, and will hopefully inform policy, intervention and the work of EPs within the borough going forward, and possibly beyond. In addition to this, the process of talking about experiences during the interviews may have inevitably helped acknowledge the YCs strengths, difficulties, likes and dislikes.

3.4 Research questions

The questions for this piece of research were as open as possible, and did not expand to include the testing of any hypothesis related to particular findings of previous research or existing/predicted theory. The questions were:

- What are the current lived experiences of individual YCs in the inner London borough?
- How do they make sense of their experiences?
- What are their experiences of support?

These questions are grounded in the epistemological position of the researcher. They are directed towards eliciting meaning, and focus on the YC's understanding of their individual experience as a YC and, also their individual experience of support.

(See Reflexive comment 1 Appendix B Reflexivity journal prior to and during decisions about research questions).

3.5 Research design

This study consisted of a qualitative research design, concerned with exploring beliefs, and personal and social constructs through the collection of data in the form of recorded language. The methodology used was IPA, an idiographic research design involving focused individual case analyses, followed by cross-case analysis and interpretation by the researcher. Eight participants were interviewed one at a time by the researcher. (See Table 1 overleaf for participant profile details). The information contained in the profiles emerged by means of information that the participants chose to reveal about themselves in the interview. For ethical reasons, this summary excludes information which could identify the individuals, but gives brief details of important situational and contextual features of each participant. To maintain anonymity, pseudonyms have replaced actual names.

Table 1 Showing some demographic profile details of participants

Name	PP No.	Male/Female	Age	Cares for
Anthony	1	M	16	Mother
Sadia	2	F	15	Parents
Salma	3	F	18	Parents
Farhan	4	M	16	Sister
Nadia	5	F	13	Father
Fabina	6	F	13	Brother
Adam	7	M	16	Brothers Grandparents
Habib	8	M	11	Mother

3.5.1 Rationale for using IPA, theoretical basis of IPA

IPA is a qualitative methodology with an interpretative approach. It was conceptualized in the mid 1990s (Smith, 1996). It has been chosen as the research method for this study because it is consistent with the epistemological position of the research questions, which invite the exploration and interpretation of YP's experience of caring for a relative. IPA is a psychological qualitative approach with epistemological roots in phenomenology (experience) and hermeneutics (interpretation). IPA is idiographic in that it focuses upon in-depth separate case studies; the ontological assumption is that caring will mean different things to different young people depending upon their individual experience, and their individual behavioral and cognitive response. This methodology assumes that the in-depth bottom-up qualitative data can tell us something about people's subjective involvement in, and perception of, the world and also how

they make sense of this. Jonathan Smith and his colleagues describe it as a ‘detailed examination of lived experience,’ (Smith, Flowers & Larkin, 2010, p. 47).

In her work as a trainee EP, the researcher often works ideographically, working with individual children and the systems around them. In line with the SEND Code of Practice (2014) EPs are trained to do this in a person-centred way – seeing the child as having unique qualities, abilities and preferences, and starting where they are at, taking into account their views, strengths, weaknesses and needs. The idiographic approach is therefore both humanistic and holistic, which fits well with the author’s research and professional paradigms.

3.5.1.1 Limitations of IPA methodology

The IPA methodology does have limitations, which are important to acknowledge. Firstly, the data gathering process relies upon the participant having a certain level of linguistic and reflective ability. This needs to be taken into account during the interview and when the transcripts are analysed and interpreted. The researcher decided to recruit the older YCs so that their level of maturity and level of language would be more developed.

The methodology also relies heavily on the expertise of the researcher as an interviewer as well as an interpreter. The researcher therefore needed to have not only a good knowledge of psychology, but also good interpersonal skills so that rapport could be built to promote a climate of empathy and care, helping the participant to feel at ease and to be able to put themselves forward for the research and express what they want to

say about their personal experience during the interview. Good listening skills were also important so that the interviewer could explore any tangents that arose in the interview.

Another limitation of the IPA is related to how the findings are to be used and applied. Because the data collected reflected idiographic experiences of the phenomenon, findings cannot be generalized to all YCs. However, the findings can be used to inform multi-agency professionals who work or might work with individual YCs, for example, EPs like the researcher, or other professionals who develop policy related to the YC's wellbeing. The findings could highlight the individual nature of the experience of caring and the need for professionals to consider the capacity and needs of YCs on an individual basis.

3.5.2 Alternative approaches considered

Whilst it was ultimately decided that IPA was the most suitable methodology to elicit the findings related to the research questions, other potential methodologies were considered before IPA was chosen. The methodologies which were considered included: Thematic Analysis (TA), Grounded theory (GT), and Narrative Approach (NA).

3.5.2.1 Thematic Analysis

TA is a 'generic approach not necessarily linked to a particular (or any) theoretical perspective,' (Robson, 2011, p.467). It 'involves sorting information into themes...recurrent ideas or topics which can be detected in the material which is being

analysed,’ (Hayes, 2000, p. 173). It can be theory-led (deductive) or data-led (inductive). IPA always begins with the data, so is bottom-up. The difference in analysis is that IPA goes beyond TA’s focus on themes, since it explores the participants’ experience beyond description, incorporating the depth of interpretation. For this reason IPA was a more favorable choice to answer the research question because the researcher wanted to add interpretative depth to the idiographic focus, which was bottom-up.

3.5.2.2 Grounded Theory

GT is often viewed as the closest alternative method to IPA as the two methods have many similarities. There are several versions of this approach and it is not restricted to psychological study, instead having ‘a strong trans-disciplinary identity’ (Smith et al., 2010, p. 201). GT is ‘used to develop a theory grounded in the data’ (Robson, 2011, p.467) and researchers usually aim to work towards creating a theory as a representation of a particular phenomenon. IPA on the other hand is used mainly in the realms of psychology and involves more detailed interpretative analysis of the lived experience of a small group of participants, the emerging interpretations of which are then compared and contrasted. The endgame is to obtain a better understanding of particular individual lived experiences.

The way the data is collected differs between IPA and GT. In GT, data is simultaneously analysed as it is being collected and uses ‘thick description to ask theoretical questions,’ (Charmaz, in Smith 2008, p.89). IPA therefore was chosen because the aim was to explore the meanings the participants made of being a YC and looking at their convergence and divergence so that individual experience was the focus

rather than the phenomenon itself. The experience of individual YCs was to be explored, not generalised theoretically. IPA, was attractive for this study in comparison to GT because it sits more closely to the individual-constructionism of the research epistemology and the purpose of this study.

3.5.2.3 Narrative Approach

‘A narrative can be defined as an organized interpretation of a sequence of events’ (Murray, in Smith 2008, p. 113) and usually consists of an orderly beginning, middle and an end. NA involves an interview with a detailed series of questions to be answered to give the participant opportunity to tell their narrative account. The research analysis involves two phases, first the descriptive and secondly the interpretive. Afterwards, the narrative is connected with the broader theoretical literature which is used to interpret the story. The researcher brings to the text certain assumptions and beliefs that they use to analyse the narrative and whilst this is acknowledged there is no attempt to bracket assumptions or ideas so as to get as close to the participants expression as possible, as is the case in IPA.

The researcher decided that if she were to encourage the YCs to construct their story about their lives and experience of being a YC it might have led to the construction or fabrication of a story which might serve to hide the true nature of their experience and the sense they were making of it. NA gives a structure but the researcher wanted to see if a structure was intuitively created as this is relevant to the experience and interpretation, in itself. The sense of order in ones life is important and to request an orderly account assumes that the individual already has one, or might lead them to

create one as the interview unfolds. Therefore the researcher chose IPA because the mode of response is more open and does not require a specific orderly account, which might interfere with the individual response.

3.6 Data collection

3.6.1 Recruitment

YCs are a hard to reach group, especially if one wants to include them in research as potential participants. This is not only because the group includes CYP who need to be able to give informed consent from themselves and parents, but also because young caring is a sensitive and sometimes hidden issue. Many YCs (as stated in the Introduction) remain unidentified for various reasons. Therefore it was necessary to recruit YCs who were already known to the authority and were easy to access in the safe location of their YC's project group.

Once the researcher had discussed the research with two senior leaders in Children's Social Care of the borough, obtained ethical approval from the University of London ethics committee, she was granted access to potential participants via an existing project that provides support and activities for YCs. The recommended YC's group was approached and the researcher first met with a senior manager together with a YC's group project manager to discuss the research, her attendance at the group and how she intended to recruit and interview.

The author then attended a number of YCs sessions in order to become a familiar presence to the YCs.

At the first YCs session the researcher introduced herself and gave a brief introduction about the research, inviting those who were interested to approach her individually if they wanted to take part or if they wanted to discuss further information. Over the following two terms, from June 2014 to October 2014 (See Appendix C for Audit trail log) the researcher took the time to engage personally with the YCs and staff within the YC's project sessions in order to explain the aims of the study and to build a relationship of trust. To do this she engaged in activities such as table tennis, board games, and creative projects alongside the carers and youth workers. At these times the researcher did not talk to the YCs about their experiences as YCs but was available if they wanted to ask questions about participating in the research. This was in line with the suggestions of Kennan, Fives and Canavan (2012, p. 280) who offer reflections on research aiming to access vulnerable and hard to reach populations.

As the older YCs showed initial interest in taking part in the research, and they were the most likely to have the more advanced linguistic development and maturity, the researcher decided to direct her recruitment to the older YCs. This also meant that the homogeneity criteria could be adhered to as much as possible. Therefore she approached the older YCs during the sessions when they were free and chatted to them about the research. The researcher was careful not to impose or coerce the YCs in any way. Those who were interested in taking part were given written information and consent forms to take home for themselves and their parents (see Appendix D for the Timeline of the Research Process, For recruitment and interview dates, please see

Appendix C Audit Trail Log, Appendix E for Information and consent form given to parents, Appendix F for information and consent forms given to YCs).

3.6.2 Sampling framework and research participants

In line with IPA methodology, this research used ‘purposive homogeneous sampling’ (Smith, 2010, p. 49). The sample of the study was purposeful because the research explored a particular experience - that of YPs in the inner London borough. Therefore a purposive homogenous sample was sought. IPA requires a small sample size to ensure psychological variability can then be examined within the sample, by analysing the pattern of convergence and divergence across the cases. With IPA’s commitment to idiography, ‘less is more,’ as it is believed that ‘fewer participants examined at greater depth is always preferable to a broader shallow and simply descriptive analysis of many individuals’ (Hefferon & Gil-Rodriguez, 2011).

Eight participants were recruited to allow for attrition but none dropped out. Whilst this sample was ‘homogenous to the extent that [the participants] shared the same experience of a particular event,’ (Willig, 2008, p.58), the researcher aimed for a sample which met an even stricter criteria for homogeneity. She aimed to recruit: YCs in the inner London borough; of similar Ethnicity; secondary aged young people of the same or similar age; either all male or all female, or equal number of both; minimum length of caring e.g. 2 or more years caring for parents or siblings. It was hoped that the YCs were also to be homogenous in terms of the type of care they give, who they care for – either sibling or parent, and the nature of the cared-for person’s needs being similar. However, due to the YC professionals’ understandable adherence to client

confidentiality it was not possible to access demographic information about the YCs until they had already been recruited. Therefore the final sample was feasibility-driven, and the researcher approached the older YCs first of all so that the sample could be homogenous in terms of age. The sample not only depended on which YP were accessed via the project group, but it also depended on which of them were willing to give consent and managed to get and return the consent form signed by their parent. The researcher was sensitive to the wishes of the participants and their parents and did not try to coerce the YCs to return consent forms. Instead she gently reminded them once or twice if they still seemed keen to take part, but if they did not bring back the signed consent forms she did not pursue this further as she did not want them to feel obligated to take part. For this reason, and as predicted in the research proposal the ideal sample criteria was met as closely as possible, but whilst this sample was reasonably homogeneous and purposive it also involved an element of opportunity sampling as well.

3.6.3 Data gathering

Once informed consent had been obtained from both parents and participants, the researcher invited the YCs to take part in an interview lasting up to an hour, and carried out on the premises of the YCs' project so that they would feel comfortable and at ease. The interviews were conducted as face-to-face, individual semi-structured. A semi-structured interview schedule was drafted which followed the procedure described by Smith (1996) (See Appendix G for the schedule of questions). Consistent with IPA, the schedule included open questions, which refer to the areas of interest to be explored during the interviews. These were used as a guide rather than to dictate the course of the

interview. As Crotty (1998) identifies, the reason qualitative researchers use open-ended questions is so that the participants can express their views.

(Please see author's reflexive comment 2 in Appendix B, for the author's reflexive commentary at the time of gathering data).

3.7 Data analysis

Smith, Flowers, and Larkin (2010) do not advocate a prescriptive IPA procedure, 'there is no clear right or wrong way of conducting this sort of analysis' (Smith et al., 2010, p.80). Instead they promote a 'healthy flexibility' and the importance of seeing IPA as 'a set of common processes (e.g. moving from the particular to the shared, and from the description to the interpretative) and principles (e.g. a commitment to an understanding of the participant's point of view, and a psychological focus on personal meaning-making in particular contexts) which are applied flexibly, according to the analytic task' (Smith et al., p. 79, 2010). In spite of this flexibility, an outline has been suggested for those who are novice IPA researchers, as it is acknowledged that 'the first analysis attempted will probably see the most difficult' (p. 81). As it was the first time that the researcher had used IPA it was decided that the proposed stages were followed and these stages in data analysis were employed:

- Reading and re-reading
- Comments/coding on individual transcription
- Developing emergent themes
- Searching for connections across emergent themes

- Repetition of each stage with other participants
- Compare and contrast themes across participants.

Apart from following the stages above, the author aimed to go back and forth between stages in order to promote an iterative and inductive analysis.

Verbatim transcription of the interviews was carried out by a recommended professional service, which adhered to strict ethical and anonymity codes. The reputable company that was used declared ethical sensitivity and guaranteed confidentiality with a secure online transcription platform using a secure server for uploading encrypted and password protected transcripts. Even so, recordings did not contain real names or identifying information. Once the researcher had received all the transcripts she went through each of the analysis stages with each transcript in turn so that each transcript was analysed using all the stages before moving onto the next transcribed interview.

3.7.1 Stages of analysis

The following will provide information on how the author followed the stages of analysis described above.

3.7.1.1. Reading and re-reading

The researcher carefully checked and corrected the transcription by listening to the recording and reading through the transcript. As the transcriber had not added pauses, ‘uhms and ahs,’ or repetitions, these were added at this stage since the researcher felt

that they were important for the analysis and interpretative purposes. In doing this she also became fully familiar with the recording and the transcript before she began the process of systematic analysis; she recorded her observations about the interview in her reflexive diary. See Appendix H for example of transcript.

3.7.1.2 Comments/coding on individual transcription for each participant

This stage of the analysis began with the creation of a table in which the transcript was copied and pasted into the middle column. On either side of the transcript was a column (for example of Table of coding and emerging themes, see Appendix I). On the right hand side the researcher typed the initial notes and explorative comments examining the semantic references and language used. The descriptive element of the initial exploratorion involved the researcher staying close to the explicit meaning expressed by the participant. This highlighted the issues that mattered to the participant. How it was expressed through language was also noted and the researcher made comments on the linguistic elements (noted in italics). By identifying more abstract concepts, and on occasions employing strategies of de-contextualization such as jumping to different sentences or reading paragraphs backwards, the researcher was then able to move on to make more interpretative sense of the participant's account, noting down the interpretative comments (underlined).

3.7.1.3 Developing emergent themes

During the initial noting stage a substantial amount of data was created; this next stage of turning the notes into emergent themes however, involved reducing the amount of

detail but at the same time retaining the complexity and depth of the connections and patterns between the exploratory notes. At this stage the researcher shifted from working on the original transcript to working with the initial notes. Thus the re-organization of the data to identify the emergent themes involved the breaking up of the narrative flow of the interview (the whole) to create a set of parts of interpretation. Related to a particular part of the text, the themes were expressed as short phrases encapsulating the most important aspects of the psychological essence captured in the exploratory comment. The emerging themes were noted in the left hand side column. The descriptions obtained from the expression of the participant were merged with the interpretations produced by the researcher, creating the hermeneutic circle.

3.7.1.4 Search for connections across emergent themes

At this stage themes were drawn together to create a more structured interpretation of the emergent themes for the participant. In order to look at how the emergent themes fitted together and to interpret connections between the themes, each emergent theme was written onto a small card (4 x 5cm), creating a set of themes for the participant. The emergent themes were then laid out one at a time on a table according to how closely they were connected to each other. Those cards that contained themes that were very closely related were placed spatially close to one another on the table. See Appendix J for a photo of process for one participant as an example. This process involved both abstraction and subsumption. Abstraction is the analytical process of bringing together similar themes to create an overarching superordinate theme. Subsumption is similar, except it 'operate where an emergent theme itself acquires a superordinate status as it helps to bring together a series of related themes' (Smith, Flowers & Larkin, 2010, p.

97). Sometimes the cards were placed close together because their themes were connected in terms of contextualization: including temporal, cultural or narrative themes. Other themes were related in terms of a shared function. Once all the cards had been placed on the table in relation to each other, a note was made of the connections in the form of a hand-drawn mind map. See Appendix K for a photograph of an example.

The cards were then collected up in order of their ‘connectedness’ and the back of the cards numbered to reflect this order of interconnection and spatial proximity. To further explore how the emergent themes were interconnected, the emergent themes were then listed in order, and superordinate themes were finalized and identified using the continued processes of abstraction, subsumption, and taking into account polarization, contextualization, numeration and function. See Appendix L for an example of a summary of themes list for Anthony.

Numeration, or frequency that the themes can be evidenced gave some indication of importance but one off themes were explored and given importance too. For example Anthony spoke a lot about the Young Carers’ group in terms of it being a context of positive support and friendship. Function is another process of analysis and involves the interpretative level of analysis of themes considered in terms of the function they serve for the participant. For example the Young Carers’ group is a theme related to Anthony’s need for a place of belonging and sharing. Other themes have been analysed in terms of the functions they serve such as mechanisms of coping, reframing, avoiding, transferring or representing an emotion such as a cry for help.

(See Reflexive comment 3, in Appendix B, for an example of notes made in research diary during this process of analysis and decision-making.)

3.7.1.5 Repeat each stage with other participants

The next step involved moving to the next participant in order to repeat the process. The researcher tended to start this on a different day and was mindful to bracket the ideas which had emerged from the previous case as an adherence to her commitment to the idiographic approach which the research was following. This allowed her to focus more directly on the participant in hand.

After these stages had been carried out for each of the participants the researcher presented her codings and emerging themes tables of individual transcripts for credibility cross checking. This was done with her Director of studies and also the London IPA research group to which she belongs. It was carried out at this stage to further acknowledge and interrogate her initial interpretations, enabling her to continue to be open and freely curious to alternative interpretations and possible meanings before moving on to the final stage. (See reflexive comments 4 in Appendix B Reflections on Feedback from IPA colleagues).

3.7.1.6 Compare and contrast themes across participants

In order to look for patterns across the cases the researcher laid out each table of superordinate and subordinate themes for all participants on the table and looked for cross connections which were either divergent or convergent. Then she cut up all the 8

summary lists into strips of themes, and grouped the strips on a table according to cluster themes, eventually leading to three overarching superordinate themes (see photograph in Appendix M). A final summary of cross-case superordinate and subordinate themes was listed (see Appendix N). In order to continue the cross-case analysis a table was created with the superordinate and subthemes in the left hand column and space for evidence from each participant account on the right hand side. For each theme the author looked for evidence in each of the participants emergent themes and interpretations. These were copied over to the new table. See Appendix O for the Table of cross-case analysis.

3.8 Trustworthiness and reflexivity

3.8.1 Role of the researcher

The researcher of this study had multiple roles. She was the designer of the research, deciding on the aims of the research, the chosen methodology, and the procedure. She also carried out the research in terms of setting up the research with professionals, recruiting the participants, collecting the data via interviews, and carrying out the interpretative analysis.

Qualitative researchers are also ‘aware of their role in the (co)-construction of knowledge. They try to make explicit how inter-subjective elements impact on data collection and analysis in an effort to enhance the trustworthiness, transparency and accountability of their research,’ (Finlay, 2002, p. 211). The researcher as interviewer

was aware, through reflexive focus during and after the interviews, of this co-constructive process, and also the potential researcher bias and power imbalance.

3.8.2 Research quality control – trustworthiness

All research needs to be useful, and the findings trustworthy, if it is to be worth reading. However, it is widely acknowledged that the quality control of qualitative research is ‘typically less straight forward than that employed for quantitative work’ (Rodham, Fox & Doran, 2013). Keeping in line with epistemological and ontological perspectives, it is more appropriate that qualitative research is trustworthy. Rodham, Fox and Doran, (2013) believe that it is important not only to make sure that the analytical process is trustworthy but to say *how* this has been achieved.

The researcher has followed Yardley’s guidelines (2000, 2008), cited in Smith, Flowers, & Larkin (2010), and Smith (2008) for maintaining and assessing validity in this qualitative study, applying her criteria, (which was devised to be used to judge the validity of qualitative research), to the IPA methodology, (Smith, Flowers and Larkin, 2010). The elements that Yardley’s guidance considers when evaluating qualitative research are: Sensitivity to context; Commitment and Rigour; Transparency and Coherence, and Impact and Importance. The researcher has also considered some of the criteria presented by Donna Mertens (2010): Credibility, Transferability and Dependability.

3.8.2.1 Sensitivity to context

Sensitivity to the research context should be shown in all areas of the research process, even at the initial choice of the research, and the planning at proposal stage. Once the research is underway sensitivity to context can be shown at the data collection stage. For example Yardley points out that it can be demonstrated by ‘an appreciation of the interactional nature of data collection within the interview situation’ and by ‘showing empathy, putting the participant at ease, recognizing interactional difficulties and negotiating the intricate power play where research expert may meet experiential expert,’ (Smith et al. 2010, p.180). At the analysis stage, if the process is to be sensitive to context it needs to be ‘immersive and disciplined’ in terms of the attention paid to the participants’ account and what can be interpreted from the data, (Smith et al. 2010 p.180).

3.8.2.2 Commitment and rigour

Commitment is shown in the ‘degree of attentiveness to the participants during data collection and care with which the analysis of each case is carried out’, (Smith et al. 2010, p. 181). The researcher made participants comfortable and listened closely and respectfully to what they said. To be rigorous means being thorough, for example in the recruitment of an appropriate sample, picking up on important cues from the participant and digging deeper during the interviews. These were skills the researcher drew upon from her experiences and training as an EP. Also it was important that the researcher was ‘sufficiently interpretative, moving beyond a simple description of what is there, to an interpretation of what it means. Good IPA studies tell the reader something important

about the particular individual participants as well as something important about the themes they share,' (Smith et al. 2010, p. 181).

3.8.2.3 Transparency and coherence

The transparency of research refers to how clearly the stages of research have been described in the write-up. Coherence relates to how the research flows and hangs together in terms of argument, themes, and the choice of methodology, and 'the degree of fit between the research which has been done and the underlying theoretical assumptions of the approach being implemented,' It also requires that 'ambiguities or contradictions [are] dealt with clearly,' (Smith et al. 2010, p. 182).

3.8.2.4 Impact and importance

Finally, the true validity of a research study, according to Yardley's guidelines, depends on 'whether it tells the reader something interesting, important or useful,' (Smith et al. 2010, p.183). This will be assessed in the viva, professional presentations and future attempts to disseminate information in an academic journal.

3.8.2.5. Credibility

Credibility in qualitative research is considered by Guba and Lincoln, (1989), as the equivalent to internal validity, which is so important in positivist research. Mertens (2010) explains that it involves the 'prolonged and persistent engagement' (p.256) of the researcher as well as 'member checks and peer debriefing.' (p.257).

Member checks require the researcher to seek verification from the respondent participants about the findings that have emerged as a result of data collection and analysis. At a later date after VIVA and the study has been accepted, the participants and youth workers will be offered the opportunity to have a feedback session in order for them to hear about the findings and interpretations.

In terms of peer debriefing, the credibility of the interpretation was checked during a presentation and feedback session with research peers in the London IPA research group of which the researcher is a member. The researcher also obtained feedback from her university supervisor who was involved in validating her interpretations. Feedback was used so that the researcher could interrogate her own interpretations and reflexive commentary.

3.8.2.6 Transferability

Transferability, seen as the equivalent to positivist's need for external validity (Guba & Lincoln, 1989, cited in Mertens, 2010, p.259), involves the researcher providing sufficient detailed description to enable 'the readers to make judgements about the applicability of the research findings to their own situations,' (Mertens, 2010, p. 259). According to Smith et al., (2010, p. 51) 'the effectiveness of the IPA study is judged by the light it sheds within this broader context.'

3.8.2.7 Dependability

Dependability is seen as being equivalent to reliability and stability over time (Guba & Lincoln, 1989). However, in idiographic and constructivist research this is not relevant, since change is expected. Instead, the focus is on the documentation of the details of each step in the research process (Mertens, 2010, p. 259).

Each of these elements described in Yardley's guidelines, as well as Mertens suggestions for evaluating qualitative research have been considered carefully by the researcher throughout the process and have led to the use of certain processes within the methodology, such as reflexivity and the recording and presentation of a detailed audit trail. Descriptions and justification for these can be found in the following sections.

3.8.3 Reflexivity.

The method of IPA acknowledges that the process of the 'double hermeneutic' (Smith & Osborn, 2008, p. 53) inevitably means that our experiences, values and preconceptions will influence our response to, and interpretation of, our data. Therefore 'it is vital for researchers to find ways to analyse how subjective and intersubjective elements influence their research,' (Finlay, 2002, p.531).

For example, it is important that the researcher takes care when identifying themes, to make sure that these themes actually exist in the data of the transcriptions and have not been superimposed. Reflexivity is a tool used to ensure trustworthiness and is defined by Finlay as being 'where researchers engage in explicit, self-aware analysis of their

role, (Finlay, 2002, p.531). The researcher used the process of reflexivity, for example to interrogate her interpretation of the themes and returning to the data with mindful openness and curiosity to further possibilities.

The researcher's perspective was acknowledged within a process of reflexivity. As it is difficult to carry out value-free research a process of reflexivity is necessary, therefore the researcher kept an ongoing reflexive diary which increased the awareness of what she brought to the study, the reasons for the decisions she made and how the study was progressing at each stage. In the diary she reflected on the significance of her being an EPiT and currently working on placement at an inner London Educational Child Psychological service. She thought it was also necessary to reflect on the influence of her having previously worked with children of ages 7 to 19 years old, in the role of a teacher, and the fact that she has two daughters aged 11 and 13 years. The researcher understood the importance of acknowledging what she brings to the interview, interpretation and analysis of the qualitative data collected. (Please see Reflexive comment 1 Appendix B extracts from Reflexivity journal prior to and during decisions about research questions.)

3.8.4 Audit trail

In order to promote transparency, an audit trail was created with a research log recording:

- dates for recruitment (showing dates when letters given out to prospective participants and their parents, as well as dates when these were returned).
- dates for data collection (log of dates when interviews took place).

- dates for data analysis (log of dates when stages of data analysis took place)

Please see Appendix C for Audit Trail Log.

An example of transcribed interviews can be found, along with tables of typed annotations of interpretations and emergent themes, in Appendix I.

3.9 Ethical considerations

This research involves CYP who are potentially vulnerable; therefore close attention to ethical issues was paramount. The researcher, in carrying out this study adhered to ethical standards in particular following the guidelines set out by the BPS (2009) and their four ethical principles of ‘respect’ ‘competence’ ‘responsibility’ and ‘integrity’ (p.9) and the standard protection of research participants’ with consideration to ‘all research from the standpoint of research participants, for the purpose of eliminating potential risks to wellbeing, physical health, personal values, or dignity.’ (p.19).

Key ethical elements were addressed when seeking approval from the University of East London (UEL, 2014), such as the ‘quality of the research,’ ‘protection from harm of both the participants and the researcher,’ ‘anonymity and confidentiality so participants cannot be identified’ and ‘informed consent including the right to withdraw through the participant information sheet.’ Please see Appendix P for the email stating ethical approval received by researcher. Codes of ethics from the Health and care Professional Council’s various guidelines (2012) were also adhered to. The research proposal was submitted to both UEL’s Ethical Committee and the borough’s research governance panel and was granted approval prior to being started.

3.10 Chapter summary

This chapter has outlined the method and procedure of the research process. It includes the epistemological and ontological position of the researcher, the aims and research questions, the rationale for using IPA alongside consideration of alternative approaches.

The data collection and analysis are described in detail, including the importance of reflexivity, audit trail log and ethical considerations.

CHAPTER 4: RESEARCH FINDINGS

4.1 Overview of chapter

This chapter will first present an interpretative account, detailing what was found as a result of the analysis of the data collected to elicit the experiences of YCs. Reflexive commentary will also be included where it highlights the author's awareness of what may have influenced her interpretation. The analysis and interpretation will thus address the research questions:

- What are the current lived experiences of individual young carers in an inner London Borough?
- How do YCs make sense of their experience?
- What are their experiences of support?

4.2. Themes

Superordinate themes have been identified through a thorough process of close reading, analysis and interpretation of what each participant had communicated in their interview. From this data, superordinate themes have been identified, by considering patterns of convergence and divergence within the data across each of the cases. These are represented, along with the subthemes of each superordinate theme, in Figure 1 below. Each theme will be presented and discussed with a focus on interpretation of the experiences which are shared by the participants, and also those which are unique to some participants. Reflective comments have been included where the researcher believes that reflexivity is particularly relevant to the explanation of the interpretation.

The researcher agrees that, ‘a good IPA study will always have a considerable number of verbatim extracts from the participants’ material to support the argument being made, thus giving participants a voice in the project and allowing the reader to check interpretations being made,’ (Smith, Flowers & Larkin, 2010, p.180). Therefore, quotations have been extracted from the transcripts and included to illustrate the interpretative findings. Each quotation is referenced with participant name and page number so that it can be found within the original transcript, (e.g. Anthony, p.2).

‘Interpretations are presented as possible readings and more general claims are offered cautiously,’ (Smith, Flowers & Larkin, 2010, p.180). Smith, Flowers & Larkin, 2010, p.180).

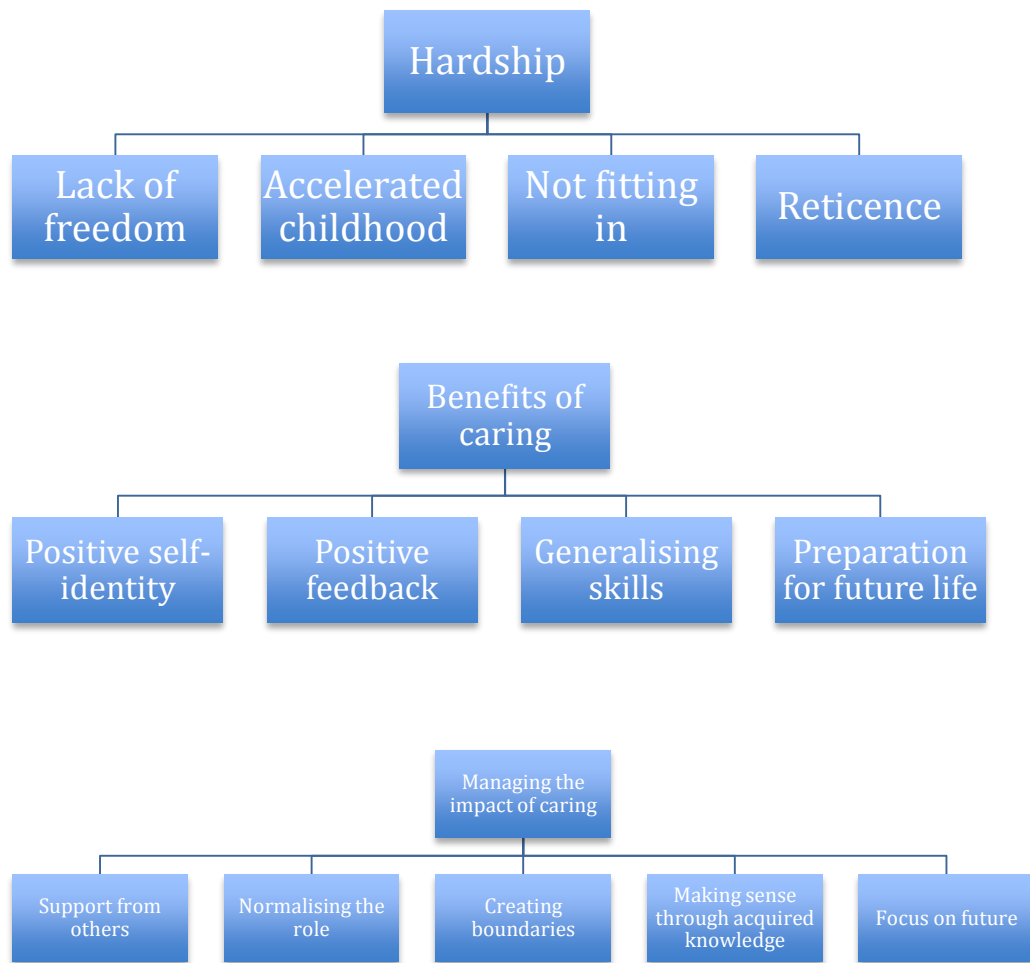


Figure 1: Superordinate and subthemes

4.3 Superordinate theme: Hardship

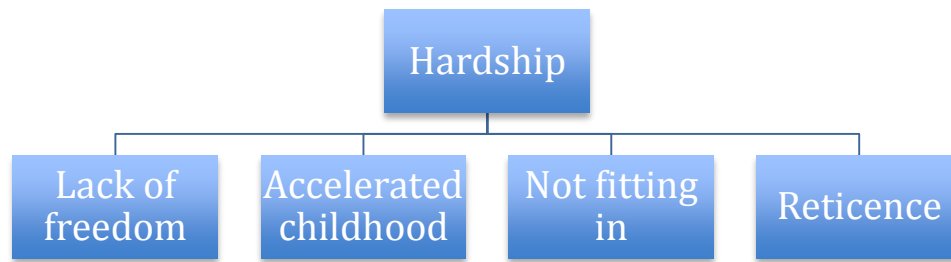


Figure 2: Hardship

This relates to the YCs' references to their experience of hardship; or as an experience that one has 'suffered,' (Anthony, p.12). This is a saturated theme as all participants, except Sadia, expressed some aspect of hardship experienced as a result of being a YC, whether it was physical or emotional hardship.

The theme of hardship in the young caring role comes across in the extent of the caring that the YCs are involved with and the duration over time. For example, Adam cares for several people in his family:

I care for my brother, he's got epilepsy, behavioural problems and was yeah. Like sometimes, because my brother's got a heart condition sometimes I help him as well and also... 'yeah. And sometimes when I go round my nans I'll tend to help my nan, my granddad and my uncle. My nan's got a heart condition. My granddad's got COPD which I believe is um something wrong with his lungs, like you get tired very quickly and so on, and my uncle is in a wheelchair.

(Adam, p.4/5).

The description of his extensive caring responsibilities literally seems to swamp his reference to his own difficulties of getting 'tired very quickly.

He is aware that he has been caring for a long time, so long he has forgotten exactly the number of years: *'I have been helping them five, no about seven years, seven years I*

think. It's been, it's a long time,' (Adam, p. 6); his repetition emphasizes that it feels like a long time for him to be helping. Perhaps, as it is for adults he is so busy that time passes very quickly.

Four subordinate themes (represented in the Figure 2), reflecting different aspects of hardship, were identified:

- Lack of Freedom
- Accelerated childhood
- Not fitting in
- Reticence

These are explored below.

4.3.1 Lack of freedom

This theme reflects the YCs' experiences of lack of freedom and choice, which arises when they have a family member to care for. There is no sense of blame expressed, but instead the inevitability and lack of choice about caring for a family member and the impact it has on their lives is communicated in different ways.

When YCs describe caring for their member of the family:

Of course I've been caring for my mother for three years...
(Anthony, p.2),

a sense of inevitability comes through the repetition of phrases such as 'of course' or 'obviously,' suggesting that YCs have no option related to their caring responsibility:

Well she suffers from mental illness and uhm of course she doesn't know English so I have to be there for her because, I'm the, a, only one...
(Anthony, p.5).

She obviously can't support herself, so obviously she does have to have 24 care.
(Farhan, p.7)

The repetition, and the use of the word '*just*' in Fabina's account: '*Just look after him. Just look after him,*' (Fabina, p. 6), could be suggesting the monotony and relentlessness of her caring role, or it could be that she is down-playing what she has to do.

Adam also seems to believe that some things in people's lives are inevitable and just need to be accepted with positivity, as he eloquently says, '*sometimes you've got to take stuff by the hand and just carry on with it,*' (Adam, p.16).

Whilst seen as an inevitable role, caring for family members is not easy for the YCs. Some of them are quite explicit about their caring role being difficult. As Anthony says, referring to the young carer's group, that he likes to meet others who have, '*kind of suffered the same,*' as he has, (Anthony, p. 12). When asked what he means by having 'suffered' he refers to having to live an '*upsetting*' life story that he hasn't chosen:

It's like somebody kind of has specifically picked you out to be the odd one out and when you have to live through that type of life, you, know, that they didn't choose, and it's like a really upsetting kind of a, a story I guess,
(Anthony p.13).

There is the suggestion of things being just the way they are, and the absence of freedom to change this life course and make an alternative choice because there is no one else to help apart from members of the family. In order to express this given situation, some YPs make metaphorical references to life as a story, which could either be '*upsetting*' as it is for Anthony, (Anthony, p.13) or on the contrary, uplifting and positive for Farhan, who believes each young carer's '*story is different,*' (Farhan, p. 18).

Several of the YCs notice that their caring role means they don't have the time to do what they would like to do. For example, Fabina explicitly reveals that she feels stressed by her caring role, because caring for her brother limits her time spent doing what she would really like to do:

I feel, uhm, kind of stressed because I always have to look after him and like see what he does, I can't really like most of the time, I can't really, I can't really spend time with my friends or do what I really want to do, I have to mostly look after him, (Fabina, p. 6).

The author has interpreted the hesitancy in her repetitive expression here, not as a suggestion of resentment, rather a slight fear of betrayal, which is at odds with her need to take the opportunity of expressing the fact that she lacks freedom and variety in her life.

Similarly Adam talks explicitly about the fact that as caring takes up so much of his time he has no time for socializing or going out. He is not free to go out whenever he wants,

....if I'm helping at home or Nan's or if I'm helping anyone um it does take time off, if you know what I mean, like sometimes you can't go out, you can't be social. Well you can, but not like you can go out every day and stuff,' (Adam, p.8)

Adam sees having the pressure of time as difficult, and has consequences for his social life and doing things he wants to do: *'you don't get enough time to go out or do whatever you want..... It's really tough,' (Adam, p.9).*

Whilst some YCs express their lack of freedom directly, others elude to it when discussing what they 'would like' to do 'if' their situation were different:

If I am not busy with my studies or uhm, anything at home then I would like going shopping and uhm going out or socialising with friends or maybe spending time on my own sometimes just to have a bit of fresh, like, time out, with myself, (Salma, p.3).

Salma's relaxation and choice activities come after other responsibilities such as her school work and caring role. She describes herself as someone who '*used to be active and optimistic,*' (Salma, p.2), which suggests that she no longer feels she has the opportunity to be active and optimistic or to be herself; she lacks the freedom to be how she used to be.

Farhan compares his life with that of other young people of his age. He says whilst,

they will be doing this, they'll be doing that, my kind of day to day, like kind of revolves around my family and trying to help everyone out, (Farhan, p. 9).

His life is to some extent restricted because it 'revolves around' his family, suggesting that his caring role is the centre of his life rather than his own needs. This struck the author as poignant, because she thinks of children needing to be the centre of their parent's life. (See reflexive comment 5, Appendix B). Farhan explained that his sister is at the centre of his life because of 'love,' '*coz I love my sister more so...*' He also explains that it is right that his life revolves around her:

because we're kind of seen like normal and she's yeah, she's like an angel or whatever. So, yeah (...), (Farhan, p. 12).

His use of the image of an angel as a simile suggests that his sister is seen as sacred and the epitome of special goodness. Ending this point with, 'So, yeah' communicated to the interviewer that he is clear that this is the way it is and the way it should be.

It is clear that the YC's interests are dictated by the amount of time they have available, hence conditional on the freedom (or lack of it) that they have. Most seem to get very limited time to follow their interests, do the things they would like to do, or to have time for themselves.

Nadia talks of her interests such as 'bike riding', 'science', 'detective stories on TV' and 'swimming'. However, she says, '*I'm not really that good at swimming, I'm scared of deep water,*' and this may symbolize a feeling that she has been thrown in at the deep end caring for her Dad and does not feel fully prepared or ready for the role. Or this expression of fear may be positioned as an excuse for why she does not swim very often. Alternatively the concept of Nadia liking swimming, but being scared of deep water could reflect her lack of confidence to take on the difficult situations which are out of her comfort zone, even though she would like to be able to.

She refers to the YC's group, describing it as, '*really fun.*' In particular she says she likes the '*fun trips*' and being able to '*express*' herself, (Nadia, p.10). There is the hint here that perhaps fun and the opportunity to express herself is missing in her life as a young carer.

The YCs also seem to resign themselves to the fact that they need to accept what the future brings. Adam realizes that he does not have the freedom to be in control of this. The uncertainty is related to his brothers and family '*because I don't know how my brothers will turn out to be in the future or my family so I've got to wait and see from there,*' (Adam, p.16). His future is, to a certain extent, dependent on things beyond his

control and linked to his caring role, so in this sense he lacks freedom and control over his life with the responsibilities for others at an early age.

Habib did not talk about lack of freedom in terms of lack of time to do what he wants do, but his lack of freedom did come across in his reference to his self-identity. When he was asked what sort of person he sees himself to be, there were lots of pauses suggesting that he cannot decide what to say. Eventually he revealed that he is '*stuck in the middle*' saying he doesn't see himself as '*good*' or '*bad*.' His reference to feeling '*stuck*' suggests that he feels passive, doesn't see himself as being in control because he can't change things about himself. Feeling that he is '*in the middle*' suggests that he thinks that he should be one thing or the other, good or bad, and therefore feels uncertain of his identity. Eventually he accepts that he is neither because, 'no one's perfect,' (Habib, p.5). He explains that he was 'really good at mostly everything' and so others called him 'ACE,' but he explained that he prefers to be called by his own name. This could be because he doesn't want to have the pressure of living up to an externally imposed identity which is linked to competitive perfection - as the nickname 'ACE' suggests. It is as if others try to define him but he wants to resist this because it is too much pressure for him.

Summary of theme - Lack of freedom:

- Caring role is inevitable
- No choice but to care for relative
- Caring role is part of life story
- Lack of freedom to do what YCs want
- Lack of autonomy

4.3.2 Accelerated childhood

The theme of accelerated childhood refers to what YCs might be missing out on in childhood and in terms of early responsibility they have, particularly caring for others which is usually associated with adulthood. This subtheme is saturated because many of the YCs are involved with regular daily chores carried out at home. Many of these are physically and emotionally demanding and often conflict with activities associated with a child or YP, or add to the usual demands that most children face as they move through childhood and young adulthood, such as education and school work.

Some of the YCs voice their perceptions of this aspect of their role as hard work. For instance Anthony explained that he regularly helps his mother ‘a lot’:

I help her with a shopping, groceries....and also I clean the house, do chores in the house. That’s a lot,’ (Anthony, p.4)

Whereas Fabina sees her role as a ‘job’ when she says caring for her brother and sister is ‘kind of like a hard job,’ (Fabina, p.3)

In a different account, Nadia describes how she helps her Dad:

My dad has arthritis, which is uhm, like very hard for him to walk and everything so we always help him we always, uhm like, massage his leg or his foot and like we always make him food or uhm tea and like, always get his snacks and whatever he wants we do that, and like we always help him around the house, (Nadia, p. 6)

with the repetition of ‘always’, suggesting that she does a lot or regular chores for her parent. It could suggest that the adult/child’s roles have been reversed (see Reflective comment 5 in Appendix B).

Some YCs do not go into a lot of detail about the caring role. For example, Sadia just mentioned varied areas of help that she gives: ‘*cleaning*’ ‘*helping out*’ and ‘*reading and stuff like that,*’ (Sadia, p.4), whereas Habib also found it difficult to express his help:

Um well because um a couple of years ago there has been (pause) there has been like a sudden (pause) a sudden problem with her eyes then it’s like she couldn’t see properly, it’s cloudy, so um she has eye drops so I help her take her eye drop, I clean the house and um make her breakfast sometimes in the morning, (Habib p.7).

It is likely that this is an emotional topic for YCs to speak about. Some do manage, however, to launch into long descriptions as if the support is one long continuous story.

The extra chores that the YCs carry out are described by some as physically and emotionally challenging. Anthony refers to his experience as a young carer, describing the hardship he has to endure saying, ‘*it can drain you a lot, it will, it will, exhaust you, and it’s, it’s just hard, yes*’, (Anthony, p.2). His use of the word ‘yes,’ in this extract and others suggests that he needs to self-affirm the situation he is in, perhaps to help himself to feel sure that things are alright and that he can manage. He also explicitly refers to the ‘mental’ strain he is experiencing:

For mentally is, is mostly, like trying to please the other family member, as the person you’re caring for, and it’s hard that you, you know, if you did all this stuff and then they don’t appreciate it, (Anthony, p.8).

It seems that these physical and emotional hardships, not usually associated with childhood, can also conflict with more usual childhood activities such as school work, building friendships, developing interests and hobbies.

Salma says of her experience as a young carer:

in the past it affected me negatively because I couldn't concentrate on my studies, (Salma, p.11).

and she talks about the negative impact retrospectively, perhaps because she finds it easier to talk about past experiences rather than talking about the present. Or perhaps she never had the opportunity to express the difficulties in the past, and things for her have changed now that she is not technically a YC, having just turned 18 years old a few days earlier.

Anthony also talks about the juggling more usual childhood responsibilities of school, which could conflict with his caring responsibilities. He told me '*school is a priority so I guess I just have to really put it aside first*', (Anthony, p.11). He seems resigned to having to do this as he has no alternative, but this is clearly not an easy decision for him as he tries to state this without emotion or justification.

Some of the participants expressed an awareness that they have become more mature and have had to fast-forward their childhood:

because of the type of situation I am in I've become more of a older person and yeah, that's about it, I've become more mature, yes, ... (Anthony, p.14).

This seems very clear, he repeats and clarifies his identity and the type of person he has become due to his circumstances.

Similarly, Salma refers to when she started to care for her parents:

...after I became more mature at the age of 12, I tried to do other things, researching everything, finding out about people's health and so on. Then it came to me that, oh my word, these people need help, so that's why after doing

research I became so happy and then it was like I put my mind straight on my family and then education, (Salma, p.11).

It seems that a better understanding of the parents' illness, coupled with her maturity, helped her focus on being able to cope with caring, and her education was secondary to this.

Farhan also said he believes that being a carer has made him, '*more mature...I did have to grow up quite quickly (pause) so to adapt to the situation,*' (Farhan, p.7). He seems to feel that he has had to grow up quickly but has been able to adapt and become more mature. He views caring 'in a good light' where it has 'matured' him and this has allowed him to do 'different things,' (Farhan, p.7).

In spite of the hardships endured in the caring role the participants communicated a sense of acceptance and inevitability about having to step into more of an adult role, and none of the YCs explicitly say that their childhood has passed too quickly.

Farhan described his maturity as needing to fill a gap and the necessity of stepping into the adult role because he feels responsible because they are a lone parent family:

So yeah, me and my older sister do make up for that gap that my dad left. So it's not that much harder but you've got that much more responsibility rather, (Farhan, p.18).

It is as if because his Dad left, there is a void of responsibility that needs filling and whilst this is necessary, it adds some pressure, compounding the effects of being a YC.

One participant, Salma, seemed to speak out on behalf of YCs, particularly the youngest YCs, expressing that the young caring experience has consequences. Salma, who had just turned 18 during the data collection, explained that she considers the YC's role as difficult for the younger ones. She said '*studying issues*' make it '*really hard*' for them because she doesn't '*think they can handle education and chores and family within themselves,*' (Salma, p.5). The phrase, '*within themselves*' – suggests that difficulties are having to be kept inside or internalized, confined to the CYP and not shared. Her use of the word '*handle*' suggests that she is questioning whether YCs are physically or mentally able to manage or juggle the emotional and the practical demands. This advocacy for younger carers, seemed to give her the opportunity of distancing herself from the experience she was describing, yet wanting to share. It could have been an indirect reference to her own hardship and acted as a shield for her own privacy, but an opportunity to describe how things are for YCs.

Salma carries on saying that whilst education is important, younger carers need time to themselves:

Because it's like education is important, they have their own little, how can I say, they have their own little freedom because it's not all about work throughout the day...especially if it's to manage household chores and education, ' (Salma, p.10).

Speaking of chores and education she says that:

handling both at the same time then it's going to....lead to depression and stress and then it's going to become harder, ' (Salma, p.10).

As Salma is talking about the difficulty of sustaining a fine balance between the caring role and usual childhood/young adult activities and needs, this suggests that she thinks

that it is often too much for young carers to handle as this perhaps has been her experience. She is explicit in saying that she thinks:

the younger carers might need professional support such as, uhm, how can I say, like a carer, like you can help the parents instead as children, (Salma, p. 10-11).

I know culturally children are meant (to help parents) as it can lead to the future but it's like not their time yet, (Salma, p.11).

Again, she uses repetition here, referring to cultural expectations as if to question them, not for herself, but for other young carers.

Summary of theme – Accelerated childhood:

- YCs do chores and hard work instead of adults
- Mental and physical challenges
- Reaching maturity early
- Cultural expectations of children and readiness to 'handle' the challenges

4.3.3 Not fitting in

Another aspect of hardship expressed by the YCs was their experiences of feeling isolated or not fitting in.

Anthony's short factual sentence, '*It's just me and my mother*' (Anthony, p.5), and the way that he said this quite mournfully during the interview, suggested a bare, socially isolated existence, with the word 'just' implying that it was not enough and he would like more.

Adam refers to YCs feeling as if they are alone in what they do. *'Sometimes I feel like I am the only one,'* (Adam p.7). He thinks that YCs need to know that there are other YCs like them to *'tell them they're not alone,'* (Adam, p.13). He sees this as an important function of the Young Carers' group, perhaps because he feels better knowing that there are other YCs like him.

There were various responses of the YCs related to feeling 'different'. Anthony referred to isolation and not fitting in, particularly with peers. He felt that because he was more mature this meant that it was difficult to fit in with his friendship group:

being stuck in like an environment where it's just with your mother you, the person, the person you are is, is a lot more mature than other people at school, (Anthony, p.10).

He goes on to say that it is this, which means it is difficult to fit in:

For example, er, sometimes my friends don't really get my jokes because they see it as a, like a big person's joke, like an older person's joke. Yeah, er, it's just hard to really fit into like a, like a friends group, (Anthony, p.10).

His use of the idea *'big person'* is interesting because it is an unusual phrase, suggesting ambiguity. He is referring to being older and mature without actually being 'older.' Perhaps he feels small in 'big person's' shoes or wearing clothes that do not fit properly. Or maybe this is the way his communication skills and thought processes have adapted to fit in with his caring role and his situation at home, but that he also finds it difficult to regress so that he can fit in with his peers.

Other YCs seem to have reframed being different as something positive. Farhan openly says:

I like to be different, I'll put that out there, I am not someone that wants to be kind of normal etc. I just want to stand out, (Farhan, p. 3-4).

Farhan is aware that his life is different from his peers and is not afraid to recognise this openly. He has come to terms with it and is proud of being different, saying that he doesn't want to be someone '*kind of normal*.' Perhaps because he knows his sister is different, he is happy to join her being so.

Salma repeatedly referred to herself as an '*individual*' (e.g. Salma, p.2) as she may be aware that she is different but has reframed herself as an individual because this has a more positive connotation, as it is celebratory and suggests being special.

Nadia also sees herself as different:

I am a bit different to everyone else coz I'm a carer for my dad, but that doesn't really affect uhm, anything coz I have my friends to talk to and if anything happens. Nothing really happens though, like I have something to say I tell my friends and they always listen so it doesn't really affect me that much, (Nadia, p.5).

Not all participants explicitly or implicitly referred to experiences of isolation or difficulty with fitting in. However, it might be that they did not want to admit to this, or as will be discussed in the next section, they wanted to remain reticent about the hardships they were experiencing. The author concluded, for instance, through her interpretation of Fabina's transcript that she did experience some aspects of isolation and not fitting in. For example she described herself as an '*annoying person*,' (Fabina, p. 2-3) and the author found this curious, as it was not clear why she felt this. The author wondered who it is that she thinks she annoys, and if anyone has told her this. Perhaps it is something she likes to do for amusement, to be noticed, albeit negatively.

Some clues might be given by her statement, '*Sometimes I'm shy and sometimes I'm loud,*' (Fabina, p.3). Whilst this shows an awareness of how she can act differently at different times, it could also suggest that her behaviour is inconsistent because she wants to fit in with others, so as to minimize her difference.

Summary of theme – Not fitting in:

- Feeling Isolated – not fitting in with others
- Feeling different/individual
- Changing behavior to try to fit in

4.3.4 Reticence regarding hardship

As it was noted previously, the participants in this study have, at times, been explicit about the hardships associated with being a YC. Nevertheless there were some instances when they preferred to be closed about their experiences. Many of the younger carers were understandably reticent when talking about difficult or more negative aspects of their experiences of caring. This may have been because they do not see their roles as carers as particularly difficult or it might be that they do not want to betray those who they care for, and they may be afraid of revealing their hardship for fear of what might happen as a result. It was interesting that the older carers were more likely to express their difficulties.

It was apparent that Anthony, for instance, was mostly open and matter-of fact about his chores and suffering. However, when it came to talking about his mother's difficulties and needs he was hesitant and reluctant to elaborate. He indicated that his mother 'suffers from has mental illness,' (Anthony, p. 5) but he also added, '*Oh yeah I guess*

that's a bit confidential,' (Anthony, p.9). It may be that mental health still comes with a societal stigma attached to it but also might be too painful for him to talk about. He also found it particularly difficult to speak about what helps him cope, expressing:

Right, er, yeah I guess so. Uhm. Yeah, I try to.... Oh I don't know, I try to, I try to er, Oh, I don't know, sorry,' (Anthony, p.14).

It could be that coping or not coping is irrelevant to him, perhaps he hasn't really thought about it because he just has to get through as best as he can, as he has no choice. He also seems unsure that he is coping. His repeated apologetic 'sorry' and 'I try to' could reflect his continued efforts and might demonstrate how much he tries, but also his guilt or disappointment that he is finding it hard to cope, or that he is not sure that he is coping. He goes on to say:

I'm having a difficult day today, sorry. Yeah, er...(pauses) can I get back to that one?" (Anthony, p. 16).

It could be that he would rather answer this question when he feels that he is coping.

Similarly Salma was reticent about her own experiences of hardship as a YC but talks openly and freely of the difficulties that other younger YCs are facing. She, for instance says, when asked about the disadvantages of being a YC: '*there is nothing bad going on,*' (Salma, p. 5). It is interesting that she used the phrase 'nothing bad going on.' It is as if she assumes that I think something bad is going on. It might be that she does not see any disadvantages about being a young carer or maybe she might be hiding or denying that she has any difficulties.

Salma did explain the reasons for her reticence with her teachers. She talks of teachers asking her if she was OK. She knew that they suspected that things were not OK

because she said she ‘used to look a bit depressed,’ (Salma, p. 12) But she admits to hiding the truth,

I just used to say everything’s fine...because I wouldn’t say it to the teachers otherwise they’re going to put Social Services in, or somet, but I was fine, (Salma, p. 12).

She concludes, ‘*but I was fine,*’ as if trying to convince herself, or the interviewer that this was the case. She went on to admit that she was afraid of being reported to social services when she was younger. Currently she indicates that she is more confident in seeking help and advice from professionals because:

they won’t put social Services in because it’s like I’m 18 now so I’m okay, but before it was a bit worrying,’ (Salma, p.12-13).

It seems that she needed to remain reticent because of her age and the fear that there might be consequences such as being taken into care.

Sadia, Habib, Nadia and Fabina were all particularly reticent about hardship in the interview. This could have been because they are unaware of any hardship and do not feel that they are particularly suffering; or it could relate to their age, and their fear of speaking out, as Salma had said she was when she was younger.

Sadia is rather vague about who she cares for. When asked about this she says, ‘*The people here,*’ meaning the other young carers. But when asked about circumstances at home she said, ‘*My Mum and Dad, my brother and sisters,*’ (Sadia, p.3). This was either because she was not aware who she is a carer for, and did not really understand the meaning of ‘*Young carer*’. Or she did not really want to talk about it. In terms of expressing why her parents need help, she was equally vague, saying, ‘*My Dad got illness and my Mum got illness as well,*’ (Sadia, p. 4).

Fabina also gives little away about the extent of her caring responsibilities, 'I just need to look after him and that's it, and help my Mum.' (Fabina, p.5). She also uses the word 'need' as if it is not her choice but a requirement or necessity; but the use of the word 'just' may be playing down her role – making it sound minimal.

When asked if being a carer has affected her she says '*sometimes....they like...*' but then stops herself and says, '*actually it doesn't really affect me.*' It was as if she wanted to explain something but then decided not to continue. It is unclear who 'they' are, and what she wanted to say. By starting and then stopping herself she appeared to be guarded and it would have been interesting to know why this might be. Fabina also admits that she would not talk to others about her situation '*if it's personal stuff like proper personal then (she) wouldn't say it, if it's like OK to say it (she) will*' and wouldn't mind, (Fabina, p.9). This shows that she is cautious about what she reveals to others and suggests that she could also have been guarded during the interview also. She perhaps keeps her barriers up so as to prevent disclosure to others.

Summary of theme – Reticence

- Not wanting to speak about difficulties – avoiding stigma
- Finding it emotionally difficult to speak about experience of caring
- Speaking of hardships of other YCs instead – distancing/externalizing
- Wanting to hide the truth
- Fear of social services and professionals

These themes of hardship show that the YCs are individually, experiencing or have experienced, differing degrees of hardship. However, the other emergent themes which

will now be described suggest that these hardships are balanced with the more positive aspects of caring.

4.4 Superordinate theme: Benefits of caring

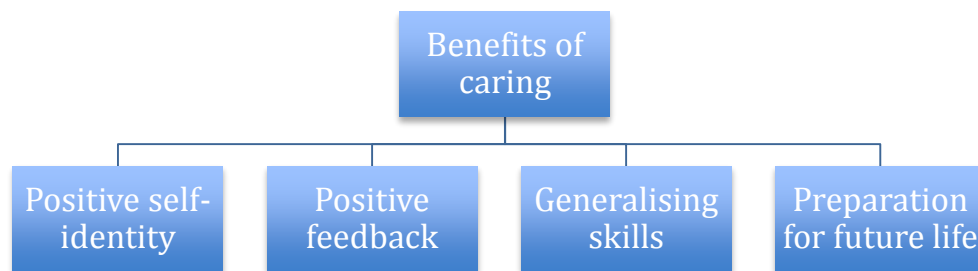


Fig. 3: Benefits of caring

Amidst the feelings of hardship that the YCs experienced, they were also able to recognize positive aspects of being a YC, such as the personal benefits which they gained. Adam for example refers to this double sidedness of his experience when he says that caring is:

Um good and bad. Good because you know you're helping people and that it builds your confidence up in looking after people and that, but no because you don't get enough time to go out or do what ever you want and stuff. It's really tough, (Adam, p.9).

This quotation illustrates the next superordinate theme which encapsulates the interpretation of the benefits that the participants experience as a result of their caring roles. Four subthemes (represented in the Figure 3) relating to the benefits of caring are identified:

- Positive self-identity
- Positive feedback

- Generalising skills
- Preparation for future life

4.4.1 Positive self-identity

This is a saturated theme as most of the participants described themselves in a positive light, and their sense of self-identity was related to aspects of their selves which are observable or related to their interaction with, and caring of others. In particular they saw themselves as ‘*caring*’ (e.g. Sadia p.2) or ‘*kind*’ ‘*nice*’ ‘*helpful*’ ‘*mature*’, and it was as if their caring role had become part of their positive identity. For example, Nadia, when asked to tell me about herself, proudly said ‘*I am a young carer for my Dad,*’ (Nadia, p.2). Being a carer for her dad had become part of her self-identity and she seemed to view this with positivity.

The YCs also saw their YC role as an opportunity to be helpful and caring, as if to bring to it and use positive aspects of their personality. For example Sadia identified that being a carer is positive as she ‘likes to help,’ Sadia (p.5). Adam, too, thinks that caring ‘is a good thing because you’re helping obviously and because there’s people out there that are less able to do certain stuff,’ (Adam p. 10).

Some of the participants express that caring for a family member has changed them for the better. Farhan describes how he has become ‘more mature’ (Farhan, p. 7), whilst Adam sees himself as a ‘good person’ because he helps members of his family. He also believes that caring has made him less lazy and more active. He thinks that when someone is caring:

then you’re not lazy like what I am, like it tends to like to get you up and you doing stuff and that. So you’re basically active most of the time. (Adam, p.10).

The implication is that the participants believe that caring can bring out the best in the YCs and offers the opportunity for self-improvement leading to a positive self-identity and more confidence.

The caring role not only allows the YCs to feel good about themselves, but also to have positive self-identity which is also observable by others. For example Adam says he feels ‘confident’ about himself and likes to ‘go out there and show people that (he) can do it,’ (Adam, p.13). It is as if these individuals see caring as an opportunity to prove themselves, or as Salma says, to show that she is a ‘worthy individual,’ (Salma, p. 3).

Only one participant, Fabina, did not reveal that she saw anything good in being a YC, (Fabina, p.6). When asked if caring for her brother has affected how she sees herself Fabina says ‘uhm, (pause) I haven’t really noticed,’ (Fabina, p. 7). She appeared to be unsure, or it might simply have been that she did not want to speak about this.

Summary of theme – Positive self-identity:

- Caring role becoming part of how the YCs see themselves
- Caring has changed them for the better

4.4.2 Positive feedback

A few of the participants talk favorably of the positive feedback they receive from others as a result of being a YC. For example Sadia recognises that what she gives to others is important: ‘*people hurt and I care for them.*’ The feedback she gets is that her fellow YCs who she offers support to at the Young Carers’ group ‘*have fun with*’ her.

She sees herself responding to the needs of others, and is pleased with the positive feedback she gets there (Sadia, p.1). Like many of the other YCs it is noted that she does not say anything about positive feedback that she receives from her family or from school.

Farhan is the only YC who explicitly describes himself in terms of how others see him, and this is because he says he doesn't like talking about himself:

I'm going to kind of run on what other people would say about me rather than what I'd say about myself, because I don't, I don't like speaking about myself a lot so taking it from people like the young carer adults that they see me as a leader, someone who's enthusiastic and a good communicator, (Farhan, p.3).

It seems that he respects the views of others and listens to them, obviously getting positive encouragement from the YC's youth workers.

He says his views about himself:

are based upon what other people see as, for instance stuff I do at home, the work like I do at school and stuff like that, people do say oh, you're not like this person or like that person etc., so people do give me that recognition. So I take that on board and obviously put it out there,(Farhan, p.4).

He seems to enjoy and value the recognition. This suggests that, in addition to the intrinsic motivations he gives for caring, to a certain extent he is externally motivated to care, and that positive feedback is appreciated and important to him.

Several of the YCs do not talk of positive feedback from the people they care for. In fact, for example, Anthony reluctantly states that, hypothetically, one can feel disappointed if your hard work is not appreciated by the person who one cares for:

It's hard that you, you know, if you did all this stuff and then they don't appreciate it, (Anthony, p. 8).

Summary of theme – Positive Feedback (not a very saturated theme)

- Responding to the needs of others leads to positive emotions
- Caring role results in positive recognition from others

4.4.3 Generalising skills

Several of the YC participants talked about caring for others beyond their caring responsibility at home. Some generalized their caring role and skills to other members of their family, or extended family. Sometimes the caring was generalized to caring for other YCs at to the Young carer's group, or to future career aspirations. The YCs seem to want to draw on their experience and what they had learnt as a YC and apply it elsewhere. For example Salma says:

It's like trying to learn from what I've learnt from Health and Social care from that, advancing my knowledge to the extent that I know exactly how to handle people, even though its not going to be a family member, it might be someone else like my grandparents or an elderly person in the street, (Salma, p.14).

This is perhaps because the caring role has become part of their self-identity. The YCs could feel empowered by the experience so feel confident to extend it to other areas of their lives. Or it could be interpreted as an expression of the YCs wanting to help others in ways that they would like support for themselves. (See Reflective comment 8 in Appendix B).

For example, Nadia wants to take her caring experience into her future career, she wants to be:

a detective or a doctor..... I want to be someone who would help people, because I've been helping my dad and my dad said you can be whatever you

want to become, so I is thinking of doing something that would help people like nursing in (like) homes... (Nadia, p. 10).

Generalising the caring role beyond the family could demonstrate that empathy has been well developed as a strength which YCs can apply elsewhere. Some participants talk of caring for other carers at the Young Carers' group, as Farhan for instance says he listens to others: *'like their backgrounds and what they're going through and stuff'* he says, *'you feel quite sad for them, so in that sense you kind of like you come here to help as well,'* (Farhan, p.15).

Farhan shows empathy for others; this could well be a strength that has developed as a result of his own experience. But perhaps generalising the caring role to beyond the family also functions as a distraction from one's own emotions. Supporting others in a similar situation at the Young Carer's project could help the YC to deal with what they are managing at home, as a kind of deflection or transference, perhaps. Or it could simply be a continuation of the particular self-identity which has evolved as a result of the caring experience.

Habib equates his YC role very closely with his role as a member of the Young Carer's project group rather than speaking about his role at home looking after his Mother. He says, *'we have to look after the younger ones,'* (Habib, p.10). This could be something that has been encouraged by the youth workers in the YCs' group. Or it is linked to his generalized self-identity of being a carer and his role of looking after others. Perhaps this is easier to talk about because it is more public and less private; there is less possibility of having to talk about his mother and his relationship with her and how caring for his mother impacts his life.

Summary of theme – Generalizing skills

- Learning from experience of caring
- Confidence to care for others beyond the YC role
- Development of strengths such as empathy
- Helping others is a kind of respite as it is less emotionally difficult - deflection and transference

4.4.4 Preparation for future life

A theme which came through in some of the participants' interviews was the idea that being a YC prepares for a future self or career. Young caring is referred to as an experience which prepares for the future in the sense of identity-forming. For example, Salma says:

being a young carer for me is about uhm helping parents and it's about becoming who you are later in the future,' (Salma, p.3).

She then goes on to repeat the idea:

So I think being a young carer is showing us of who we are meant to be and how we are meant to look after our parents as in the future it would help us when we are older, it would help us to understand how we are meant to be, (Salma, p. 4).

The repetition of 'meant to' suggests that she feels the need to fit into an expectation of the right way to be and the correct way to act in the future, and being a YC is a way of learning how she is meant to behave. There is also the suggestion that the experience will help her for 'the future' when she will 'get married,' (Salma, p.5) and assumes the gender role associated with her cultural back ground for '*us females*' (Salma, p.7). It would be interesting to explore if this idea has come explicitly from her parents or of this is her own way of accepting the role by reframing it in a positive way.

Another example is Habib seeming to imply that his experience as a YC has been a good preparation for a future career as a pilot because both require the tolerance of pressure:

Um my inspiration for being a pilot um because pilot, you have a lot of pressure on your shoulder. When you transport people from country to country in planes and that's what we're doing here, we have to look after the younger ones and makes sure nothing really goes wrong with them so um they don't get into trouble with no fights. And so far it's been so good, (Habib, p.9).

It is as if he parallels the challenge of becoming a pilot with what he's been 'doing here' as a YC. He thinks the ability to withstand the demands and pressures of being a YC means that he has the qualities to be a pilot. YCs feel highly efficacious about becoming who they want to be in the future.

Summary of theme – Preparation for future life:

- Preparation for future career
- Young caring contributes to the person you are or will become
- Cultural expectations

Challenges of YC equated with other challenges linked to career in the future.

4.5 Superordinate theme: Managing the impact of caring

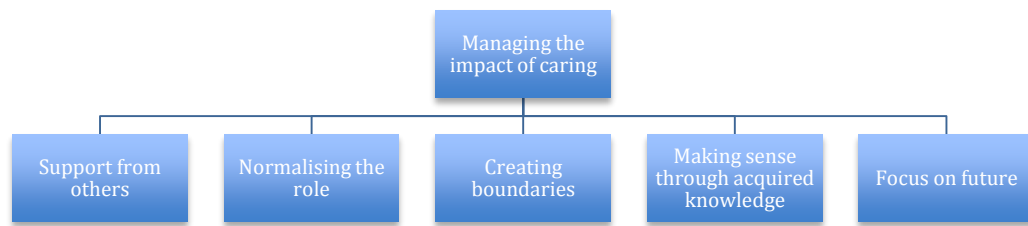


Fig. 4: Managing the impact of caring

Whilst YCs have indicated the difficulties and hardship associated with their role, they also communicate what the author interprets as resilience, and their ability to manage the impact. The subthemes which emerged (and represented in Figure 4) suggest that this is achieved through:

- Support from others
- Normalising the role
- Creating boundaries
- Making sense through acquired knowledge
- Awareness of strengths
- Focus on the Future

4.5.1 Support from others

Most of the YCs communicated that other people's support is important to them; they talked about friends and family being very important to them. For example Adam says:

the most important people in my life I'd say is my family and close friends because they really like support me, (Adam, p.2).

Habib also suggests he values the support of long-term friends:

my friends are important to me, keep me going through life um especially the ones I've known for a long time, (Habib, p. 3).

However, whilst he says his family is important to him too, he does not speak of them in terms of secure long-term support. He is just hoping they will always be there for him:

Er family's important to me because also they've been keeping me going though life and er I hope er they'll keep me going until I die, (Habib, p.4)

The repetition of 'keep me going' suggests that he is aware that he needs others to support him through his difficult life. But perhaps this also highlights his insecurity and uncertainty about whether his family will always be there for him.

The YCs recognize that good friends are those who are supportive because they understand their lives and situation. Through their experience they have learnt what true friendship looks like and they rely on this for support. For example, Farhan says:

if they say for instance I do have to be home by a certain time to be able to take my sister home so obviously it, for instance if my friends were like oh, how come you can't stay after school and they'd moan about it then I don't see them as being my friends, my friends are people that accept that and understand that and sometimes they'll come with me in that sense, (Farhan, p.8).

It seems that once friends understand their situation then they become more helpful.

The young carers also spoke favorably of the support which they get from the Young Carers' Group Project. Some referred to it as a '*club*' to belong to, a place to meet and make new friends with others in the same situation, and so would understand. For example, Anthony talks of meeting others who have '*kind of suffered the same*' as he has. Salma says she likes to meet '*new people and new other carers,*' (Salma, p.9).

She says they '*talk about how they are coping*' and '*the ways that (they) can help each other out in situations like this.*' She says it is a chance to '*share opinions*' and talk about '*ways to find positive and negative ways in helping our parents.*' '*So I really enjoy it*' (Salma, p.9).

The Young Carers' group is seen as a club, or extended family, which offers a chance to experience a sense of belonging, which is so important to these young people who feel different from others because of their circumstances. It gives them a shared wider identity and place to fit in. Habib, for example says:

A young carer, part of being in this project is like, it has, it's like it's a part of me, coming here, enjoying to see people, friends, having a nice time, two hours of every Xday spend it with friends away from family. But some people here, er friends, I consider them as family, yeah, (Habib, p.6).

The group is an important part of the YCs' lives as it is a place for them to belong to and spend time having some fun. Habib goes on to comment that he enjoys seeing people, '*friends, having a nice time, two hoursto spend it with friends away from the family.*' It is as if he is suggesting that there is a need for the YCs to have a family away from the caring responsibilities associated with their actual family. (Habib, p. 6).

The Young Carers' group offers a place to relax, have fun and to '*let loose*' (Nadia, p.9) or feel free to enjoy oneself away from the responsibilities at home. For example Anthony acknowledges that coming to YC's project helps him de-stress, relax and do some activities that perhaps he might not usually do:

I guess coming, coming here is a help. Maybe also I I do other stuff, other things maybe that can sort of release some stress, (Anthony, p.16).

Several YCs also acknowledge the opportunity for mutual support. Anthony, for example refers to the fact that he can ‘share’ ‘experiences’ and help the younger ones. There is the suggestion that the YCs like to impact/help others because this is important to them. This might be because it helps them connect with others or helps to create cohesion and unity, which is perhaps missing elsewhere in their lives. Maybe at home the young carers don’t feel that they are sufficiently effective in their caring role. For example Anthony does not talk of impacting/helping his mother at home in the same way he talks about it in relation to the YC’s group.

Only one of the YC talks about support from school but this exception is illuminating. Farhan explains that he has a good supportive relationship which seems to have been very successful in helping him. He implies that even the teachers just knowing about what was happening at home and what he is going through was supportive. Speaking appreciatively about his school and the teachers he says:

....they’ve beena lot through the exam period my sister was in and out of hospital and the school kind of knew about that. And because I’m quite close to my teachers and my head of year etc. like the help was put in place, so in that sense I was helped there and I didn’t really move to college because I didn’t want that kind of support system to go away. Because I was planning to move away to a different college but, at the end I didn’t see it as a good way of (pause), because then I’d have to build that whole relationship up again and then the trust and so on, but if it’s still the same school then that’s still there, everyone still knows you, (Farhan, p.13).

Farhan is explicit here about the support system he has had at school and he recognizes the importance of his relationship with the teachers at school – building the relationships, developing trust, and the fact that everyone knows him is important. It helps him have a sense of belonging and the school acts as a protective factor to support him.

He goes on to talk about the specific kind of help/support that he got from school. He says they were flexible and showed kindness towards him:

For instance when I was running late they kind of gave me extra time at the end and like every so often I didn't have breakfast and a lot of teachers would go and buy me some and stuff like that. So, (Farhan, p.14).

He says the teachers are:

like a lot of my friends, they understand the situation, they respect that and help out when they can, (Farhan, p.14).

(See reflective comment 3 on support from others in Appendix B)

Summary of Theme – Support from others

- Friends and family – understanding important
- YCs' group supportive – meeting others in similar situation, mutual support and sense of belonging
- Support from school, building good relationship and trust is very helpful but not a saturated theme

4.5.2 Normalising the caring role

Many YCs seem to want to play down their caring role, expressing it as part of their lives, as if it is normal, and they do not think of their lives in any other way. Some show acceptance, or the ability to reframe their hardship, and some justify their role in terms of cultural, including gender (find example), and religious expectation. The author interprets these as possible mechanisms to help the YCs to manage their role.

Some YCs express the idea that their lives have not changed because they are caring for others:

'Things just are the same,' (Anthony, p.12)

'I feel normal er I've been through it for a long time so I get used to it,' (Habib, p.8).

Habib's language suggests that his caring role has been difficult but he has adapted and it is now normal to him.

Nadia says of her experience as a YC:

I feel quite normal. It's not like very big, coz my dad's the same like how any other girls would see their dad, it's like, it's just like helping around and that's it really, it doesn't really affect me now. (Nadia, p.9)

These expressions of normalizing their caring roles might occur because these CYPs have not known anything different and demonstrates that they want to see themselves as 'normal.' But these expressions could also function to give the impression that things are fine when they are not.

Other YCs, however, normalize the role in terms of the cultural expectations that they are both aware of and want to live up to. For example Salma sees her caring role as part of her cultural reciprocal duty to her parents:

traditionally it's we like in my culture and my religion is that we look after our parents no matter what stress they are going through, no matter what pain. (Salma, p.6)

She goes on to repeat the influence of culture and religion and justifies the idea of reciprocal obligation and duty:

through my cultural and religious beliefs that we, I believe culturally we are meant to look after our elders, including our parents because it's like we show

respect to them and like we're not meant to put them down, We are meant to make them feel happy and feel that we still value their experience because our parents have taught us a lot though our younger age until as soon as we leave home, (Salma, p.6-7)

Whilst Farhan says he likes 'to be different,' he normalizes and justifies his caring role by relating it to his religious beliefs:

In a good sense I have to refer back to my religion that when someone like a family or anyone like that is given a child with a disability it is more seen as a good thing than a bad thing, (Farhan, p.10).

He sees it is as if he has been given a gift from God and he believes that he can rise to the challenge:

that God won't burden us more than (we) can carry, (Farhan, p.11).

Farhan goes on to explain that:

if he's (God's) given you a trial....He has obviously given that for a reason.

He seems to view caring as a trial or a test and if a person treats:

that child with a disability right, may be a way you can get into heaven. It's what you do to that child, which kind of after she, my younger sister came out, that's how I like think, that if I do this for my sister, if I did that for my sister, then maybe I'll make my way up there. (Farhan, p.11)

Here we see Farhan rationalizing and reframing his sister's disability as a positive challenge and an opportunity to prove himself worthy of a place in heaven.

There are many ways that the YCs try to normalize their situation. It could be that this is a way of helping them manage the situation by helping them to fit in, or to justify the hard role that they take on.

Summary of theme – Normalising the caring role:

- Caring role part of normal life and not changing anything, reframed as normal.
- Caring role normalized in terms of cultural expectations
- Caring role justified in religious terms.

4.5.3 Boundaries

Another way in which a few of the YCs try to manage the role that they take on as a YC is by establishing boundaries. It seemed that some of the YCs separate out different areas of their lives, with some keeping the part associated with caring quite private and separate from the rest of their lives.

Anthony separates ‘home’ and ‘outside of the home environment’ seeing himself as different in different environments, a kinder self outside the home:

‘maybe at home I’m not that nice to my parent but outside, outside of the home environment I, I tend to be more er more kind I guess. And er, I am a person who takes the initiative, I er,if there is no one that is going to take part in a, in a event I’ll try to step in first and hopefully that will motivate the other people....’ (Anthony, p.3)

It seems that he feels more influential outside his home but this may be because he feels powerless at home, that he has little impact in making real changes for his mother. It is as if his circumstances as a YC has created dual environments – home where he feels less effective, and beyond the home where he can help motivate others.

Salma also separates her time clearly. When at college she accepts that she is ‘unable to help (her) parents’, making her education a priority. However, ‘as soon as she goes home she takes over the responsibility ‘the duty of both (my) parents,’ (Salma, p.7).

As referred to previously, Farhan is one YC who manages to merge the two areas of his life, allowing his friends to help out and getting support from teachers at school. He is quite open with others about his role as a carer and this means he does not have to create boundaries.

Summary of sub theme - Boundaries

- Boundaries established to separate different parts of YC's lives
- Mechanism to cope with different competing priorities
- Merging the different parts of their lives can work for some who have the skills and confidence.

4.5.4 Making sense through knowledge

A few of the YCs are explicit about how they have used knowledge to help them make sense of their caring role. Both Salma and Farhan, two of the eldest YCs, have been diligent in finding out as much as they can to support them with their responsibilities.

Salma says:

I became more mature at the age of 12, I tried to do the other things, researching everything, finding out about people's health and so on. Then it came to me that, oh my word, these people need help, so that's why after doing research I became so happy and then it was like I put my mind straight on my family and then education, (Salma, p11.)

After doing this research she realized she had to help her parents, perhaps because she realized the necessity. It was as if she became empowered with the knowledge she had acquired.

Farhan describes how he felt when he first discovered that his sister had a disability. Using figurative language he says it was: *'like walking into a wall, perhaps,'* (Farhan, p.5). This simile suggests something sudden and shocking, a barrier to be surmounted, something hard-hitting and potentially painful. But he says he read books to help him understand his sister's disability. He read *'a lot of books by different professors and stuff how to deal with it,'* (Farhan, p.5). Now he is extremely articulate when describing Rhett Syndrome (Farhan, p. 6). He talks about how he now remembers what he read and still applies what he learnt. He says, *'you have to prepare yourself when you do have someone in your family ...like that.'* Having a practical reaction to aid his emotional response, preparation for his input, seems to have helped him cope with coming to terms with it.

A couple of YCs, Salma (p.4) and Farhan (p.18), also referred to things that they had learnt from their studies at school to make sense of their situation as a YC. For instance, Salma refers to sociological terminology such as *'primary'* and *'secondary socialization,'* when speaking of how she has learnt from her parents. Her studies in Health and Social Care seem to be relevant for supporting her in understanding her caring role.

Summary of theme - Making sense through knowledge

- Researching their relatives' illness or disability helps to empower YCs
- Alleviates the shock of discovering the illness – helps surmount the challenge
- Practical application of what is learnt from researching the illness or disability.
- Drawing on some things learnt at school can support YCs' understanding of their situation.

4.5.5 Awareness of strengths

Few YCs explicitly expressed an awareness of their strengths. As we have seen in a previous section, Anthony is aware of being influential and having leadership qualities outside of the home. Farhan too is aware that he has '*got to lead the group*,' as others see this as a strength in him. He also says that a lot of people tell him he has '*good time-management*' skills, which he is aware have helped him especially during his school examination period. It is clear that Farhan is good at building and sustaining good relationships, such as we have seen he has done with his teachers to gain their support.

Salma refers to her 'personalities' and sees herself as '*helping, understanding, loving caring...*' (Salma, p.2). She also likes to accept challenges when they come her way to show that she is '*a very worthy individual.... Not like someone who would just stay around the home.*' She seems to be using her strengths to reframe her circumstances as a YC, which could be a coping mechanism which helps.

Adam talks of two strengths: '*helping*,' and '*football*.' There is a balance here between a strength related to benefitting others and one which involves something for himself.

Again it seems to be the older YCs who are showing more personal insight and awareness, or perhaps they are more comfortable speaking about these things.

Summary of themes – Awareness of strengths (not a saturated theme)

- Some YCs are aware of their strengths
- Strengths used by some to positively reframe their caring role

- Ideal to balance the strengths used to benefit the self and others who are cared for.
- Older YCs seemed to be more aware of their strengths.

4.5.6 Focus on the future

All the participants, except one, Fabina, express some focus on the future, with plans and or aspirations. Anthony is very upbeat and certainly thinks a lot about the future saying that he would like to be a police officer so that he can create a ‘stable, cohesive community’. It is as if he wants to aspire to having some kind of power and authority to help make a better community. He says:

I mean like the community we live I, we are very diverse, there is a lot of ethnicity but the thing is we don't really get together. So that is what I'm really thinking about now about the future, (Anthony, p.17).

However, Anthony does express some fear that he may not achieve his goals:

...there are some worries that I feel like that maybe sometimes my confidence will kind of (pause) kind of fail me, because to become a police officer, it's really hard to get in and I'm just thinking to myself, you know, would I become a police officer and if I did how would I tackle situations within a community..... (Anthony, p.19).

Sadia too has plans for her future but keeps an open mind: *'I'd like to do nursing or a TA or a teacher.'*

Salma is positive about her future, saying *'soon I'm going to get married,'* (Salma, p. 9) and she hopes to *'do an NHS course,'* (p. 13). She feels that she will have more control over her life in the future: *'.... it's like you have your own future,'* (Salma, p. 12), which could suggest that her present and past has not been her own. *'my future it's going to be brighter than how it used to be in the past,'* (Salma, p. 13).

Habib is also energized and positive about this future plans:

I see myself as a successful person in the future getting good levels and getting a good job,' (Habib, p. 11).

He has *'a lot of ideas,'* (Habib, p.11) and wants to be *'an inventor, an engineer, a pilot,'* (Habib, p.11)

Adam, Nadia and Farhan explain that they are less certain about the future. Adam says he sometimes thinks about *'what will happen in the future, because you never know what's going to happen in the future,'* (Adam, p.15). It appears that his uncertainty is related to his brothers and family situation:

...because I don't' know how my brothers will turn out to be in the future or my family so I've got to wait and see from there, (Adam, p.16).

He later says that he would like:

to finish college with good grades, maybe get a job or do my dream which is to being a footballerand yeah, just carry on caring if I need to, (Adam, p.16).

Adam is hopeful in spite of the uncertainty; and is as if at the back of his mind he knows a lot might depend on his brothers and if he needs to continue to care for them.

Nadia has some ideas for the future, however the way she trails off when asked if she thinks about the future she says: *'I do, coz it's mainly what I want to become when I'm older and stuff. Yeah'* (Nadia, p. 10) suggests that she is uncertain:

Probably I'm going to be in college. I'm not sure what I really want to become but I have some ideas,' (Nadia, p.12).

It would have been interesting to explore more explicitly whether thinking about the future was helpful to the YCs, and if focusing on it gives them a sense of hope and optimism, as interpreted by the author.

Summary of theme – Focus on the future

- Some YCs are more positive about the future, seeing it as something to look forward to and aspire to.
- Other YCs are less certain about their future because they feel they need to consider those they are looking after.

4.6 Chapter summary

This chapter has reported all the findings from the research in detail, with the YCs' words at the centre. Following the IPA principles this analysis is not a definitive account, but the author's interpretation, and the reader may like to consider the findings in terms of their own perspective.

CHAPTER 5: DISCUSSION

5.1 Overview of chapter

In this chapter the author will outline the main findings of the study already detailed in Chapter Four. These findings will be related to the research questions and compared to the research highlighted in the literature review, including those studies which take a balanced positive psychological and solution focused approach as well as those which focus on a purely needs and risk assessment approach. The findings will then be considered in the light of two psychological theories, which define psychological wellbeing. The discussion will lead on to looking at the relevance and implications of the findings for EPs and other professionals. A strategy for disseminating the research will be proposed and questions for future research will be suggested after a consideration of the distinctive contribution and limitations of the study has been made.

5.2 Major themes emerging discussed in the light of research questions and previous research.

In answer to the research questions:

- What are the current lived experiences of YCs in this multi-cultural inner London borough?
- How do they make sense of their experiences?
- What are their experiences of support?

This study found that caregiving is a multi-dimensional experience. Whilst all the participants in the study experienced elements of hardship related to being a YC, themes also emerged which suggested ways that many of the YCs coped or managed these hardships, and themes which highlighted some beneficial aspects of young caring were also found.

5.2.1 Hardship

One of the themes related to hardship is lack of freedom. Because the responsibilities associated with the caring role imposed time constraints on YCs, most of them felt they had little time to do what they wanted, such as see friends or give sufficient time to schoolwork. Interestingly, this finding was also found in a number of other studies such as research of Lackey & Gates (2001), Thomas et al. (2003), Bolas, (2007), and Moore & McArthur (2009).

As found in previous studies (e.g. Thomas et.al., 2003; Bjorgvinsdottir & Halldorsdottir, 2014), this research has found that the YCs express their caring role in terms of both mental and physical difficulty. Additionally, this study found that the YCs saw that their role as inevitable and that they had little choice but to support and look after their relative who needed care. They lacked autonomy, and some saw their caring role as part of their inevitable life story, which had not been written by them, but for them.

The theme of accelerated childhood emerged as a result of YCs referring to the extensive chores they had to do (in the present study it was apparent that this was sometimes due to cultural expectations). The theme also emerged because many YCs

believed they had developed maturity early, and had to balance mental and physical challenges with hard work usually associated with adults. Bjorgvinsdottir & Halldorsdottir (2014) also found that the YCs were doing a lot of chores unsupported by adults.

Isolation and not fitting in with others because of feeling different was another hardship expressed by many of the YCs in the study. Several of the reviewed studies found similar issues (Lackey & Gates 2001; Bolas, 2007, and Bjorgvinsdottir & Halldorsdottir, 2014). It seemed that some of the participants in this study felt pressure to change their behaviour whilst others developed more helpful coping mechanisms which will be discussed further.

In the light of the Modified Labeling theory (Cullen, Strueng, Shrout, & Dohrenwend, 1989), which suggests three common responses to the acquisition of the stigmatized label of mental illness: secrecy, educating others, and withdrawal, Bolas et al., 2007 found that the YCs expressed feelings of isolation, and linked this to a fear of stigmatization, with the participants responding with secrecy and withdrawal rather than trying to educate others about being a YC. The present study found similar expressions of isolation and only one participant in this present study was successful in educating others; interestingly this participant (Farhan) also managed to gain support from his school by being open about his situation with teachers, thus building a trusting relationship.

Whilst many of the YCs voiced their views of hardship there were some who were reticent - not wanting to speak about their difficulties, possibly to avoid stigma or topics

linked to their caring role which they found emotionally difficult to speak of. Lackey & Gates (2001) had similar findings. In this present study, however, some participants spoke of hardships by highlighting them in other younger YCs instead. A possibility is that they may have adopted such an approach in order to externalize and distance the hardship from themselves through the process of projection, a psychoanalytical term related to a psychological theory which suggests that when people want to deny that they have certain unpleasant characteristics or feelings they attribute them to others instead. There were some YCs who perhaps wanted to hide the truth for fear of betraying their loved ones, or wished to avoid the consequences, which they believed might be imposed by social services, for example, or by other professionals. It could be that the reticence is a symptom of 'hardship' experienced, but it could also be a coping mechanism to avoid others finding out their difference, or a way to internalize their difficulties.

5.2.2. Benefits of caring

In spite of the hardships, other more hopeful themes became visible in the light of the open person-centred positive psychological approach taken in this research. The researcher was interested in exploring all aspects of the participants' experiences to see what was working for them and the extent to which these individuals are flourishing and experiencing psychological wellbeing in the midst of difficulty and challenge. This approach balances and compliments traditional psychology which tends to focus on why things go wrong for people, and how to fix their issues (Seligman & Csikszentmihalyi, 2000). Again, some of these themes correspond with previous research, which has also aimed to explore the full experience of YCs such as Bolas et al., (2007) and Doutré et al., (2013).

Several themes emerged which suggest the more positive aspects of YCs' experiences. The creation of a positive self-identity was one benefit which the participant YCs communicated. The researcher interpreted their experience of the caring role as becoming part of how the YCs see themselves in a positive light, such as helpful, confident and caring, and some referred to the experience as having changed them for the better. This theme of YCs seeing themselves in a good light was in accordance with findings of Lackey & Gates, (2001); Moore, & McArthur (2009); Smyth, Blaxland & Cass (2011) and Doutre et al., (2013). During the author's interpretation and analysis she wondered to what extent the development of a positive identity is an outcome or a coping mechanism – or a combination of both. Bolas et al. (2007) saw participants' positive attributions, for example of pride related to their caring role, as a means of counteracting the negative judgement of others, and feelings of uncertainty and isolation. Doutre et al., (2013) reported that participants felt different from peers but they tended to reframe their identity using positive attributes such as bravery and pride as a way to broaden their self-identity.

Positive feedback, although not a very saturated theme, was experienced by the YCs who find that responding to the needs of others leads to the awareness of positive emotions as well as positive recognition from others. Nevertheless the author acknowledges that it was surprising for her that positive feedback from others was not a more saturated theme. Whilst most of the YCs seem to be intrinsically motivated to care for family members, the author could not help feel that they deserve positive feedback and gratitude in response to their caring role. This view, however, is likely to reflect the author's own cultural expectations and experiences, which she has reflected upon in her

reflexive diary. (See reflexive commentary 8 in Appendix B). It was found that some YCs in this study, and others, made it clear that they do not want to be treated differently, or that caring is just what they do, and is part of their cultural experience.

The themes of generalizing skills, and learning from the experience of caring, came through in the findings. Many participants communicated their confidence to care for others beyond the YC role, and some recognized or demonstrated that they had developed personal strengths such as leadership and empathy. This was consistent with the studies of Lackey & Gates (2001) and Heyman & Heyman (2013). It seemed in the present study, that helping others beyond the home provides a respite effect as it is less emotionally difficult, and could act as a kind of deflection or transference. (See reflexive commentary 8 in Appendix B).

Preparation for future life was also interpreted as a benefit of being a YC. This was in terms of developing skills and confidence in readiness for a future career or marriage, in one case. Several YCs seemed to suggest that young caring contributes to the person they are, or will become. For some participants the challenges of being a YC equated with other challenges they might face in future careers, with many of them hoping to enter helping professions. Others who experienced caregiving in this way appeared to be responding to cultural and religious expectations. Some understood, through cultural or religious beliefs, that if they cared for a family relative this would prepare them for adulthood and in one case, entry to heaven.

5.2.3. Managing the impact of caring

The importance of receiving support from others was a saturated theme, since all the participants referred to the value of support from the friends and family who understood their situation. Previous research has also presented this as an important theme: Lackey & Gates (2001); Thomas et al. (2003), Nichols et al., (2013). However, it appeared in this study that support from school staff varied, which coincided with the lack of awareness, flexibility, acknowledgement and sensitivity experienced in schools by YCs, and reported in previous studies (Barry, 2011; Hamilton & Adamson, 2012; Thomas et al., 2003). One participant in the present study, however, was explicit about the support gained by building good relationships and trust with teachers, but unfortunately this was not a saturated theme. This will be discussed later as an implication for EPs, since lessons can be learnt from this resourcefulness.

It appeared that almost all the YCs in this study found the YCs' group supportive. In particular they valued meeting others in similar situations, having fun away from the family and the mutual support helped them achieve a sense of belonging to balance the feelings of isolation and not fitting in. This is in accord with previous studies such as Thomas et al., (2003); Smyth, Blaxland & Cass (2011); Bjorgvinsdottir & Halldordottir, (2014) who concluded that talking to others was important. In addition to creating a sense of belonging the author also hypothesises that mutual support could be interpreted as a form of transference, whereby care is given to others beyond their relative who needs their care at home, because it is an easier relationship. This said, the researcher should acknowledge that this might be a source of bias as possibly she is putting her own personal values and experiences in this interpretations, as this how she sometimes feels about caring for her parents. Being an EP and helping others is easier, emotionally,

than caring for her own parents full time, so it could function as a kind of transference and thus possibly a coping mechanism. Her empathy for her parents could be partly transferred to others.

In this study many of the YCs seemed to want to play down their caring role, expressing it as normal and just part of their lives, a finding consistent with Smyth, Blaxland & Cass (2011) and Dautre et. a., (2013). It was as though they could not or did not want to imagine their lives any other way. It may be that trying to normalize the caring role is a mechanism to avoid the stigma, the isolation and unwanted intervention which can occur as a result of being a YC. The subtle difference between the present and cited studies is that, in this present study, it was found that several participants normalized their caring role in terms of cultural (including gender), or religious expectations. This was no doubt due to the demographic make-up of the sample.

One or two YCs in this study were more open about their caring role and seemed particularly secure in themselves to highlight and be proud of their differences, and expected their friends and teachers to respect their situation and be supportive. This adaptation to the YC role might be most useful as it is focused on self-trust and agency and the author considered the possibility that other YCs could be under great pressure to fit in and be like everyone else. The author also wondered if the explicit cultural expectations of some YCs resulted in them feeling obliged to take on this responsibility, and if this is the case she wonders to what extent this is fair on them as YP. This is posed as a possible interpretation and would require further sensitive exploration.

The establishment of boundaries separating different parts of YCs' lives was a theme which emerged in this study, and that of Barry, (2011). For some it seemed to be a mechanism for coping with different competing priorities in the YCs' complex lives. For a few participants, who appeared to have the social skills and confidence, however, the merging of the different parts of their lives was possible.

The author concluded that having clear boundaries might be important to some YCs who might need to exercise containment of their experiences, so as to separate the place where they can and cannot talk about thoughts and feelings related to their caregiving. The YC group, which the participants in this study attended, seemed to go a long way to serve this purpose, but maybe within the YCs' schools more could be sensitively done, for example, in the way that Farhan had discreet acknowledgement and support from key teachers and friends. This will be considered in the section on implications for EPs.

For some of the participants in this study, making sense of their situation as a YC was facilitated through gaining knowledge. By researching their relatives' illness or disability, and practically applying what is learnt, the YCs seemed to feel more empowered, and their self-efficacy appeared to be raised. For participants, gaining knowledge alleviated the shock of discovering the illness and subsequently helped them to surmount the challenge. Some YCs also drew on things learnt at school to support their understanding of their situation. Research by Lackey & Gates, (2001) and Nichols et al., (2013) also found that acquired information about the illness or tasks was helpful to the YCs. It is noteworthy that none of the YCs said they gained knowledge from medical staff or other professionals.

Heyman and Heyman, (2013) believe that since the mid 90s the policy response to YCs has problematized the caring role as a risk factor, particularly for future personal development. Research has focused on understanding the needs of children with caring responsibilities (e.g. Aldridge, 2008), the restrictions on their childhood and developmental vulnerability (e.g. Becker et al., 1998), claiming that YCs often assume the main responsibility for care tasks and carry them out with little assistance from others (e.g. Moore 2005). This current study, and more recent research, however, identify ‘the duality of caregiving,’ (Doutre, et.al.,2013, p.36), and highlight that the YC participants have adapted to their situations albeit often without tensions. For instance, one participant describes caring as:

Um good and bad. Good because you know you’re helping people and that it builds your confidence up in looking after people and that, but no because you don’t get enough time to go out or do what ever you want and stuff. It’s really tough, (Adam, p.9).

Katrin Bjorgvinsdottir and Sigridur Halldorsdottir (2014) focused on the negative impact of being a YC, finding caring expressed as ‘social exclusion’ and as a ‘burden.’ However, this study came across some positive outcomes which were presented as lessons learnt by participants, such as important lessons learnt such as becoming strong through responsibility of caring (p.44) and learning values such as ‘not taking anything for granted,’ (p.44).

Given the findings of the current study and the existing body of literature in the area, the author believes that a balanced approach might be the solution when understanding the YC’s lives. She believes it is unhelpful to equate being a YC purely with vulnerability and disadvantage. There should be the opportunity to look at how and when individual YCs are doing well so this can be acknowledged and celebrated. It is a case of getting

the balance right for the YC as well as in the focus of research and findings. In the light of this view, relevant psychological theory will be considered.

5.3 Relevant psychological theory

In this section the author describes two psychological theories which she deems appropriate and relevant to establish and formulate the implications of the findings in a way that they can be applied to professional EP practice. The theories have been chosen because the author believes they can accommodate what has emerged from the findings as the multi-dimensional ‘balancing act’ of caregiving, and can potentially be used to structure the professional input for the YCs’ assessment process and person-centred support. They are positive psychological theories which are holistic, person-centred, and strive to empower the individual to become the ‘fully functioning person,’ which humanist psychologists such as Rogers (1961) believed all people strive to become (p.186). EPs are accustomed to taking a positive psychological, strengths-based approach in their practice, (Stobie, Boyle & Woolfson, 2005). Assessing and promoting psychological wellbeing (PWB) is also important in their work. Therefore, in the light of the findings in this study, the author concludes that it will be important for professionals such as EPs to focus on the PWB of the YCs, since this could indicate their ability to sustain their role as a YC, and influence other important personal outcomes such as educational achievement, mental health, future independence and full inclusion in society. Most importantly it could also indicate the type of support and intervention they might need.

The author believes it is useful to look at the findings of her research in the light of particular theories of wellbeing. She acknowledges that most definitions and models of

wellbeing could be applied to YCs, such as Seligman's well known 'PERMA' theory (Seligman, 2001, p. 16), which sees wellbeing as made up of five pillars: positive emotions, engagement, relationships, meaning and purpose and accomplishment. However, the author highlights that she has identified two particular theories which are more pertinent and useful because they incorporate the ideas of self-acceptance and balance, which from the findings of the study are important elements of YCs' experiences.

The first theory of PWB which the author presents as potentially useful for applying to YCs, is that of Carol Ryff (Ryff & Keyes, 1995; Ryff & Singer, 2008). Inspired and influenced by Carl Rogers, (1961), their theory of wellbeing includes the importance of: self-acceptance, purpose in life, environmental mastery, positive relationships, personal growth and autonomy as the core dimensions of psychological wellbeing. In line with this theory, the author proposes that if YCs are supported to become aware of and promote each of these dimensions in their lives, this could potentially increase their wellbeing and reduce problematic risk. This possible application of findings will be discussed in the 'Implications for EPs' section.

Another more recent model of PWB which complements the current findings about YCs is the new definition of wellbeing proposed by Dodge, Daly, Huyton and Sanders (2012), which places central importance on the 'state of equilibrium and balance that can be affected by life events or challenges,' (p.222). In this model, wellbeing acts as the central fulcrum and there is a drive towards 'homeostasis', while the individual exists in a dynamic fluctuating state of balancing physical, social and psychological challenges with physical, social and psychological resources. As the authors of the

model suggest, ‘this puts the pursuit of wellbeing in the hands of the individuals by teaching them that they can increase their resources or challenges to maintain a sense of equilibrium.’ (p.23). The model acknowledges that if resources are high and challenge is low this also negatively affects wellbeing. The author also believes that perceptions of resources and challenges are relevant to this model as well.

This is an ideal model for assessing and supporting YCs because as we have seen from the findings: YCs situations are individual and complex, involving an ever changing balancing act between hardship, benefits of caring and ways of managing the impact of these. Wellbeing exists when resources balance the need to meet particular physical, social and psychological challenges. When challenges outweigh resources, wellbeing will dip and vice versa. The EPs could facilitate YCs assessment of their resources and challenges, to establish if the resources need to be increased through intervention, or if challenges ultimately need to be reduced.

In the next section the author focuses on the implications for EP practice in the light of the findings and the above theoretical frameworks. Implications, interventions and approaches will be advocated so as to apply the theoretical focus of the findings.

5.4 Implications of the research and relevance to EP practice

5.4.1 Helping other professionals to identify and understand YCs

The Department of Health’s consultation in 2010 highlighted the need for more to be done by services to identify and support YCs (HM Government, 2010). As one participant says, maybe carers, especially the younger ones need ‘just a bit more

support,’ (Adam, p.14). But knowing how much support and which YCs need it, is difficult to assess. Health and social services, schools and youth services have a central role to play in identifying YCs. But EPs are also well placed, with their regular contact and working with individuals, families, multi-agency professionals and schools, to help identify and support YCs. EPs work holistically, systemically and with a person-centred approach. They have legislative and psychological knowledge and are experienced in skills of consultation, assessment, research and intervention. They have undergone rigorous and high level training, and have experience in promoting psychological wellbeing, inclusion and equality, which are all relevant to YCs.

The author therefore advocates that EPs can be instrumental in supporting YCs either directly and or through working with other professionals who support these YP. The author agrees with Thomas et al. (2003) that ‘it seems (that) children remain invisible to professionals whose focus is elsewhere’. She agrees with his view that ‘there should be a clear expectation on all professionals working with families where there is illness or disability, to spend time with the children and to consider their needs for support,’ (p. 45). As an example, EPs could, in the light of the findings of this study, help medical professionals understand that YCs benefit from knowledge about their relative’s symptoms, illness, needs and prognosis. The importance of these being explained to them, as well, as the patient is paramount.

Some YCs (e.g. Salma p.12) in this study admitted to keeping quiet about their hardships for fear of being taken into care. This fear is a potential reality, especially if the family member is hospitalized or dies. The Department for Children Schools and Families (2009) estimated that 5% of YCs in 2008 were admitted to state care due to

parental illness or disability, and Dearden and Becker (2004) report that being a YC is the 3rd most common reason for being taken into care in England. EPs' involvement and the use of their skills, could bridge relations with social workers to address the social care fears that YCs have expressed. EPs could draw on their solution focused and explicit person-centred approach to develop the YCs' trust in professional involvement so that those who most need it are supported appropriately without the need to hide difficulties when they arise. The approach could be similar to Signs of Safety (Turnell & Essex, 1999), which is already used in some Social Care services in some boroughs. As part of the assessment of YCs, EPs could facilitate the focus on the YCs' individual psychological risks and protective factors, by focusing on their personal resources, which balance the challenges. This would be done in a person-centred manner with the YC in the position of the expert in his/her own life.

5.4.2 Individual approach

Another implication from the findings of this study is that an individual approach needs to be taken since, as Farhan says, YCs' experiences cannot be generalized '*because each story is different, everyone's got their own experience and stuff.*' (Farhan, p.18). Individual experiences of YCs need to be understood as the findings show that they vary. As Bolas et al. (2007) points out, 'Understanding the lived experiences of YCs will facilitate the adoption of person-centred interventions and support, which should be grounded within the individuals' own framework of meaning'. (p. 846).

In this study, Adam suggested that professional support for YCs could be:

having one-to-ones, asking them about their week, ...finding out about them....such as hobbies or something like that and maybe.... getting them into it a bit more. (Adam, p. 15).

If EPs were to put the voice of the young person at heart in their work, it seems that more interaction with adults for the YCs would be supportive. Adam specifically promotes adults and professionals showing more interest in the YCs, perhaps suggesting that he thinks YCs need more care themselves and the perceived role reversal needs balancing, (p.15).

The findings of this study have shown that some YCs feel isolated because they feel different and find it hard to fit in. By explicitly applying the two psychological wellbeing theories the YCs could be helped to accept themselves, acknowledge that their situation is different from others but look for the benefits and to celebrate their difference and their achievements.

Many of the YCs refer to pursuing caring professions in the future. Perhaps this generalisation of the caring role beyond the caring responsibility as YCs offers an opportunity for the YCs to aspire to doing something that they know they can do. If this is the case, then it may be an area where these YP can be given additional support to help them build on or explore their strengths, ideas and motivations for entering helping professions.

Through sensitive consultation EPs could support YCs individually to assess and promote psychological wellbeing. There are several interventions that EPs have at their fingertips to use with YCs and some of these will now be highlighted.

5.4.3 Interventions EPs could use with YCs

There are various interventions and therapeutic approaches which EPs are trained and experienced in using. These could be used to ensure YCs' wellbeing is promoted, especially by using interventions which focus on those dimensions mentioned in section 5.3. As well as supporting YCs, the skills of EPs could also be used to identify and assess these CYPs.

Some of the intervention and therapeutic skills EPs use include: the Solution Focused (SF) approach (e.g. see Ajmal & Rees, (2001; de Shazer, Dolan, Korman, trepper & McCollum, 2007); Strengths Finding (Peterson & Seligman, 2003); Mindfulness based approaches, including acceptance and self-compassion (Williams & Penman; 2011; Davis, 2012); developing hope (Snyder, 1994), promoting optimism (Seligman, 1991), gratitude interventions (Eamons & McCullough, 2003,); Personal Construct Psychology approaches (Kelly, 1955, Ravenette, 1999); Circle Solution interventions (Roffey, 2011); and Narrative therapeutic approaches (White, 2004). Some of these will be outlined below.

Many EPs use a solution-focused approach in their consultation (Stobie, Boyle, & Woolfson, 2005). The author agrees with Doutre et al (2013) that this would be an ideal positive approach to use with YCs. This is because it could be used to boost self acceptance and environmental mastery as it incorporates: resource activation; finding and learning from exceptions; scaling; preferred future; and the miracle question. It also allows the facilitation of reframing problems, and for the YC to try out new strategies and solutions. The use of a SF approach opens up possibilities for YCs to acknowledge

their challenges, identify their strengths and resources, and ultimately see themselves in more positive ways.

The use of mindfulness based approaches (see Williams & Penman, 2011; Davis, 2012) can also help raise self-awareness, self-compassion, self-acceptance and could help the YCs to manage anxiety or stress, which some participants in this study expressed.

It was apparent in this study that some YCs did not demonstrate enough strengths awareness, especially considering that these YCs are very strong individuals, managing challenging situations. Strengths finding activities could involve activities with strengths finding cards, or online assessment such as Virtues in Action (VIA) (Peterson & Seligman, 2003), so that the YC can become aware of the strengths that they have and how they can utilize them more as a psychological resource.

The practice of gratitude may also be useful to YCs. It involves more than just saying thank-you, but is an awareness of what's good in one's life and involves drawing the attention to things that can be appreciated in the present moment, and in spite of more difficult aspects of life. Gratitude activities such as regularly focusing on blessings, could help increase hope, positive emotions and positive relationships for YCs (Eamons & McCullough, 2003).

Also from the findings of this study it was apparent that many of the participants see themselves within a story which they have not written. This could suggest that they do not feel autonomous in their lives. By using a narrative approach (see Payne, 2011) EPs could help the YC to take control of their narrative, looking at ways to reframe their

story according to different time perspectives: the past, the present and the future. There could also be the potential, if necessary, to externalize the caring role or reframe their lives by helping them to look beyond the caring role to other aspects of their lives where they do have more control.

Finally, the author also advocates using interventions related to Personal Construct Psychology (Kelly, 1955; Ravenette, 1999). For example an activity called Drawing the Ideal Self (Moran, 2001; 2014). This could be used as part of the YCs assessment and would also facilitate the YCs' awareness of their personal growth and self-identity, helping them to explore how they see themselves and how they would like to see themselves now and in the future.

5.4.4 Working with schools

The findings highlighted that the YC group, which the participants attended, seemed to go a long way to create a sense of belonging, and a place to make friends with other YCs who understood their situation. The author believes that with sensitivity and an inclusive approach, YCs' schools could also provide such support.

As mentioned above, EPs can help with raising awareness in schools about the strengths and needs of YCs. Dautre et al. (2013) called for raising the profile of YCs who have complex lives, so that sensitive individual and flexible response can be put in place. EPs, again are well placed to work with teachers to promote the sensitive acknowledgement of YCs' individual complex situations and needs.

EPs can facilitate open, yet discreet, communication and the building of good trusting relationships between YCs and their teachers in school. This study found an example, albeit an exception, of a participant who received great support from his school.

Farhan's self-acceptance and ability to build relationships with his school led to the school's sensitive acknowledgement, understanding, flexibility, kindness, positive feedback and appreciation, which seems to have helped him enormously, (Farhan, p. 13).

From the findings we can learn from Farhan's experience of school support, even though this experience of support was not expressed by other YCs. The findings highlighted that the reason Farhan managed a good relationship with his school could have been related to him being a self-confident, positive and proactively sociable YP. Other YCs may not have the confidence or social skills to form such trusting links with school. EPs could work with schools to reach out to such YCs, helping staff to think about the support they give YCs. EPs could facilitate the development of school policy for YCs which could include advocating a key teacher for each YC who checks in with the YC regularly and acknowledges on the part of the school the great work they are doing as a caregiver and how hard this must be. The key teacher could also be available to help the YC seek solutions to any issues that arise, to ensure psychological wellbeing and equal opportunities within school and education.

EPs could help schools understand the importance of this acknowledgement and positive feedback to the YC for their maturity and ability to balance their caring role with educational challenges. Also, as previously mentioned, the EP could help the YCs

within individual sessions to promote and facilitate good relationships with their school so support is there if they need it.

In the findings, support from friends was very important to the YCs. However, it required understanding on the part of the friends and not all of the YCs were successful in educating peers about what it is like to be a YC and what they needed from the friendship. Therefore, EPs could also work with other pupils within school so that together with the YC they can educate other students so they understand, support and include YCs within school. This could be done by using the Circle of Friends intervention (Newton, Taylor & Wilson, 1996). Peers could learn to understand that the YC has difficult things to manage, and the peers could be encouraged to think about what they can do to support.

The implications of the findings of this research and the author's application of two theories of PWB suggest that what needs to be promoted and assessed is a balance of risk factors (challenges) and protective factors (resources). This is in line with Dautre's (2013) research which, citing (Gladstone, Boydella & McKeever, 2006), acknowledges that 'not all carers experience negative effects associated with caregiving', that there are 'mediating factors,' (p. 32), such as the nature of the care receiver's illness, type of caring responsibilities, age, gender and social context. All these factors are important to bear in mind as implications for professionals and policy makers.

5.5 Proposal for dissemination of the findings

The author has planned to feedback her findings to the EPs with whom she works in the inner London Borough Educational Psychology Service. She also agreed to present her findings to the staff in Children's Social Care at the same inner London borough, including the staff of the YCs' Project. If permitted and considered appropriate, the author aims to return to see the YCs at a session of the Young Carers' Project, to give feedback about the findings.

Each year the University of East London hosts various conferences. The researcher is aiming to present this research study at one of these conferences in order to share findings with EPs and other professionals. For example there has already been the opportunity to feedback findings to peers in the 3rd year of the Professional Doctorate in Educational and Child Psychology, and there will be further opportunity to share findings and implications.

It is also hoped that the findings will be sufficiently enlightening to be published in a journal related to Educational Psychology so that they can contribute to the body of research in this area, enabling it to reach a wider audience and potentially the suggestions applied to EP practice.

5.6 Limitations of the Study

In this section the author acknowledges the limitations of this study, considering how some areas of the research methodology may have been improved.

5.6.1 The interviews

This study accommodated retrospective views expressed by YCs in the interviews, as well as current experiences, with YCs referring to past experiences and the future. However, a longitudinal approach to the study of YCs' experiences would have been useful to see how experience changes over time. It was interpreted that some participants in this piece of research referred to past experiences by referring to other younger YCs they know. The author proposes that yearly follow-up interviews would have been illuminating if time permitted. It is proposed that future research should focus on a longitudinal approach to gain further insight into the life and development of YCs.

There were times when the interviewer could have furthered the exploration during the interviews. For example she found Fabina's description of herself as 'annoying' (Fabina, p. 2) quite curious, because it was not clear why the participant felt this. The author wondered who it is that she thinks she annoys, and if anyone has told her this. Perhaps it is something she likes to do for amusement, to be noticed, albeit negatively. On reflection, there were few instances in which the author might have explored a little further, the puzzling, curious aspects of the expressed experience such as these.

There were one or two occasions where the interviewer dropped into therapeutic mode during the interview. Therapeutic skills can be useful in interviews in terms of being able to put the participant at ease and help them to feel good about themselves, however, positive reframing or giving encouraging feedback is not appropriate as this is making a judgment, albeit positive, and may contaminate the expression of experiences. The interviewer reflected on this and took it into consideration during her analysis.

In the study by Bolas et al. (2007), the authors incorporated a good way to generate the exploration of experiences using a camera, with the YC choosing photos to take and bring into the interview. Also the initial reflections and preliminary interpretations were shared with YCs, which meant that meaning was co-constructed. In this IPA study the data was gathered in single interviews because this was as much time that the researcher and the managers of the YCs' project felt that YCs could be expected to give of their limited free time. Whilst the interviews were in-depth, it should be recognized that these were snapshots, and the data gathered could have been influenced by the mood, feelings of the individual YCs on that particular day. Their perceptions of their YC role could have been affected by their feelings at that time. The participants could have been influenced by having to answer sensitive questions with someone face-to-face, resulting in them giving socially desirable responses, and therefore possibly creating response bias.

5.6.2 The sample

As mentioned in the methodology section the sample was to some extent a self-selected sample because only those YCs who wished to take part were included in the study. This could have caused some sampling bias because there may have been something about all the participants who put themselves forward and also managed to get consent forms back. They could have been the more confident and organised YCs.

Another aspect is that all the YCs in this study already receive some level of support, since they all belong to the YCs' project. Whilst this boosts the homogeneity of the sample, it has to be acknowledged that the research cannot explore (because it is

impossible to access) the experiences of caregiving and support of those YCs who are not known to professional services or schools. This is unfortunate, albeit understandable, because it could be that these YCs who remain hidden, experience YC in a very different way. They could be totally isolated in their private sphere, rather than receiving support. It is not easy for YP to join a group and they often need encouragement. Yet it may be those who need the YCs' group most who are not able to join and remain hidden.

In the study by Doutre et al. (2013), initial reflections and preliminary interpretations were shared with YCs, which meant that meaning was co-constructed. In this study this was not possible since access to YCs for interviews was limited, as the author and the youth workers felt that the YCs could only be expected to give up more than one hour of their free time for the research interview. Nevertheless, preliminary interpretations were discussed with the author's tutor and her peer IPA research group gave general feedback.

5.7 Future research opportunities

Due to recruitment difficulties, and the fact that YCs are hard to reach group, the research does not explore the experiences of caregiving and support of those YCs who are not known to professional services or schools. Therefore this is an important area of research for psychologists to continue to pursue, perhaps focusing research on YCs who are recently discovered. This would mean that we could explore experiences of YCs before they receive support from services; or professionals could seek out YCs more actively by increasing awareness of YCs even more, especially in schools and via other professional agencies.

In the light of the implications discussed in this study the author suggests that further research could explore more specifically how EPs might already be involved, or could become involved, with assessing and supporting YCs. This could be done through national information gathering within EP services, followed by a piloted program of EP involvement in selected services in the UK, after which effectiveness could be measured and interpreted. Ideally this would be a longitudinal mixed methods study taking account of person-centred outcomes and perceptions of EP involvement.

The author agrees with Doutre et al., (2013) that research needs to continue to explore protective factors and benefits experienced by YCs, but in the meantime EPs could draw on evidence-based practice linked to wellbeing, and become more involved in identifying, assessing and supporting YCs.

5.8 Reflections on the research journey

Throughout the research journey the author has kept a diary in which she has written reflexive commentary, which includes her response to the research process, recognition of what she has brought to the research and an explanation of how this may have influenced her interpretation. In the final part of the diary the author has reflected on what she has learnt from the research journey and the process along the way. (See Appendix B Comment 9)

5.9 Research conclusions

In conclusion, this research has achieved its aims by addressing the research questions:

- What are the current lived experiences of YCs in this multi-cultural inner London borough?

- How do they make sense of their experiences?
- What are their experiences of support?

In spite of the limitations outlined above, the findings of this study contribute in-depth interpretation and understanding of YCs' experiences of caregiving and support within a multi-cultural urban area of inner London at a time when austerity cuts within the UK are deep. Taking a positive psychology perspective, the author has then detailed the possible implications for EP practice. In particular she has considered how these skilled professionals can help services meet their obligations related to YCs, by working within multi-agency teams to identify, assess and support these potentially vulnerable but also incredibly resourceful YP.

An advantage of this study was that the researcher was herself an EP, and has extensive knowledge and experience in Educational Psychology, and in particular with a solution-focused and positive psychological perspective. This meant that she could suggest additional ways that YCs can be supported. With her role of working as an EP in a LA, she also has experience and knowledge of how multi-agencies operate and understands how EPs might be deployed to support YCs in practice, both individually and systemically.

Another strength of this study was that the sample was fairly homogenous in that all were of a similar age, all had received support from the young carers' project and all lived in the same multi-cultural urban area. It was also a suitably sized sample for this IPA study, allowing in-depth exploration which was truly bottom-up.

The findings of this study highlight the difficulties and the stresses that YCs experience: lack of freedom, accelerated childhood, difficulty fitting in with others. However, they also demonstrate that YCs can be resilient, drawing on their psychological resources and the support of others to manage the impact of caring. The important issue is that of balance, between the level of challenge and the resources the YC has to deal with those challenges. YCs can be supported in the balancing act. The challenges, or perception of challenges can be reduced and the resources (including awareness of resources) can be increased. The findings also show that some YCs experience benefits from their caregiving, experiencing personal growth in their role of YC, developing psychological strengths, such as leadership and self-confidence. Others have felt supported by others merely acknowledging and understanding what they are coping with. The author believes that with further sensitive support and intervention from EPs, these psychological aspects of the experience can be improved for all YCs.

Further research will be needed to deliver an evidence base for this proposal. The research will need to evaluate the effectiveness and impact of EP input to assessment, and intervention support for YCs. Ideally this research would be longitudinal and would include those YCs who have not received any support as well as those who are already known to professional services.

The YCs who took part in this study, and indeed all those who belong to the group which the researcher attended to recruit participants, were admirable, worthy and special individuals of commendable character. The researcher has found the research process, and working with them, a humbling experience, resulting in an increased determination to improve their support.

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Appendices

Appendix A: Notes for decisions for Exclusion/inclusion of studies from systematic literature search. Abstracts read to decide.

- 1) **Doutre G (2013)** Listening to the voices of YCs using IPA and a strengths-based perspective. **Include.**
- 2) **Bjorgvinsdottir, Katrin et al (2014)** Silent, invisible and unacknowledged: experiences of young carers of single parents diagnosed with multiple sclerosis. Scandinavian study, 11 YCs who had cared for parents with MS. At time of interviews many had already moved on from caring roles so therefore. Semi-retrospective. Phenomenology lived experience. Abstract only Findings -ve impact noted. **Include.**
- 3) **Rose and Cohen (2012)** The experiences of young carers: a meta-synthesis of qualitative findings. **Exclude** but look at original source articles too.
- 4) **Hamilton M G (2012)** circumstances, experiences, perspectives and service needs of YCs of family member with disability or long-term illness. Qual methods two cohorts. Decisions and aspirations shaped by barriers and contexts. Impacts of caring on pps education, employment, health and social life. Implications for services. **Include.**
- 5) **Helen Bolas, (2007).** The well-being of young people who care for a dependent relative: An Interpretative phenomenological analysis. Explores personal experiences of young carers in relation to their well-being using IPA. 5 YCs. Findings relate to sense of self. **Include.**
- 6) **Cassidy Tony et al (2013).** Study aimed to explore The Young Carers Perceived Stress Scale to clarify the dimension of benefit finding. Questionnaire data collection. 329 YCs, children aged 12-16. **Exclude but maybe refer to in discussion?**
- 7) **Elf, Mikael et al. 2011** the web is not enough, it's a base' – an explorative study of what needs a web-based support system for young carers must meet. **Exclude .**
- 8) **Monica Barry (2011)** I realized that I wasn't alone" the views and experiences of young carers from a social capital perspective. Scotland. Sample 20. Interviewed semi-structured about their views and experiences of social networks family and at school social care and wider community. Past achievements, experiences of friendships and support networks as well as future needs and aspirations. **Include.**
- 9) **Smyth, Ciara; Blaxland et al. (2011)** 'So that's how I found out I is a young carer and that I actually had been a carer most of my life'. Identifying and supporting hidden young carers. Australian. Focus groups and interviews with YCs circumstances and responsibilities if being YC. 68 in total. 11-25yrs. Is about identifying themselves as YCs. **Include.**
- 10) **Heyman & Heyman (2013) 'The sooner you can change their life course the better': the time-framing of risks in relationship to being a young carer. (2013).** UK study. Article compares the accounts given by young carers and specialist support workers about the riskiness of becoming a carer relatively early in life. Support workers tend to see young caring in terms of risk for future YCs themselves identify not only with the stresses but also personal gains from their experiences. Abstract only available. **Include.**
- 11) **Grant Charles (2011)** Bringing Young Carers Out of the Shadows. **Exclude** – not research but more of a discussion article. Australia. Telephone interviews and a group interview with YCs across Australia. Interview schedule asked YCs about their circumstances, their experiences of school, the level of support that were provided to them in school and their views of possible strategies that schools could implement. Qual data analysed quantitatively. Specific about views about school. **Include.**
- 12) **Change and Adaptation in Families with Young Carers. 2010.** **Exclude** as about family perspectives not individual YCs experiences.
- 13) **Burns Catherine, et al. (2010)** Young Carers in the End of Life Setting: A Population –based Profile of an Emerging Group. **Excluded** as it is a population-based analysis not about individual experiences.

14) Skovdal Mortenm (2010) Children caring for caregivers: exploring the caring arrangements in households affected by AIDS in Western Kenya. **Excluded** due to sample caring in an area of high level poverty – orphans who have been fostered in Western Kenya.

15) Gray, Ben, (2008) Invisible Children: young Carers of Parents with Mental health Problems- the Perspectives of professionals. **Excluded** as study about professionals' views not those of Young carers.

16) Lackey, N, et al. (1997) Combining the analyses of three quantitative data sets in studying young caregivers. **Excluded** as the process used in designing and conducting the study and analyzing the data rather than the findings are emphasized.

17) Andreouli, Eleni et al. (2013) A study which explores Young carers representations of their global peers. Reflections of British YCs after having visited an exhibition displaying photos and stories articulating the caregiving experiences of young carers in Zimbabwe and Kenya thematic network analysis of the data. Abstract only. **Excluded.** Might include in discussion if can find whole text.

18) Skovdal, Morten et al (2013) Supporting 'young carers' in Kenya: from policy paralysis to action. Abstract only. **Exclude.** Not relevant.

19) Lackey Nancy (2001) Adults' recollections of their experiences as young caregivers of family members with chronic physical illness. US. **Include** as aim of study to explore the meaning and effects of the caregiving experience on those individuals and examine positive and negative effects of caregiving then and now. Descriptive stats and semi structured interview analysed using content analysis.

20) Elf Mikael et al. (2012) Young Carers as co-designers of a web-based support system – the views of two publics. Participatory design. **Exclude.** YCs views of design of a web-based system directed to them and differences between their views and the views of the project representative.

21) Shifren, Kim et al. (2003) USA Does early caregiving matter? The effects on Young caregivers' adult mental health. Mixed methods study. Long term effects of providing care. 24 pps 21-58yr olds. Semistructured interview about experiences. Questionnaires exp/ mental health and early child relations. Finding most reported more positive than negative mental health. But 42% high depressive scores on CES-D. **Include.**

22) Nichols K, (2013) When dementia is in the house: needs assessment survey for young caregivers. Canada. Needs and experiences for YCs of patients. Focus groups. 14 young carers 11-18. Semi structured interview. Transcripts narrowed to a data set for descriptive analysis using a coding scheme to reveal the main themes of their responses. 7 overlapping theme areas were identified. Website was launched on the basis of these responses. **Include.**

23) Thomas, N, Stainton, T., et al. (2003) 'Your friends don't understand': Invisibility and unmet need in the lives of 'Young Carers'. Swansea. Study of experiences of YCs. **Include.**

24) Richardson, K et al. (2009) Qualitative evaluation of a young carers' initiative. Focus group. 24 YCs between ages 11-16. Thematic content analysis. Abstract only. **Exclude** but maybe refer to in discussion if full text found.

25) Roche Jeremy et al. (2003) Extending the social exclusion debate: An exploration of the family lives of young carers and young people with ME. Abstract only. **Exclude** as it appears to be a study comparing day-to-day activities of YCs and YPs with ME (myalgic encephalomyelitis).

Total 12 included.

Appendix B: Reflexive Comments – extracts from reflexive research diary

Reflexive comment 1 Reflexivity journal prior to and during decisions about research questions.

When I devised these research questions I did find myself wondering how CYPs *really* feel about caring, how much support they feel that they get, or feel they need, and what works best for them. I wanted my research to dig deep. Part of me felt a concern that they are not really given a choice and it may be that society burdens them at a time in their lives when they should be having a childhood and at a time when they have not had the chance to learn coping skills or resilience. So I wanted to delve as deeply as possible. Nevertheless, I needed to be aware of this concern and to step away from it so that it did not influence my research data collection or analysis and interpretation. However, I was aware that the YCs may not want to betray their loved ones and reveal their true feelings about caring; or they may have already reframed their experiences as a mechanism for coping. I know I have been aware of the guilt I feel in relation to my own experience of caring for my parents; you never feel you do enough, and when I am doing something nice or fun I often think I should be with my parents, taking care of them. Also the sadness and the helplessness I feel when caring for my parents; it is like a slow bereavement to see my Dad deteriorate with Alzheimers and my Mum struggling to look after him, I feel guilty doing things for myself – such as this doctorate course!

These CYPs have all this as well, I am sure? But this is a presumption and I need to set it aside. Each individual will be different and have different strengths and sensitivities. But I do reflect on the fact that I am an adult and my childhood was not being affected/taken from me, and I am not having to worry too much about the future. These children need some freedom from extra anxiety and burden. I am grateful that my childhood was stress free and fun, and I was well cared for and I did not have the responsibility of caring for anyone else then. Now it feels acceptable that I have caring responsibilities for others as I am giving back to my parents what they did for me all through my life and I am giving back to others what they gave to me.

So I need to acknowledge that I have these concerns and that I may be looking for certain parallels in the CYP's experience. I need to let these concerns go and be open to what I find. My practice of mindfulness has helped me in the reflexive process. It does mean, however, that I need the participants to feel that they trust me enough so they can say what they really feel. This is why I will go every week to take part in the YC group sessions. Nevertheless I need to acknowledge that the CYPs are still going to find it difficult to say what they really feel and I have to be aware of this. I also have to notice what they are not saying and how they are expressing their views (such as tone of voice, non-verbal communication, fluency or hesitancy, affect, and making sense of their experience, when it comes to the interviews.

Reflexive comment 2 at time of gathering data:

'Interviews augment experience, rather than simply reflecting it,' (They alter meaning, instead of delineating it. They change people,' (Beer, 1997, p.127) Thinking about this I wonder, did I get the participants to reflect on something they had not previously reflected upon? Such as the effect of being a YC or how they see themselves.][When I designed the questions I started as open as possible not asking

them about themselves as YC but just as themselves – I thought it was important not to impose an identity – wanted to know about them separate from their caring responsibilities. In spite of this, some participants described themselves as YCs or having qualities related to young caring. I had to be very careful not to show any judgement – even positive feedback, but this was not easy.

Reflexive comment 2

I noticed that Salma (p.11) recognizes that children can learn from the caring role, but she thinks it is before their time. It is perhaps easier for her to talk in the context of others who are younger carers now because this externalizes the experience and distances herself from controversy and the possibility of betraying her family and cultural ideals. Is this a kind of projection or transference on her part? A way of telling me her views indirectly? Why is she doing this?

Reflexive comment 3

From support of others I can relate to the significance of this – in my university the tutors are very supportive and understanding- if I've been a little late to lectures sometimes, the course director knows that on these days I was wanting to take my children to school at the price of being 20 mins late to lecture (wasn't able to take them to school at all when on placement). I was trusted to make the right judgment, and I appreciated this. However, there were some other students who didn't understand and made insensitive comments/jokes..., if I couldn't go out with them after lectures or if I was occasionally late. Sometimes this made me feel stressed/upset. But I learnt to forgive them and put it down to their lack of understanding, and I suppose their insensitivity to people who are not in the same position as them. To balance this there were several students on the Professional Doctorate who were very supportive (some in a similar situation of caring for elderly parents and or children who were sick). We supported each other through difficult times and knew when it was appropriate to make jokes. Like Farhan, I know who my friends are and I focus on them. People making comments or joking about people being different is a form of bullying and perhaps this is a potential area of support for YCs who feel different because their circumstances are different. I think being a YC is an important aspect of diversity.

Reflexive comments 4 Reflections on Feedback from IPA colleagues

I decided to take my initial ideas about themes to my IPA research group so as to use the IPA researchers' feedback to interrogate my themes and coding. This cross checking involved:

First of all I briefly introduced my research to the group of 20 PhD and Professional Doctorate students from several courses around the UK, all were at different stages of their own IPA studies and were from different disciplines such as Counseling psychology and health psychology. I then handed out the 8 anonymised participant interview transcripts, with 2 readers per case. They were asked them to skim through the transcript and codings/emerging themes in pairs for about 15 minutes. They were then asked to give feedback of their initial impressions of the codings and emergent themes/interpretations to the group: to see if there was anything they particularly agreed with, disagreed with, or felt had been missed out.

The group gave positive feedback and told me that my interpretations were good and appropriate. Some said that I needed to do more interpretation. I followed their

collective advice and became a bit braver and more open to possible interpretations. I thought back to the interviews, remembering how the words were spoken – sometimes I listened again and this helped with a deeper interpretation. I used the practice of mindfulness to enhance my awareness of what I bring with me to the interpretation – not judging myself or fighting with the interpretation but allowing myself to be open to other possibilities - being curious about other possibilities and letting go of those which I decided were not true to the transcription or the recording.

Reflective comment 5 – Author’s reflections on adult/child role reversal.

Here I am trying to interpret what the YCs are communicating, but I have to acknowledge that this could be according to the role I assume for a child, from my experience, in my culture, and in my situation. My husband and I do everything for our children and they do very little for us at home, but then we are not ill.

Reflexive comment 6

I have been thinking to what extent the YCs perception of their experiences are constant? I reflect on my own experience of different difficult circumstances. I had a difficult situation several years ago and the narrative that I assign to this changes at different times. Some days I feel that what happened was intolerable and I need to do something about it, other times I believe that I have reframed it well and am coping fine. I recognise that the narratives of experiences created by the participants about their experiences could change, because the complexity is shifting all the time. Therefore I think that longitudinal research is needed, perhaps including some daily journal writing for YCs.

Reflexive comment 7

Today at YCs project a new girl attended but she was reluctant to join in, even though other YCs and youth workers tried to involve her. She was extremely negative and my professional view was that she could possibly be suffering from depression. She did not return to the session in the time that I was there, yet she appeared to be in great need of support. How do we reach those YCs who may be suffering in silence and who may be the ones who most need the support?

Reflective comment 8 – Generalising skills

Perhaps here, my interpretations are influenced by my own experience of generalizing my caring role beyond caring for my elderly parents. I have often wondered why I spend so much time helping others outside of my family in my role as an EP. When I do care for my parents and spend time with them it is very painful, sometimes almost too painful, and certainly too painful for me to decide to help my Mum and Dad full-time. I feel too emotionally close, caring for them all the time would be all-engulfing emotionally, as well as physically. Perhaps helping others legitimizes a distance or time away from the caring role, giving emotional respite since caring for others is easy in comparison. Caring for others beyond the family gives some distance from the emotionally difficult caring role but allows the carer to take the identity of carer with them. Perhaps I am transferring my desire to care for my parents onto others because it is less emotionally difficult. Whilst I think this is what I believe that I do, I need to take care not to assume that this is what the carers are experiencing.

I also reflected on my thoughts about the Young Carer's not receiving any gratitude. Through reflection I became aware that my interpretation of the YCs not getting the 'gratitude they deserved' was related to my own cultural expectations. I am aware that I believe that those who care for others should get the recognition and thanks. However, I am aware that this was not the perspective that the YCs generally took because they their personal and cultural expectation tended to be that caring is just what you do.

Reflexive comment 9 - What I have learnt from the research journey

I have learnt that the journey is long but varied. It offers various challenges that require, not only problem solving but also resilience to keep going to the end.

I felt personally challenged but I have learnt a great deal about my capabilities from the research process. I have learnt to use my knowledge of psychology not only in terms of devising and carrying out the research but also to help me remain resilient, self-efficacious, self-determined to get through the process. I have focused on my strengths, such as my love of learning, organisational skills, grit, and perseverance. I thought back to previous times when I have been successful in completing research and this helped me believe that it was possible.

Along the way I made an effort to pace myself and to have some balance between trainee placement, university assignments, thesis, and time for my family and parents. I have learnt that is important to be boundaried so that I can focus on one thing at a time. At the beginning of my second year placement it was hard to stop placement work spilling over into my research and assignment time. I had to become very boundaried.

I have also learnt about the process of IPA in practice. For a while I have known about the theory but putting it in practice is not easy. The most challenging and delicate was the interpretation and development of themes. I used mindfulness to help me to be aware of my thoughts, beliefs and values that would have been impacting my interpretation. Mindfulness helps ne to become aware of your thoughts, non-judgmentally. This helped me to bracket my beliefs so that I could zoom into what the YCs were communicating.

The YCs were amazing and I learnt a lot about the complexity of their lives. They showed themselves to be resilient and had a great sense of fun and community when they were at the YCs' group sessions.

Appendix C: Audit Trail Log

Log of dates researcher attended Young Carers' Project Sessions

01/07/14
15/07/14
22/07/14
09/09/14
16/09/14
23/09/14
30/09/14
07/10/14
18/11/14

Log of dates when consent forms returned:

08/07/15 x3 forms
15/07/15 x2 forms
09/09/15 x1 form
07/10/15 x1 form
14/10/15 x1 form

Log of Data collection – dates of interviews at YCs' project

22/07/14 x 1 YC
16/09/14 x 1YC
30/09/14 x 1YC
07/10/14 x 3 YCs
18/11/14 x 2 YCs

Log of Data analysis

18/11/14 – 12/12/14 Transcription of interviews
13/12/14 Started transcription read through and check
29/12/14 Started data analysis coding and themes case by case – see reflections
(8/10/dec)
11/01/15 Finished cross case data analysis – Superordinate and subthemes

Log of Thesis Write-up

31/10/14 Systematic Literature Search
11/01/15 Started Methodology Chapter write-up
14/01/15 Attended IPA group. Feedback about initial coding and emergent themes.
01/02/15 Finished writing Methodology chapter.
04/06/15 Started writing up Findings chapter
19/06/15 Finish Findings chapter write-up
25/07/15 Start Literature Review chapter write-up
13/08/15 Finish Literature Review chapter write-up
23/08/15 Start Discussion write-up
03/09/15 Finish Discussion Chapter

Appendix D: Timeline for the stages of research process

What was achieved:	Dates
Initial contact is made with lead professionals in inner London borough permission, advice about feasibility and method of accessing hard to reach participants in the LA was given.	October 2013.
Research proposal was submitted as an assignment for Prof DECP. Research Proposal was submitted for ethical approval.	December and January 2014.
Initial contact made with professionals, such as those working in the 'Young Carers' Project in inner London borough	20/05/14.
Systematic literature search – read abstracts and methodology – not findings.	October 2014 while awaiting ethical approval.
Ethical Approval from University of East London.	28/03/14
Inner London borough Research Access Approval.	03/06/14
Attended YCs' group to build rapport and introduce study and invite potential participants to take part.	01/07/14
Consent given out and some received back. Recruited 8 participants	08/07/15- 14/10/15
Collection of data: and obtained informed consent from themselves and parents. Carried out interview of up to one hour for each participant.	01/07/14 – 30/09/14
Transcription of interviews	Between 01/10/14 and 13/12/14
Analysis of each transcript in turn	29/12/14 – 11/01/15
Identification of themes across cases	12/01/15 - 2014
Attend IPA peer group for initial emergent themes feedback	14/01/15
Write-up of research	11/01/15 – 15/08/15
Submission of research thesis	15/08/15

Appendix E: Information and consent forms given to parents



School of Psychology
Stratford Campus
Water Lane
London E15 4LZ

08/07/2014

Dear Parent of Guardian,

My name is Karen Mary Wadey. I am a student at the University of East London, studying for the Professional Doctorate in Educational Child Psychology. I want to tell you about my research because I would like to know if you would give permission for your son/daughter to take part.

I am interested in exploring Young Carers' experience of caring in London Borough of XXX. Your son/daughter will be asked to take part in an informal interview lasting about an hour in which he/she will be asked to talk about their experiences as a young carer. The interviews will either take place in a Young Carers' Project location or your child's school.

The interviews will be recorded and typed up so that I can analyse them later. All names and identifying information will be changed to protect the young person's anonymity and confidentiality. Confidentiality will be guaranteed unless the participant tells me something that I feel needs to be shared as a means of protection for the young person.

If you don't want to give permission for your son/daughter to take part in this study, you don't have to. Even if he/she does get involved he/she will be free to withdraw at any time without having to say why. All I ask is that I can use their anonymised data in the write-up of the study and any further analysis that may be conducted by me.

Please feel free to ask me any questions. If you are happy for your son/daughter to continue you will be asked to sign a consent form before we start. Please keep this invitation letter for reference.

If you have any questions or concerns about how the study has been conducted, please contact the student's supervisor Dr Helena Bunn, School of Psychology, University of East London, Water Lane, London E15 4LZ. Telephone. Email address]

Or

Chair of the School of Psychology Research Ethics Sub-committee: Dr. Mark Finn, School of Psychology, University of East London, Water Lane, London E15 4LZ.
(Tel: 020 8223 4493. Email: m.finn@uel.ac.uk)

Thank you in anticipation.

Yours sincerely,
Karen Mary Wadey

Educational Psychologist in Training
Karen.Wadey@London Borough of XXX.gov.uk
Tel: 07736546855

Parental Consent Form



School of
Psychology
Stratford Campus
Water Lane
London E15 4LZ

Title: Young Carers caring in xxxxxxxxxxxx. An Interpretative Phenomenological
Analysis of their Experiences

I have 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 son/daughter will be involved have been explained to me.

I understand that his/her 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 son/daughterto participate in the study which has been fully explained to me. Having given this consent I understand that he/she will have the right to withdraw from the study at any time without disadvantage to myself and without being obliged to give any reason. I also understand that should he/she withdraw, the researcher reserves the right to use the anonymous data in the write-up of the study and in any further analysis that may be conducted by the researcher].

Parent's Name (BLOCK CAPITALS)

.....

Parent's Signature

Date

.....

Researcher's Name (BLOCK CAPITALS)

.....

Researcher's Signature

Date

.....

Appendix F: Information and consent forms given to YCs



School of Psychology
Stratford Campus
Water Lane
London E15 4LZ

08/07/2014

Hello Young Carer,

My name is Karen Wadey. I am a student at the University of East London, studying for the Professional Doctorate in Educational Child Psychology. I want to tell you about my research because I would like to know if you would like to take part.

I am interested in exploring Young Carers' experience of caring in the London Borough of XXX. It will involve me interviewing some Young Carers individually for about one hour. The interviews will either take place in a Young Carers' Project location or the participant's school.

The interviews will be recorded and typed up so that I can analyse them later. All names and identifying information will be changed to protect the participant's anonymity and confidentiality. Confidentiality will be guaranteed unless the participant tells me something that I feel needs to be shared as a means of protection for the young person.

You don't have to take part in this study if you don't want to. Even if you do get involved you are free to withdraw at any time without having to say why. All I ask is that I can use your anonymised data in the write-up of the study and any further analysis that may be conducted by me.

Please feel free to ask me any questions. If you are happy to continue you will be asked to sign a consent form before we start. Please keep this invitation letter for reference.

If you have any questions or concerns about how the study has been conducted, please contact the student's supervisor Dr Helena Bunn, School of Psychology, University of East London, Water Lane, London E15 4LZ. Telephone. Email address]

or

Chair of the School of Psychology Research Ethics Sub-committee: Dr. Mark Finn, School of Psychology, University of East London, Water Lane, London E15 4LZ.

(Tel: 020 8223 4493. Email: m.finn@uel.ac.uk)

Thank you in anticipation.

Yours sincerely,
Karen Mary Wadey

Educational Psychologist in Training
Karen.Wadey@London Borough of XXX.gov.uk
Tel: 07736546855

Consent to Participate in a Research Study



Title: Young Carers caring in London Borough of XXX. An Interpretative Phenomenological Analysis of their Experiences

I have 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 I will be involved have been explained to me.

I understand that my involvement in this study, and particular data from this research, will remain strictly confidential. Only the researcher 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 participate in the study which has been fully explained to me. Having given this consent I understand that I have the right to withdraw 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, the researcher reserves the right to use my anonymous data in the write-up of the study and in any further analysis that may be conducted by the researcher.

Participant's Name (BLOCK CAPITALS)

.....

Participant's Signature

Date

.....

Researcher's Name (BLOCK CAPITALS)

.....

Researcher's Signature

Date

Appendix G: Schedule of Interview Questions for Semi-Structured Interview.

The following questions are not fixed. They should be used to engage the young person in talking about their experience of being a YC. Prior to these questions the young person will be put at ease and some rapport will be built between the researcher and the young person.

Before starting I will say:

I would like to hear about your experience of being a carer. I will ask you some questions to get you going but please feel free to pass on any you don't want to answer. If you want to go back to any questions feel free to do so. You can add what ever you think is important. The interview will be recorded so that I can transcribe it but at that point I will change any identifying information and it will be anonymous. Is this OK and do you want to continue?

*Tell me about yourself

Prompt: I know very little about you so what would you think are important things about you? Age, favorite hobbies, what you like to do, what is important to you?

*How would you describe yourself as a person?

Prompt what sort of person are you? Most important characteristics? Happy, moody, ambitious, worried, lazy, hardworking....

* What do you think affects how you see yourself?

*Have you always seen yourself like this?

*Tell me what it is like being a carer.

Possible prompts: who do you care for, why does he/she need you to care for them? What are the symptoms? How exactly do you help at home?

*Does being a carer affect you in any ways?

Prompt: at school, friends, interests

*How do you feel about being a carer?

*What does being a carer mean to you?

Prompt: think about particular words or ideas or images that you link with being a carer. What is good about being a carer? What is not so good?

*Has X needing your care and you being a carer made a difference to how you see yourself?

*What sorts of things help you cope with being a carer?

Prompts: Others? Things that you do? Things you say to yourself to help you. Things about you such as strengths that help you?

*Is there anything which someone could do to help you?

*Do you think about the future? How do you see yourself in 5 years time?

*Is there anything else that you would like to say which I have missed?

Appendix H: Example of transcript

- I Hello,xxxxxx. I'd like to hear about your experience of being a young carer. I will ask you some questions to get you going but please feel free to pass on any you don't want to answer, okay. (INTERRUPTION FROM OUTSIDE ROOM). You're free to pass on any you don't want to answer, if you want to go back to any questions feel free to do so and you can add whatever you think is important. The interview will be recorded so that I can transcribe it but at that point I will change any identifying information and it will be anonymous. Ok, uhm. So tell me about yourself.
- R Uhm, Well my name is xxxxxx, I am a college student studying Health and Social Care in XXXX Sixth Form and uhm, I am a very lively outgoing individual who likes to help uhm, people, when it comes to my personalities which are helping, understanding, loving, caring and other sorts of uhm, personalities that there is.
- I Okay, thank you. And what are your favourite hobbies and what do you like to do?
- R uhm, Well I like, as my hobbies I used to like doing sports and I still enjoy sports with uhm my local youth club that I go to which is in XXXX, and every time when we play sports it reminds me of my childhood because ii's like my childhood I used to be a very active and optimistic uhm individual who used to love uhmm, doing sports, activities and whatever came in my way and I take the challenge to show that I'm a very worthy individual, not like, like, not like someone who would just stay around at home.
- I That's good. And uhm so what do you like doing now in your spare time if you have any?
- R During my spare time if I'm not busy with my studies or uhm, anything at home then I would like going shopping and uhm going out or socialising with friends or maybe go spending time on my own sometimes, just to have a bit of fresh like time out, with myself.

I OK, And uhm, and how do you feel about being a young carer, and what does it involve for you being a young carer?

R uhm Being a young carer for me is about uhm helping parents and it's about becoming who you are later in the future. For example, when we are children it's like we learn from our parents as our parents teach us a lot of things that go around in life and I would say that our primary socialisation is our parents and they teach us basics and what goes around traditionally, and well our second socialisation is our school, college, outside people and organisations that are working with us. So I think being a young carer is showing us of who we are meant to be and how we are meant to look after our parents as in the future it would help us when we're older, it would help us to understand how we are meant to be.

I Okay, good. And what is not so good about being a young carer?

(Noise and interruption from outside – someone comes in (pause))

I I'm sorry about that

R For me, for me, there is nothing bad going on because it's like I'm ready to, for my future, basically I'm ready, coz in the future I want to get married and it's coming to an age where I'm going to be leaving my parents behind (said v quietly), but for children who are under 18 I think and who have studying issues, for them I think it's going to be really hard because I don't think they can handle education and uhm chores and family within themselves. So I think for them they should give it their best shot, like education like how I did when I was younger.

(Interruption: Youth worker comes into the room)

I So if you focus on how being a young carer has influenced you in your life, and yeah, how has it influenced you in your life?

R Being a young carer has influenced me in many different ways as in like traditionally it's we like in my culture and my religion is that we look after our parents no matter what stress they are going through, no matter what pain.

(Interruption again)

I ((Knock at door)) Sorry for the interruption, do you want to repeat that?

R Yeah. Being a carer has influenced me in many different ways, including through my cultural and religious beliefs that we, I believe culturally that we are meant to look after our elders, including our parents because it's like we show respect to them and like we're not meant to put them down. And it's like we're not meant to hurt them in any way and we're meant to make them happy and feel that we still value their experience because our parents have taught us a lot through our younger age until as soon as we leave home.

I So how do you care for your parents? In what ways?

R Uhm, Well I go to college and it's like during the morning when I'm off at college weekdays I'm unable to help my parents, so my mum does like chores and whatever she needs to do around the house but as soon as I go back home that's when I take on the duty of both my parents, my mum and my dad. It's like my dad is not really physically unhealthy, but he's got a heart condition and for my mum she's got high blood pressure. What happens is that uhm, when I go home if my father asks me to do something I will do it, as for my mum it's basically house chores which enables us females to build up for the future procedure of the future generation.

So I'm really happy that to help my parents out, even though they're struggling more than us, than the younger generation, because it's like uhm throughout their whole entire life since we were born, they, especially my mother has taken over a lot more pain and she went through a lot, so we have to give more back to our mother than our father. But for me, even though it says to give more back to your mother it's like I was giving back more but it's like I would equalise it so it's both for my mum *and* dad.

I And how do you like coming to the young carer's group? How has that been important to you? You've been coming to this group for a while.

R To me the young carer's group has been very exciting because I've been working here as a volunteer and recently I've become working as a volunteer youth support worker and I really enjoy it because I meet new people and new other carers and we talk about how they are coping and the ways that we can help each other out in situations like this. And it's like we share our opinions in ways to find positive and negative ways in helping our parents, so it's a lot, so I really enjoy it.

I And is there anything which you feel you could get help with? Anything that you as a young carer could get more help with?

R For me personally I think for my belief that it's my I don't really need help because I'm at an age where soon I'm going to get married, so it's like for me I'm okay, but I think for the other younger carers, younger than 18, I think they would need help because it's about their education, it's about them having their, taking the time out from the family because looking after a family 24 hours it's going to be a lot harder for them than for me. Because it's like education is important, they have their own little, how can I say, they have to have their own little freedom because it's not all about work throughout the day, coz it's like, especially if it's to manage household chores and education, because if you're handling both at the same time then it's going to get depressed, lead to depression and stress and then it's going to become harder, especially when you're trying to complete your work at school.

So I think they need the younger carers might need professional support such as, uhm, how can I say, like a carer, like you can help the parents instead as children. I know culturally the children are meant to as it can lead to the future but it's like not their time yet and at a certain age, because I started caring for my parents when I was about 12 after I went to secondary school but I used to do like little chores, not too much, but then after I became more mature at the age of 12 I tried to do the other things, researching everything, finding out about people's health and so on. Then it came to me that, oh my word, these people need help, so that's why after doing research I became so happy and then it was like I put my mind straight on my family and then education.

- I So can you think of any other ways that being a young carer (knocking) has affected you now or in the past?
- R In the past it affected me negatively because I couldn't concentrate on my studies and at that time it was teachers were like is something over that home, is something okay, because I used to look a bit depressed but I just used to say everything's fine but it's because I wouldn't say it to the teachers otherwise they're going to put Social Services in, or somet, but I was fine. And now in the future, in the present now it has affected me positively because no one's going to hassle you and it's like you have your own future that you'd like to do and what there is to do. Instead of getting Sometimes you may ask for professional help as in like counselling, how it can help your parents, like I'm looking after my parents and how can I help in a way that it won't interfere with my education, they would give me advice. But they won't put Social Services in because it's like I'm 18 now so I'm okay, but before it was a bit worrying.
- I Yes, so you've just turned 18 haven't you?
- R Yes, a month ago.
- I And what do you think about the future? How do you see yourself in the future?
- R Uhm, My future, I think it's going to be brighter than how it used to be in the past because I'm going to be studying in university hopefully or maybe doing an apprenticeship in the NHS because the main thing is that I wouldn't want to leave my parents, even if they're healthy I wouldn't want to leave my parents, so I thought of going to do an NHS course, an apprenticeship in the NHS, so it depends what it is. And it's like trying to learn from what I've learnt from Health and Social Care from that, advancing my knowledge to the extent that I know exactly how to handle people, even though it's not going to be a family member, it might be someone else like my grandparents or an elderly person in the street, is that I have to know how to I'm Uhm able to help them with their holistic needs.

I Okay, so is there anything else that I've missed that you'd like to say?

R No.

I Okay, well thank you very much.

Appendix I: Example of Initial Exploratory Comments, Codings and Emergent Themes with original transcript

Initial Exploratory Comments and Emergent Themes: For Anthony participant 1. M, 16yrs, Caring for mother with mental health issues		
Emergent Themes – 30/12/14 and 31/12/14	Original Transcript Underlined: key quotes	Initial Exploratory Comments/coding – 29/12/14 and 31/12/14
<p>Ethnicity important to him – being Chinese is important characteristic.</p>	<p>I Interviewer R Respondent</p> <p>I So, Anthony, you're 16 years old and you've been caring for three to four years?</p> <p>R Yes.</p> <p>I And I just want to ask you to tell me about yourself, kind of anything really. I know absolutely nothing about you so anything you think is important about you, so favourite hobbies, what you like, what is important to you in your life, just anything about yourself.</p> <p>R Well, first of all obviously <u>my name</u> is Anthony ah, a, and <u>shall I say my ethnicity?</u></p>	<p>Key for comments: Normal text is descriptive <u>Underlined comments are more interpretative</u> <i>Italics – comments related to language spoken</i> <i>[Reflexive and reflective comments]</i></p> <p>He states his name & Ethnicity as important characteristic – <u>This is mentioned with his name equally important to participant.</u> <i>But felt the need to ask permission for this though. Unsure if it is relevant to researcher- hesitant</i> It is like he is filling in a form – beaurocracy.</p>

<p>Caring about mother is important to him</p> <p>'of course' inevitability?</p> <p>Difficult physical/emotional impact of being a YCarer</p>	<p>I Yes.</p> <p>R Oh, <u>I'm Chinese</u>, and er, (pause) <u>of course I've been caring for my mother</u> for three to four years (pause) uhm, (pause) and one of my hobbies <u>is of course table tennis, typical</u>, and er, I guess my favourite subject is maths, yes uhm. <u>Going into the experience of being a young carer</u>, is, it's, it's <u>sometimes very difficult</u> (pause) and it <u>can drain you a lot</u>, it will, <u>it will, exhaust you</u>, and it's, <u>it's just hard</u>, yes.</p> <p>I Yes. I was going to come onto a little bit more about the caring, just first of all just a little bit about you, how you'd describe yourself as a person, but we'll definitely come on to the bit about your caring. So how would you describe yourself and what sort of person are you? Important characteristics about</p>	<p><i>'Of course I've been caring for my mother...' <u>sees this as another obvious characteristic – inevitable? Goes without saying?</u></i></p> <p><i>Describes hobbies: sees table tennis as 'typical' of <u>his ethnicity? Or is it because he knows I have seen him play table tennis at the YC group. Fitting into cultural stereotype?</u></i></p> <p><i>Wants to go straight to experience about caring role – even though I haven't asked directly about it at this point. <u>He sees it as an important characteristic of himself – brings it up in answer to my question about characteristics.</u> It's part of him.</i></p> <p><i>Talks about experience of being a young carer as 'sometimes very difficult.' Language refers to physical and emotional too? Trying to hide this? impact on him: 'it can drain you a lot, it will, it will, exhaust you, and it's, it's just hard, yes.' Describing the hardship he has to endure.</i></p> <p><i>Physical and psychological. 'just' belittling it? 'yes,' self affirming</i></p>
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<p>Positive honest about his identity - 'nice' 'kind' person.</p> <p>Separate environments – 'at home and outside the home environment'</p> <p>Positive about identity – takes initiative so as to help others.</p> <p>Leadership – aware of strengths</p> <p>Positive self-portrait when outside the house- caring for others – others are important to him.</p>	<p>you?</p> <p>R So, er, So I would say, if I was to be honest ((smilingly)) I would say I'm one of the nicest people. (Laughs) I er, I er. Maybe <u>at home</u> I'm not that nice to my parents but <u>outside, outside of the home environment</u> I, I, tend to be more er more kind I guess. And er, I am a person that <u>takes the initiative</u>, I er, if there, if there is, yu know, for example if there is no one that is going to take part in a, in a event <u>I'll try to step in first and hopefully that will motivate the other people; that will, that will erhm that, that will kind of influence them, yeah, a little bit to join in, yeah.</u></p> <p>I And we might come back to explore that a little bit more. So you said you care for your, did you say your brother?</p> <p>R My mother.</p>	<p>'smilingly' starting to become more relaxed Honestly sees himself as a 'nice' 'kind' person. Refers to his mother as 'my parents' <u>Separates 'home' and 'outside of the home environment'</u> Sees himself as different in different environments – kinder outside of the home. He likes 'to take the initiative,' to lead, likes to motivate others – <u>in the subtext is this because he gets a response from others? 'hopefully that will motivate the other people.'</u> Likes to make an impact on others to '<i>influence them</i>'. But this is outside of the home and contrasts with his comment – at home '<i>I am not that nice to my parents.</i>' <u>Why does he feel this?</u> If no one is going to take part he'll try 'to step in first' Importance of people joining in – <u>so they are not left out? Isolated? Transference ?? of what he experienced?</u></p> <p><u>Prepared to take the lead – taking charge- being influential. Aware of strengths</u></p> <p><u>'step in' puts himself forward – outside the house uses caring skills outside the home too.</u></p>
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<p>Generalising the experience – creates a comfortable distance?</p> <p>Chores</p> <p>Hard work – ‘a lot’ to do</p> <p>Habitual work</p>	<p>I Your mother, sorry. Could you tell me a little bit about your caring role, so who you care for, what it involves and why you care for them?</p> <p>R uhm, So <u>I care for my mother</u>, and a the sort of things you do is er usually interpreting, interpreting er when <u>they</u>, when they don't know, er, English and also sometimes <u>I help them with a shopping, groceries</u>, and er I think that's, that's about it. And also, and also I <u>clean the house, do chores in the house</u>. <u>That's a lot</u>.</p> <p>I How often do you have to do that?</p> <p>R Because my mother already has like a social worker and an interpreter so I kind of rarely interpret it for her but shopping-wise it's I guess like <u>twice a month</u>. <u>And chores is mostly every week</u>. <u>Yeah</u>.</p> <p>I And why does your mum need you to</p>	<p>Starts off in first person and refers to his mother – <i>matter of fact</i> <i>Then after doesn't talk using personal terms – not in first person, and 3rd person is plural – not directly referring to himself or his mother – generalizing/distancing his experience 'you' not 'I' and 'they' 'them' not 'my mother.'</i> <u>Why does he do tis? To distance himself emotionally? Or to make it less about his situation so that he is not revealing information he considers private – to protect his mother's privacy? Showing respect for his mother?</u></p> <p>Describes the chores in the home. Sees it as 'a lot.' No mention of emotional support.</p> <p><u>Does not seem to get emotional support?</u> <u>Does more than would be expected of someone of his age.</u></p> <p>Describes the frequency of the practical support he gives.</p> <p>It is habitual, part of his life. 'I kind of rarely interpret it for her but shopping-wise it's I guess like twice a month. And chores is mostly every week. Yeah'. P.4</p>
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<p>Mum suffering – illness</p> <p>Needs to be there – responsibility – inevitable isolation</p> <p>Lonely – not enough support</p> <p>What’s missing – emotional response?</p>	<p>help her? What is it about her that needs help?</p> <p>R Uhm. Well she <u>suffers from mental illness</u> and uhm of course she doesn't know English <u>so I have to be there for her because, I'm the, a, only one</u> that's able to speak English and can speak Chinese at the same time. Yeah.</p> <p>I Okay, and so who else is at home with you?</p> <p>R It's <u>just me and my mother.</u></p> <p>I Is there anything else you want to say about what you do and why your mum needs help? Is there anything else?</p> <p>R <u>Uhm. No.</u></p> <p>I So you've described a little bit about yourself as a person, any other important characteristics about you?</p>	<p>Understands she's suffering from an illness – sees her mental health condition as an illness which she is suffering.</p> <p>Refers to mother's suffering. <i>Reluctant to elaborate – hesitant. Keeps private.</i> Explains in a matter of fact way that his mother has mental illness – <u>not emotional – not detailed or specific about the kind of mental illness. No mention of emotional support that his mother needs or that she gets from him – why? Is it difficult for him to talk about? Or does he not take on that role?</u></p> <p>Explains why he needs to help her. <u>Inevitability</u> – <i>'of course she doesn't know English so I have to be there for her because, I'm the, a, only one...'</i> <u>Fixed mindset re mother not learning English and also view that he is the only one – isolation in his role as a Y Carer.</u></p> <p>'yeah' Use of yeah, at the end of his statement when he talks about sensitive information. Confirming his reality for himself. Unease about the situation.</p> <p><i>'It's just me and my mother'</i> very short sentence, bare, barren – <u>reflects isolation? Factual 'just' suggests not enough. More needed?</u></p> <p><i>Reticence</i> - <u>not talking about any emotional support that he might be giving his mother but maybe he doesn't/ can't give emotional support? Or he maybe he is not be able to talk about this? Too painful? Too private?</u></p>
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<p>Cultural back ground important – but pressures from expectation of competitive community – needing to ‘stand out from people’ of be ‘one of the best.’ Hardship/conflict – pressure</p>	<p>R I don't, urhm, think there's anything.</p> <p>I And what do you think affects how you see yourself?</p> <p>R Uhm. Oh, that's quite interesting. Well because I'm part of a <u>Chinese family</u>, Urhm be able <u>to have manners</u> and <u>to be able to really stand out from people</u>, <u>especially the Chinese community it's</u> <u>it's also kind of very hard because in the Chinese culture is it's is like a conflict</u>. Not like a really bad conflict but a conflict that <u>is about hierarchy</u>, so er being one of the <i>best</i>, yeah.</p> <p>I Competitive?</p> <p>R Yes, that's right, that's right, competitive.</p> <p>I Okay. And how does that affect you, and how can you see this competitiveness or this hierarchy?</p>	<p><u>Cannot really think about many important characteristics about himself. Was open at the beginning – maybe effect of talking about his home.</u></p> <p>Interested in the question – as if he has not really thought about this before. Ethnicity significant</p> <p>His identity is associated with his cultural background – it is important for him to fit in but it is difficult – there is a pressure to ‘stand out’ to be ‘one of the best’ within the hierarchy. <u>The ‘conflict’ he mentions seems to be in the sense of something to work against. Something that is ‘very hard.’</u> Impacted by caring role? Maybe conflict is related to promotion of himself is helping his mother.</p> <p>‘to have manners and to be able to really stand out from people, especially the Chinese community it's it's also kind of very hard because in the Chinese culture it's is like a conflict.’</p> <p>[Reflection – did I give him the word or clarify what he was getting to?]</p> <p>When I clarify the idea of the conflict as the need to be competitive he is very <i>definite and repetitive</i> that this is exactly how he sees it.</p>
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<p>Competition – external related to education/ personality/ looks/ needing to perform</p> <p>Cultural pressure</p> <p>No mention of support</p>	<p>What does it look like?</p> <p>R Uhm. Usually er, it comes in, comes in terms of <u>education</u> and also the <u>personality</u> of the person and sometimes the <u>looks as well</u> (laughs). And I guess yeah, that's about it, how well, <u>how well, they perform</u>.</p> <p>I Is there anything else that affects how you see yourself?</p> <p>R Er, (pause) Let's see. No, Uhm, I don't think so.</p> <p>I Does being a young carer, having the responsibility to help your mum, does that <u>affect how you see yourself</u>?</p> <p>R Er, I think it does. Is it ok if you elaborate?</p> <p>I Yes, I mean how do you think about yourself in that role?</p>	<p><u>Pressure to be the best in competition with others in areas of 'education', 'personality' and 'looks'. But there is no mention of the community being supportive or collaborative. Pressure of having to perform for others. Needing to 'perform' well. All these things are external that others see. Relate to extrinsic motivation.</u></p> <p>[Reflexivity – did I lead too much here? Too much of a closed question? How did my assumption impact the research? Am I assuming it affects how he sees himself?]</p>
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<p>Hardship – inevitability of physical/emotional impact of caring.</p> <p>Mental/emotional impact – trying to please but hypothetical effect of not being appreciated.</p> <p>Physical hardship – getting tired</p>	<p>R Of being a young carer?</p> <p>I Yes.</p> <p>R Er Oh, I think as I mentioned it, <u>it's quite hard and it is draining, yes, exhausting, but I guess that's the way it has to be like.</u></p> <p>I So do you mean it's physically exhausting or kind of mentally exhausting? In what way is it exhausting?</p> <p>R It can actually be both ways. Er for Mentally is, is mostly, like <u>trying to please the other family member</u>, as the person you're caring for, and <u>it's hard that you, you know, if you did all this stuff and then they don't appreciate it. Physically, maybe it's because of doing a lot of stuff, you know, you get tired.</u></p> <p>I yes, yes, Ok. And is there anything</p>	<p>He does think that having responsibility to help his mother affects how he sees himself but he is not sure how. <u>Possibly this is an example of where the researcher has introduced leading questions – projected her ideas.</u></p> <p>Repeats the physical/emotional impact – emphasis. Acceptance – ‘that this is the way it has to be’ accepting his lot – inevitability.</p> <p>‘it’s quite hard and it is draining, yes, exhausting, but I guess that’s the way it has to be like.’ P.8</p> <p>Describes caring as ‘hard’ ‘you get tired’</p>
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<p>Not wishing to talk about his mother's symptoms in detail. Wanting to keep things private</p> <p>Boundaries – protects mother's privacy – privacy of the home – his own privacy.</p>	<p>else? One of the questions is tell me what it's like being a carer, you've already said who you care for and why your mother needs help, what are her symptoms and how does your help help her with her symptoms. How does it help?</p> <p>R As in?</p> <p>I Well what are your mum's symptoms in terms of why she needs help?</p> <p>R Oh. ((hesitates)) er</p> <p>I You don't have to go into it if you don't want to.</p> <p>R I mean I don't really understand the question.</p> <p>I I suppose I wanted to ask what kind of mental health issues does she have?</p> <p>R Oh, yeah I guess that's a bit</p>	<p>[Reflection – too long multi-question. I think I wanted to get to what his mother's symptoms are so I know what he is dealing with – but I think I was giving him more than one question so he could choose the part he wanted to answer.]</p> <p><u>When I asked about how his help impacts his Mother – he didn't understand – did not see how he could possibly impact her symptoms? Why? Hesitates – unsure? Is this again a leading question? [Discussion evaluative point – linked to reflexivity]</u></p> <p>He didn't mention how he might be able to positively impact his mother's mental health – perhaps he doesn't see his role beyond the practical help or cannot talk about this aspect? [Discussion – an area where EPs can help?] [Reflection, maybe I was expecting too much of him here. Maybe he didn't have the</p>
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<p>Environment in which he feels 'stuck' confined 'in like an environment'</p> <p>Isolation – alone with 'just' his mother</p> <p>Being different – finding it hard to fit in</p> <p>Friends/relationships with others outside the home</p>	<p>confidential.</p> <p>I Yes. No, that's fine. OK. Does being a young carer <u>affect you in any ways</u>, maybe at school or friends or interests? <u>Does it affect you</u> outside the family?</p> <p>R Uhm I guess it kind of does because er when when you're kind of <u>stuck in like an environment where it's just with your mother you</u>, the person the <u>person you are is, is a lot more mature than other people at school</u>. Uhm For example er, sometimes my <u>friends don't really get my jokes because they see it as a, like as a big person's joke</u>, like an older person's joke. Yeah, er, <u>it's just hard to really fit</u> into like a, like a friends group.</p> <p>I Yes, a friendship group. And do you have a good friendship group? Are you happy with your friendship group?</p>	<p>insight? Of skills to explain?</p> <p>Understandably wants to keep this private. Doesn't wish to talk about this. Why? Too painful? Doesn't want to betray mother's privacy? Doesn't want to talk about her to others? Wants to protect her privacy and his own? Fair enough. Or does he not know? Not discussed openly with him?</p> <p>[Reflection – leading question – Am I assuming it does?? Not sufficiently open?</p> <p>'stuck' – suggests cannot escape, tied, confined to a place. Suggests isolation – 'just with your mother'. 'Environment' – sense of boundary – enclosure – different place or circumstance to others.</p> <p>Sees himself as more mature than his friends at school as he has less opportunity to be other than mature.</p> <p>Makes it difficult to really fit into '....friends group', difficult to relate to friends. For example they don't get his jokes. Different form of communication 'like as a big person's joke.' <u>Doesn't explain how this difficulty to really fit in affects him. Again, the way he says this is very matter-of-fact – inevitable – unemotional resigned – can't be changed. Sense of acceptance.</u></p>
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<p>School a priority – inevitability that is has to be ‘put aside first’.</p>	<p>R <u>Uhm, Yes, I think I am, yeah.</u></p> <p>I And uhm, does being a carer affect you in any way at school?</p> <p>R Er, No, no, no (sounds unsure)</p> <p>I And what is it about you that means that it doesn't affect you? I mean it doesn't affect you <u>which is admirable</u>, so what is it about you that means it doesn't affect your schoolwork?</p> <p>R I guess, I mean <u>school is a priority</u> so I guess I <u>just have to really put it aside first</u>. Yes, I guess that's it. Yeah.</p> <p>I Oh <u>that's good</u>, so you're organised are you?</p> <p>R Yes.</p> <p>I That's good. And what about your other interests, how does being a young carer affect you in terms of your</p>	<p>Big person – he means ‘older’ but not ‘older’??</p> <p>His communication skills have adapted to the situation he is in? Can't adapt to social communication with friends – would have been the case anyway – or due to upbringing?</p> <p><i>Hesitant – <u>not sure or feels it is adequate?</u></i></p> <p><i>Sounded unsure but saying ‘no’ Repetition <u>suggests that he is trying to convince himself and me?</u></i></p> <p>Says he makes school ‘a priority’ – but has to put it aside first – matter of fact. ‘<i>I just have to...</i>’ inevitable – <u>no alternative – resigned.</u></p> <p>[Reflection on this now – sounds like he hasn't really thought about this before.</p> <p>[Reflection – expressing evaluation on his answers – not role of interviewer.</p> <p>[Discussion evaluation – me resource activation – EP role not researcher role]</p>
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<p>Interests don't really feature as important – neglected? He still has some hobbies that are not affected – keeping some normality relate to beginning of the interview.</p> <p>Lack of focus on interests or hobbies.</p> <p>Suffering hardship</p> <p>Sharing experience – helping others outside home – having impact.</p>	<p>interests?</p> <p>R Uhm what's it mean by interests?</p> <p>I Your hobbies or things that you like to do?</p> <p>R Right, Uhm, I <u>don't think that really affects</u> it. Ah yeah. <u>Things just are the same.</u></p> <p>I That's good. And coming to a group like the Young Carer's Project, what do you like about coming to this group?</p> <p>R Uhm, a the reason I like to come to this group is, er, I get to see a lot of young people that has <u>kind of suffered the same as me and uhm because most of them are, are, you know, younger than me I can, I can, share some of my experiences with the younger people and maybe I can er sometimes help them.</u> Yep.</p>	<p><u>Not understanding this question suggests that interests do not feature as important to him.</u> [Reflexivity: Or is this the impact if my questioning?]</p> <p>Says that interests and hobbies are not affected but perhaps he has not had the chance to consider this before – <u>maybe wants to give impression that all is OK? 'I don't think' suggests uncertainty about this – wants to normalize his situation 'same' – but same as what? Everyone else? Same as it has always been?</u></p> <p><u>Suffering – he acknowledges explicitly for the first time?</u> Likes to meet others who have 'kind of suffered the same' as he has. <u>He can 'share' 'experiences' and help the younger ones.</u> <u>There is the suggestion of him liking to impact/help others – this is important to him.</u> <u>Why? Helps him connect with others? Creates cohesion – later it is clear that this</u></p>
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<p>Appreciating friends made at YC group – friends opposite to isolation at home?</p> <p>Suffering – being the odd one out – being different – Living through a story not of ones choice. Lack of control over ones life. Link to inevitability.</p> <p>Emotional response ‘upsetting’</p>	<p>I That’s nice.</p> <p>R And also obviously these young people, they’re, <u>they’re really nice people, I’ve made a lot of friends here.</u></p> <p>I And you use the word ‘suffer’.</p> <p>R Yes.</p> <p>I Can you explain that a little bit more?</p> <p>R Right. <u>Suffer</u> as in, I mean being a young carer, yeah is it’s not... It’s okay, like how can I say it? <u>It’s like somebody kind of has specifically picked you out to be the odd one out and when you have to live through that type of life, you know, that they didn’t choose, and it’s like a really upsetting kind of a, a story I guess?</u> But, yes.</p> <p>I <u>But you’re doing well.</u> Do you feel you’re managing and coping well?</p>	<p><u>cohesion in society is important to him. Maybe at home he does not feel that he makes sufficient impact? Is this transference? He does not talk of impacting/helping his mother at home in this way. Maybe he feels he can’t change situation with his mother. [The researcher acknowledges that is how she feels about caring for her parents- being an EP is a kind of transference and a coping mechanism?</u></p> <p>He has made friends at the Young Carers’ group – <i>appreciates them as ‘really nice people’</i> <u>Safe place to make friends – shared experience ‘they’re really nice people’ – because they are YCs Too? Can be trusted as friends?</u></p> <p><u>[Reflection – great open question – trying to get him to elaborate on this important aspect of his experience.]</u></p> <p>Explains what he means by suffering. <i>Refers to feeling like a YC (not first person) has been picked out to be different, ‘to be the odd one out’ and YC’s living through a ‘type of life’ that ‘they didn’t choose’ – suggesting that it is out of control – inevitable. Sees (his) life like an ‘upsetting story.’ Life is a story – this a metaphor suggesting that he is within a story that has been written by someone else. A story to live through suggests that he feels it is something he has to endure. This reference to ‘upsetting’ is one of very few references to emotional response. He feels that he is part of a narrative of suffering. And is someone who has been singled out, and an ‘odd one out,’ different from others. Again refers to idea of not really fitting in. Also lack of choice – need for acceptance.</i></p> <p>Sees it as a story – not in control of. In discussion could comment on EP’s role working with them to look at rest of narrative. Potential for externalizing caring role?</p>
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	<p>Yeah.</p> <p>I And <u>what sort of things</u> help you cope with being a young carer in terms of maybe things that you do or things that you say to yourself that help you, or things about your own strengths or things that other people might do? I mean you don't have to say all of those but what sort of things help you cope with being a young carer?</p> <p>R What sort of things?</p> <p>I You're clearly coping but if you think what it is that helps you manage?</p> <p>R Right. Uhm (pause)</p> <p>I Are there things you say to yourself that help you or things that you do? Or are you aware of your particular strengths, things that you're good at? You might need a minute to think</p>	<p><u>Circumstances have created dual environments – home – lonely he's been influenced by this and this in turn influences the relationship with his other environment – outside friends.</u></p> <p><u>[Reflexivity – interviewer is assuming that being a YC is something that needs coping with.]</u></p> <p><u>[Again, - researcher is assuming that he is coping and that being a YC is something he needs to cope with. – This may be an example of projection of things which help me the researcher cope with adverse situations – self-talk, noticing and using ones strengths and thinking about what others do/can do to help me. Expand – how did this affect the richness of the data?</u></p> <p><i>Unsure??</i></p> <p>[Projections of the researcher] These are things the researcher has learnt about herself and things she uses]</p>
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Unaware of what helps him cope – or is he coping?	<p>about that.</p> <p>R Yes. <u>I'm having a difficult day</u> today, sorry. Yeah, er..((pauses for thought)) Can I get back to that one?</p>	
	<p>I Yes, that's fine. Uhm, and is there anything that somebody could do to help you? Is there anything that you could have help with, and what could that be and what kind of help?</p>	<p><u>When Anthony could not answer the question he apologized saying 'I'm having a difficult day today, sorry. Yeah, er...(pauses) can I get back to that one?' Apologetic – for finding things hard – (guilt?) Doesn't know what helps him cope – but again perhaps the interviewer's assumption is wrong – he's not coping and so avoids answering the question. This could be another hint of emotional impact of being a YC/talking about it.</u></p>
Becoming a young carer when joining the group?	<p>R <u>As in becoming a young carer?</u></p> <p>I Yes. As you are a young carer, is there anything that could help you?</p>	
Activities to help – Y Carers group –help release stress	<p>R Uhm, I mean <u>I guess coming, coming here is a help</u>. Maybe also if I do other stuff, other things maybe that can sort of <u>release some stress</u>. I'm not really too sure on that one.</p> <p>I No, that's okay, that's fine. If you think of any things that have helped you,</p>	<p><u>I think here he's referring to joining the group. Becoming a YCarer – once he has joined the group?</u></p> <p><u>Maybe also not thinking about himself- putting his needs second.</u></p> <p><u>Acknowledges that coming to YC's project ('here') helps him – important to do 'other stuff' but put as a hypothetical 'if I do other stuff' Does he do other stuff?? Recognises he needs to do other things to relieve stress – he's not sure what. 'I guess coming, coming</u></p>

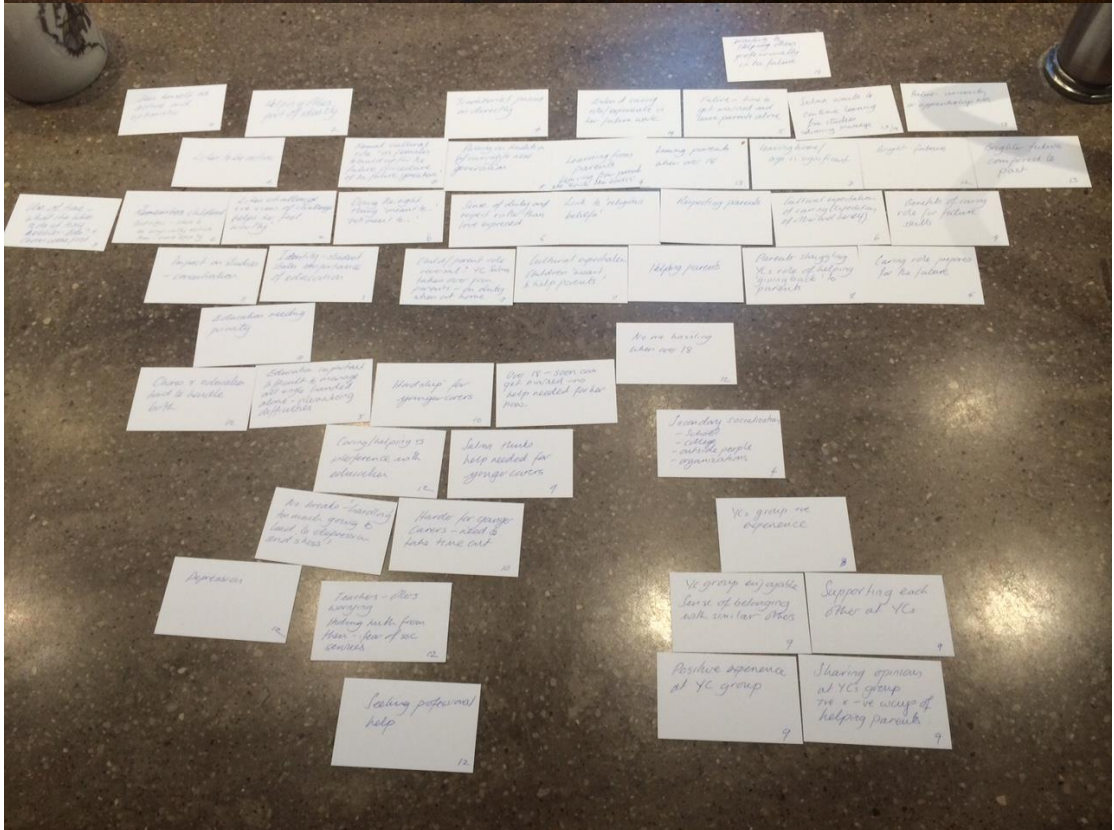
<p>Future aspirations – becoming a police officer</p> <p>Wants cohesion in society - in the diverse society. Links cohesion with stability. Opposite to isolation in own home life as YCarer?</p> <p>Balancing his narrative in the future.</p>	<p>about you, things about your strengths and we'll come back to that, if something pops into your mind just say, but we're just going to look at the future, do you think about the future much?</p> <p>R <u>Uhm I actually do. I do, I mean right now I'm kind of thinking when I become an officer how will I... Oh yeah, when I'm older I want to become a police officer and when I'm thinking about becoming a police officer I say to myself how can I, how can I maintain like a stable, cohesive community. Like I mean like the community we live in, we are very diverse, there is a lot of ethnicity but the thing is we don't really get together. So that's what I'm really thinking right now about the future.</u></p> <p>I It's like something you'd like to do to contribute to helping society be more</p>	<p><u>here is a help. Maybe also I I do other stuff, other things maybe that can sort of release some stress.'</u></p> <p><u>'Uhm I actually do. I do, I mean right now I'm kind of thinking when I become an officer how will I</u></p> <p>Upbeat and certain that he thinks of the future. <i>Repetition = certainty. Enthusiasm about his aspirations.</i> But remembers that he hasn't explained. He wants to become a police officer. Explains his aspiration to help create a 'stable, cohesive community.' <u>Police officer – enforcement to promote cohesion? Why an officer to create community? Perhaps is it about having authority, power control to create a world he would like to live in. having control where he feels he has none? Or does he see the police as people who serve the community?</u></p> <p>He demonstrates a sense of purpose for the future – where he can make a difference in society. Wants to make a wider community function better. Cohesion= stability.</p> <p><u>Recognizes diversity in his community but doesn't think there is cohesion – sees that</u></p>
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<p>Wanting to keep something personal. Boundaried about personal aspects of his future.</p> <p>Aspirations – what might get in</p>	<p>cohesive.</p> <p>R Yes.</p> <p>I Okay. So how do you see yourself in five years' time?</p> <p>R In five years' time, er, <u>I'll probably be a police constable.</u> (Laughs)</p> <p>I Oh that would be nice, yes. And anything else about how you see the future and <u>what might be different or what might be the same?</u></p> <p>R Oh, sorry, (pause) er. I'm not really too sure. I mean. <u>Of course there is some stuff but I might keep that personal.</u></p> <p>I Yes that's fine. So do you have any other kind of hopes or do you have any particular worries about the future?</p> <p>R Yeah, I means, <u>there are some worries that I feel like that maybe sometimes my confidence will kind of (pause) kind</u></p>	<p><u>there is isolation 'we don't really get together.'</u> Reflects his own feeling of isolation? Cultural and caring circumstances.</p> <p><u>Feeling isolated culturally too. Wants to change this – thinks he can make an impact here – again displacement of his impact? From mother/home to wider society.</u></p> <p>'I'll probably be a police constable'</p> <p><u>He has a goal – to impact society and others, thinking about the bigger picture beyond his own world – but perhaps parallels his own experiences? In the future wants to see diverse community cohesive.</u></p> <p>Hopeful about the future – that he will achieve his aspiration of becoming a police officer.</p> <p><u>[The researcher reflects that this might be insensitive questioning]</u></p> <p>Didn't want to talk about all aspects of the future. Boundaries – 'personal' aspects of his future wants to keep private. Maybe he's referring here to how looking after his</p>
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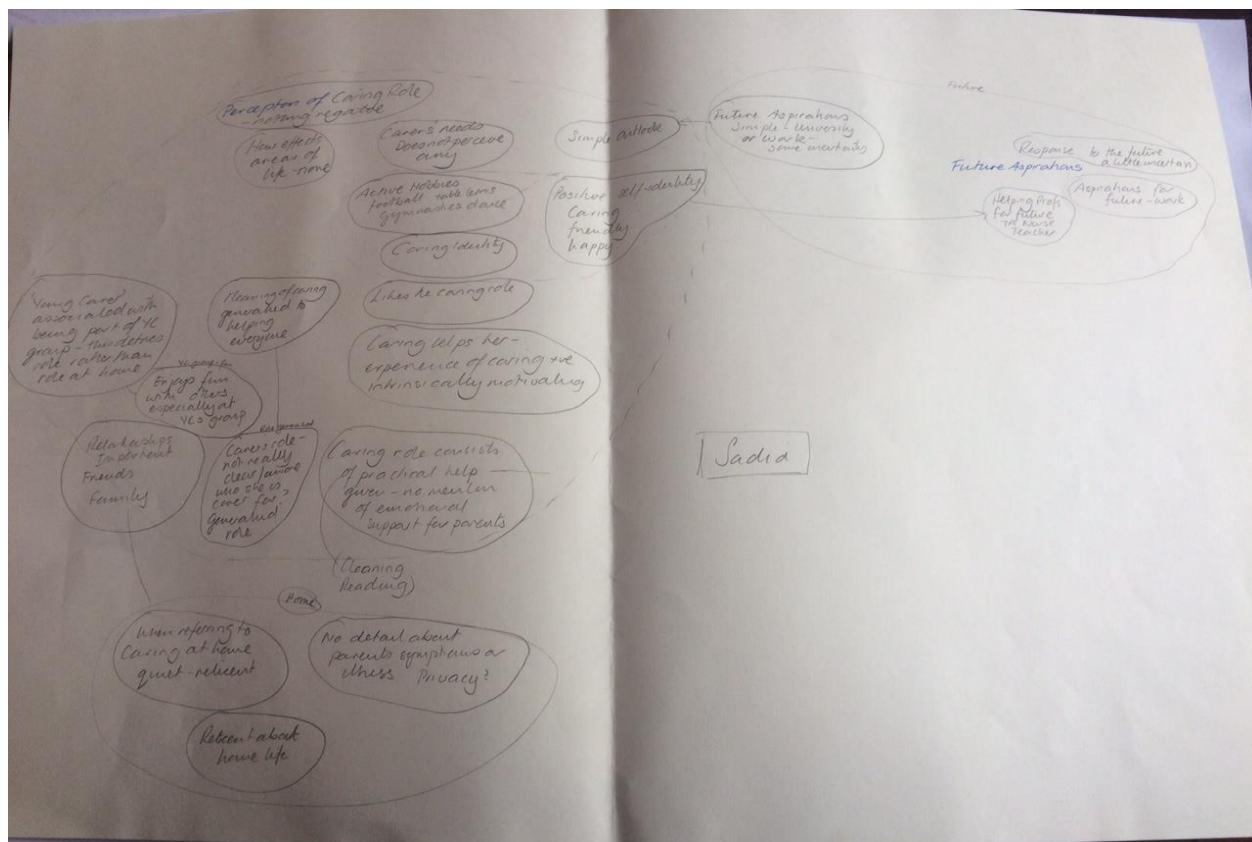
the way – lack of confidence		<u>of fail on me</u> , because to become a police officer, it's really hard to get in and I'm just thinking to myself, you know, <u>would I become a police officer and if I did how would I tackle situations within a community</u> . Those are kind of my <u>worries and how can I keep myself alive</u> . Yeah, yeah. That's about it.	<u>mother will fit into his future?</u>
Future aspirations – cohesion in community – questions his ability to tackle situations.			<u>[Discussion – reflection, not sensitive – pushing the same button!]</u>
Importance of keeping himself alive.	I	But often it's good to think of things that we've accomplished in the past to help us think about what we'll be able to do in the future.	Worries he will lose confidence. <u>Or is it that he worries about his ability to fulfill his future hopes?</u> <u>Police officer – a symbol - wish for someone who would tackle his situation? Lack of belonging? Father figure?</u>
	R	Oh right.	<u>Wondering if he will get into the police officer training not sure he would be able to tackle the things that are important to him in the future.</u>
	I	So you've talked about your maturity so that's probably a strength that will help you in the future.	Recognizes that the job – police officer- is potentially dangerous – worried about staying 'alive!' Sees this as important. <u>Needs to be around to help others?</u>
	R	Yes.	<u>[I am projecting my ideas in a therapeutic/interventive way. Too directive – not questioning – moved into EP role rather than researcher role.]</u>
	I	And is there anything else that you'd like to say about your experience as a	

<p>Uncertainty about the future</p>	<p>young carer that I've missed, anything that you think oh, I'm surprised you haven't asked me about something?</p> <p>R Er, let's see, (pause) what else? Er... ((pauses for thought)) Uhm (pause)</p> <p>NB at this point there is noise from outside and one of the youth workers comes into the room. Interruption.</p> <p>I Or did you have any thoughts about, going back to the question about what has helped you cope or what is it about...? And that can either be something about you or something about something that you do or something that you say to yourself in your head that helps you cope.</p> <p>R Oh yes, yes. I guess, I guess what helps me cope is er (pause), I guess saying things to yourself like <u>maybe it's going to be okay</u>. I mean I've never</p>	<p><i>Said in a way that <u>suggests that he has not thought about this before??</u></i></p> <p>[Using EP strategy to activate resources – not appropriate for research questioning. Although showing compassion for the interviewee.]</p> <p><i>Unsure – maybe something else but not sure whether to talk about it.</i></p> <p>[I go back to this!]</p> <p><i>"oh yes, yes. I guess, I guess what helps me cope is er (pause), I guess saying things to yourself like 'maybe it's going to be okay' p.20 But says he has 'never thought about that'</i></p>
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<p>Others who are 'outside' Others in similar situation need a place – a 'heaven' YCs group like a 'heaven' escape?</p> <p>Suffering – other Y Carers</p>	<p>thought about that, so...</p> <p>(Someone enters room)</p> <p>I Okay, <u>so you've coped but you</u>... Yes, sometimes when you ask questions it kind of starts you reflecting doesn't it?</p> <p>R Yes.</p> <p>I But is there anything else you want to ask or say about being a young carer or the experience of it?</p> <p>R Uhm, I guess I'd say, you know, if there are <u>other people outside</u>, er, you know, <u>kind of like me</u>, you know, I guess <u>suffering from a from a family's uhm (slight pause) illness or disabilities</u> I wish, I wish they'd come here because <u>this place is, although it's not perfect all the time, but most of the time it's, it's really, I guess like a heaven for us</u>, just really try to get that really, <u>ok, that stress really coagulated</u></p>	<p><i>Repetition</i></p> <p><u>Uncertainty that things will be OK. Emerging theme – trying to give himself self-assurance in order to cope?</u></p> <p><u>Doesn't think in this way.</u></p> <p><u>[Again, maybe making/pushing an incorrect assumption]</u></p> <p><u>He wants others 'like' him to join YC's group.</u> <u>'outside' – spatial imagery/metaphor used – outside YC group – suggestion of isolation – not protected – outside in the cold – exposed marginalized – Like himself?</u> <u>'suffering from a, from a family's uhm, (pause) illness or disability'</u> <u>Pause – hesitant about revealing information from within the personal boundary of his home life?</u> <u>'heaven' an escape</u></p>
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[illegible]

Appendix K: Example of hand drawn mind-map of individual participant themes clustered



Appendix L: Example the summary of themes from codes and interpretations for individual case: Participant 1 Anthony

Boundaried communities

Anthony's perceived 'environments' – 'home', 'outside the home,' Ethnic community and Young Carers group and friends

Privacy/Home – (An example of abstraction – the analytical process when themes come together to create a superordinate theme)

Mum suffering mental illness

Not wishing to talk about his mother's symptoms in detail – keeping privacy

Wanting to keep some things personal – boundaries about personal aspects of the future. Is this referring to where his caring for mother will fit into his future?

Boundaries protect mother's privacy – privacy of the home.

Constrained, limited. Feeling 'stuck' in like an environment where it's just your mother'

Separates environments 'at home and outside the home environment.'

Isolation

Just me and my mother' – isolation, feeling 'stuck' at home

Alone, lonely 'just me' not enough support from others for Mum?

Responsibility/obligation/duty

'So I have to be there for her'

'of course' – inevitability

No mention of other support – duty by default??

Suffering in the caring role. (An example of subsumption where the emergent theme becomes the superordinate theme)

Not being appreciated at home – emotional impact

Difficult physical and emotional impact of being a YC.

Chores hard work, habitual, 'a lot to do'

Physical and mental – 'you get tired' need for rest?

Stress in the body described using a metaphor – 'coagulating' getting oit out of the body, out of the blood.

Inevitability – just the way it is. Fixed.

Coping?

Upsetting 'a really upsetting kind of story'. YC a story imposed upon his life – no choice.

Community pressure rather than support

Cultural background impt to him but has pressure. Expectation of competitive community and needing to stand out.'

Competition external related to education/personality/ looks

School priority – has to come first – cultural pressure,

Compounding pressure: 'Conflict' in his ethnic community – competition – need to perform well – no mention of support or collaboration. Further source of stress?

Self-identity

Caring about mother important to him

Ethnicity important

Appendix ? continued: Example of summary of themes from codes and interpretations for individual case: PP1 Anthony

Positive about his self-identity – honest about himself 'nice' 'kind'

Leadership outside the home

Interests and still has some that are not affected – normalizing effect? Doesn't see them as different 'things just are the same.'

Maturity – tension with friendship groups difficult to fit in

Appendix L: continued:

Difficulty fitting in

Maturity – tension with friendship groups difficult to fit in

‘It’s just hard to really fit into like a friendship group’

Being different – finding it hard to fit in – friends doesn’t get his jokes ‘a big persons’ joke, like an older person’s joke.’ Aware of how others perceive him/

Being odd one out

Picked out to be different.

Difficulty fitting in with friendship groups due to his maturity

Young carer’s group – belonging/sharing

Opportunity to fit in

Experience can be generalized, shared with others in similar situation

Sharing experience of suffering – helping others outside the home – positive impact on others - reduces his own suffering? Appreciation of friends made at YCs group. Friends opposite to isolation.

‘They’re really nice people’ because, like him they are YCs? Must be nice.

positive place like a ‘heaven’ where he can help/influence/motivate others. Others who are ‘suffering like him.’

Being with others like you helps mindset – others suffering too. YC’s group place to be with others suffering too.

Being with others important – with others who share same experience helps with the positive mindset.

Becoming a YC when join the group – defining identity

Also a place to release stress – YC’s group help to relieve stress

YC’s group like a heaven – escape? Idealistic? opposite to realistic?

Becoming a YC when joining the group – identity associated with being part of this group. Place to fit in.

Future Aspirations

Hopeful but not certain

Wanting to become a police officer to ‘maintain like a stable , cohesive community...there is a lot ethnicity but the thing is we don’t really get together.’ He’s searching for a mechanism to help him fit in? Chooses authority role to help him do this – but how by force, building community relationships?

Wants cohesion in society – opposite to what he experiences in his life as a carer?

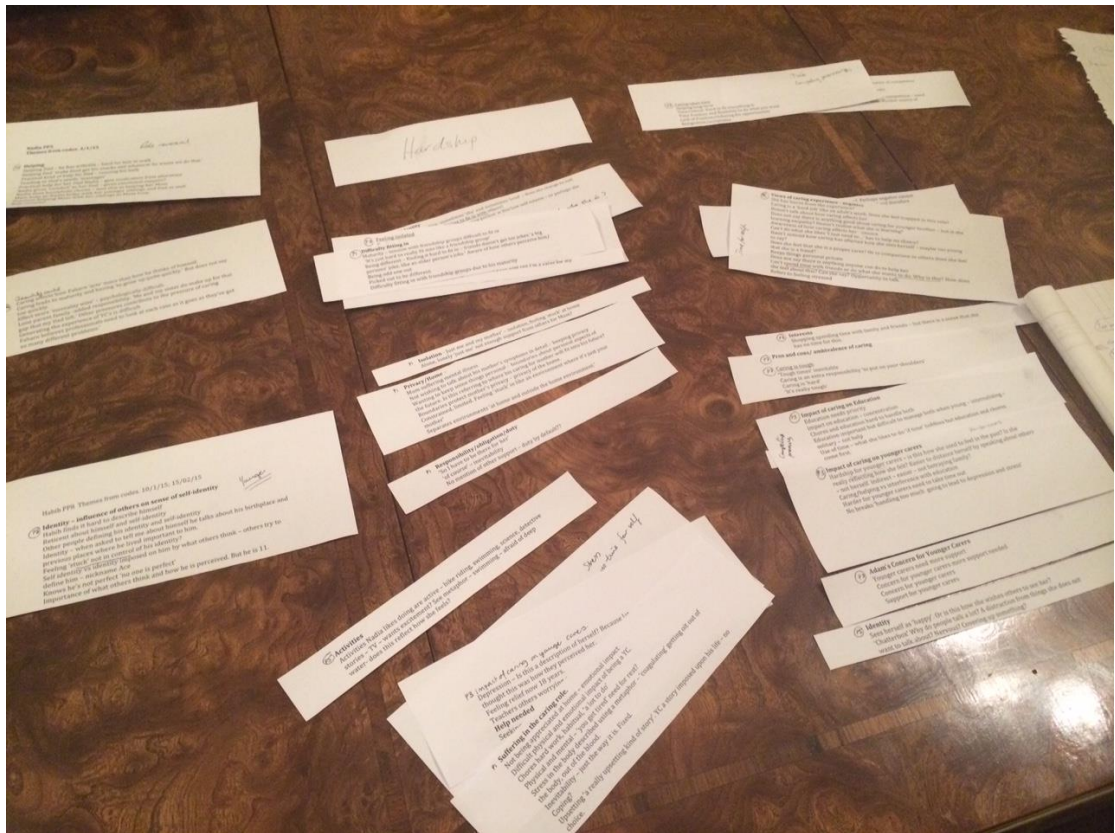
Wanting to create cohesion in community where there is diversity

Joining people together

Uncertainty

Importance of keeping himself alive. Needs to be around to help others? Dangerous career? Limitation constraint continues into future?

Appendix M: Photograph showing example of cross-case clustering of themes



Appendix N: Final summary list of cross-case superordinate and subordinate themes.

HARDSHIP

- **Limitation of freedom:** (expressing lack of choice, inevitability of their role due to circumstances,
- **Accelerated childhood:** too much responsibility, chores, regular responsibility, role reversal, loss of childhood (other contributing/competing pressures – education,) leading to stress/depression/exhaustion/physical and psychological impact.
- **Isolation/Not fitting in/** not being like others (but 1 participant celebrated being different – coping through reframing? Link to managing impact)
- **Reticence regarding hardship:** Difficult to talk about hardship, fear of betraying loved ones, fear of social services, hardship expressed indirectly, through concern about other youngers carers – is this a reflection of their own difficulties when they were younger?

BENEFITS of CARING

- **Positive self-identity:** including maturity
- **Positive feedback/regard** from others – link to self-identity.
- **Generalising skills:** to other areas of life. Internalising the role so that it is part of self-identity and thus seeing it as part of them and generalizing the role to other contexts beyond the specific caring role (this leads on to the next theme.
- **Preparation for future life:** valuing the experience and applying to future study/employment

(This theme leads on to/links with managing the impact of caring – seeing the benefits is a way of managing the impact)

MANAGING THE IMPACT OF CARING

- **Support from others** (friends, teachers, YC's group)
- **Normalizing the role** – acceptance – reframing, cultural (including gender) and religious expectation, e.g. reframing experience as positive a reciprocal duty. [Discussion – but does this make them feel obliged and is this fair? See my other reflexive comments too] Activities – hobbies.
- **Boundaries** – keeping home and outside separate – but is this healthy?
- **Making sense through knowledge:** Drawing on other areas of life – education/research. Doing your best 'give it their best shot' p. 5 Salma.
- **Awareness of strengths:** awareness of their own strengths helps them feel able to manage.
- **Focus on the future:** hopeful in spite of uncertainty, thinking of future – as a way out

Appendix O: Table of cross-case analysis of themes

Superordinate Theme 1 Hardship	Evidence from participant accounts
Lack of freedom	<p>Anthony <i>'Of course I've been caring for my mother...'</i> <u>sees this as another obvious characteristic about himself – inevitable? Goes without saying?</u> P.2 Explains why he needs to help her. <u>Inevitability</u> – <i>'of course she doesn't know English so I have to be there for her because, I'm the, a, only one...'</i> <u>Fixed mindset re mother not learning English and also view that he is the only one – isolation in his role as a Y Carer. P. 5</u></p> <p><u>Suffering – he acknowledges explicitly for the first time?</u> Likes to meet others who have <i>'kind of suffered the same'</i> as he has. P. 12</p> <p>Explains what he means by suffering. <i>Refers to feeling like a YC (not first person) has been picked out to be different, 'to be the odd one out' and YC's living through a 'type of life' that 'they didn't choose' – suggesting that it is out of control – inevitable. Sees (his) life like an 'upsetting story.'</i> <u>Life is a story – this a metaphor suggesting that he is within a story that has been written by someone else.</u> A story to live through suggests that he feels it is something he has to endure. <i>This reference to 'upsetting' is one of very few references to emotional response. He feels that he is part of a narrative of suffering. And is someone who has been singled out, and an 'odd one out,' different from others. Again refers to idea of not really fitting in. Also lack of choice – need for acceptance.</i></p> <p>Sees it as a story – not in control of. In discussion could comment on EP's role working with them to look at rest of narrative. Potential for externalizing caring role? P.13</p> <p>Sadia</p> <p>Salma</p> <p>Likes to do sports when she can Attends a youth club</p>

	<p>Sees herself as some one who used to be 'active and optimistic.' No longer has the opportunity? P.2</p> <p>Spare time – if not studying or busy at home likes 'going shopping' or 'going out or socializing with friends,' <u>relaxation and choice activities come after other responsibilities – study and caring role.</u> 'If I am not busy...' Assuming that she needs tp focus on other things – responsibility comes first. [Maybe I presumed this?]</p> <p><i>'I would like going shopping.'</i> <u>This sounds hypothetical idealised– doesn't say she does this.</u> P.3</p> <p>'I wouldn't want to leave my parents.' Doesn't want to leave parents even though she has said previously she can leave them now. Conflicting emotions – wants to leave but doesn't want to leave parents. Limitation of freedom due to obligation to continue to care?</p> <p><u>Attached to parents? Why won't she leave her parents? 'even if they are healthy' no mention of love.</u> [Reflexive comment: what I am expecting due to my Cultural behavior?] Is this significant?</p> <p>P.13</p> <p>Farhan</p> <p>F explains that his sister needs 24 hour care. 'she obviously can't support herself, so obviously she does have to have 24 care.' He finds it quite easy to talk about his sister</p> <p>Repetition of 'obviously' inevitability, acceptance.</p> <p>Recognises that his Mum cannot 'do this on her own' and his 'sister can't do this all alone so 'it's like shared care.' He cares for his Mum and siblings and sees the caring as a shared responsibility. P.7</p> <p>He has to 'be home at a certain time to be able to take his sister home' But see what else he says and how he manages. C1. P. 8</p> <p>He sees other 'kids (his) age.....' doing this and that, whereas his 'kind of day to day, like kind of revolves around my family and trying to help everyone out.' He needs to be more involved with this family than his friends might be. 'revolves around' suggests that he has to fit around his family and his caring role directs his day to day activities. P.9</p> <p>Also C2 Refers to 'love' 'coz I love my sister more so...' Unlike other pp 2 and 3 and 1?</p> <p>More than what? But he goes on to refer to other siblings.</p> <p>Talks of loving her more because of her disability 'I think my....</p> <p>'my mum, if this makes sense, loves her more than she loves us because it's just like she's got a disability so she's that much more <i>special</i> than we are'.</p> <p>Farhan's disabled sister seen as 'special' an 'angel' in comparison to the other siblings who are seen as 'normal'</p> <p>Whilst his younger siblings might be 'jealous' it is accepted by Farhan.</p>
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	<p>'Because we're kind of seen like <i>normal</i> and she's yeah, she's like an <i>angel</i> or whatever. So, yeah.' P. 12 Farhan believes that YC's experiences cannot be generalized 'because each <i>story</i> is different, <i>everyone's got their own experience</i> and stuff' Sees his situation/life like a story [Reflexive comment: would narrative therapy help YCs? Implication for helping YCs? Also for discussion – Farhan says you can't generalize YCs as all different] Farhan expressed his views believes that you cannot generalize about YC's experiences. Sees his situation as individual. Talks of YCs having problems – h=does this mean he is acknowledging his situation as difficult? Repetition of the word 'problem' Is this just the dominant discourse he is questioning as he is advocating looking at individual situations and then the role cannot simply be described in terms of problems. He believes that YC's have got so many different problems you cannot name all of them.' P.18/19.</p> <p>Nadia Activities and interests – bike riding – swimming science detective stories – TV'I like bike riding and swimming, but I'm not really that good at swimming, I'm scared of deep water, though.' Feeling like she has been thrown in at the deep end caring for Dad? Not prepared?/ Scared when she feels she is in too deep? Lacks confidence to venture into unknown? Or the difficult? But would like to. Wants to do normal activities but something holding her back? Likes the idea of exploration and adventure P.3.'I'm kind of like into science a bit. I like detective stuff and stuff like that. Sees YC's group as fun 'it's really fun' Comes regularly. Likes the 'fun trips' too and being able to 'express' herself. <u>Does this mean that she isn't free to express herself in her role as a YC? P. 10.</u></p> <p>Fabina Age is important to her and where she goes to school. Or perhaps she is responding to what she thinks an adult wants to know. She is rather unsure of her hobbies – she hesitates and then says it's, '<i>just</i> going shopping, spending time with family and friends.' I'm in year nine and my hobby uhm, is just going shopping, spending time with my family and friends.' Why does she pause? Is it because hobbies are a luxury to her and she doesn't really get the chance to have them. P.2</p> <p>'I feel, uhm, kind of stressed because I always have to look after him and like see what he does, I can't really like most of the time, I can't really, I can't really spend time with my friends or do what I really want to do, I have to mostly look</p>
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after him.'

'stressed' 'I always have to look after him...I can't really....I can't really....'

She reveals that she feels 'kind of stressed because (she) always has to look after him.' She says that she can't reallydo what she wants...she has to mostly look after her brother and feels she can't really spend time with her friends or do what she really wants to do as she has to 'mostly look after him.'

Does she resent the fact she cannot do what she wants?

No time for herself. Use full quote. Repetition hesitant doesn't really want to say this – feeling of betrayal if she does so??

Limitations of her freedom/life. P. 6

'Just look after him. Just look after him.'

The repetition and the word 'just' suggests monotony and relentlessness or is she down playing what she has to do?

Does she see herself as a carer or is that a label imposed on her by others?

Adam

Adam cares for his brothers – one has epilepsy and behavior problems. The other brother has a heart condition.

Helps other members of his extended family: grandparents and uncle (in a wheelchair)

'I care for my brother, he's got epilepsy, behavioural problems and was yeah. Like sometimes, because my brother's got a heart condition sometimes I help him a swell and also...' p.4/5.

'yeah. And sometimes when I go round my nans I'll tend to help my nan, my granddad and my uncle. My nan's got a heart condition. My granddad's got COPD which I believe is um something wrong with his lungs, like you get tired very quickly and so on, and my uncle is in a wheelchair.' P. 5.

'I normally help round the house. Yeah, I just make them food, maybe a cup of tea, anything really.' P. 6

Adam has been helping for 7 years 'I have been helping them five, no about seven years, seven years I think. It's been, it's a long time.' P. 6. Repetition emphasizes that it feels like a long time for Adam to be helping. Has lost track of the time – first says 5 years then says 7 years. Does he need some respite?

When asked if caring effects his life in any other ways he replied: Sometimes it does because if I'm helping at him or Nan's of if I'm helping anyone um it does take time off, if you know what I mean, like sometimes you can't go out, you can't be social. Well you can, but not like you can go out every day and stuff.'

Because caring takes time 'it does take time off,' Sometimes you can't go out to be social.' Does suggest that he feels that he lacks freedom? 'Not like you can go out every day and stuff.'p.8

	<p>Limited time to go out and be sociable. P.8</p> <p>When how he feels about being a YC he replied; 'Um good and bad. Good because you know you're helping people and that it builds your confidence up in looking after people and that, but no because you don't get enough time to go out or do what ever you want and stuff. It's really tough.' P.9</p> <p><u>Adam can see the good and not so good aspects of caring.</u> Says he feels 'good and bad' about being a carer. He feels it is 'good because you know you're helping people and....it builds your confidence up in looking after people.' But he feels less good about it because 'you don't get enough time to go out or do whatever you want..... It's really tough.' <u>Time pressure. Time for yourself p.9</u></p> <p>He resigns himself to what the future brings. Thinks that you have just got to get on with things 'sometimes you've got to take stuff by the hand and just carry on with it.' P.16 This is especially in respect to the future.</p> <p><u>The uncertainty is related to his brothers and family' because I don't know how my brothers will turn out to be in the future or may family so I've got to wait and see from there.'</u> <u>His future is to a certain extent dependent on things beyond his control and linked to his caring role. P.16</u></p> <p>Habib</p> <p><u>When asked what sort of person he sees himself:</u> <i>Lots of pauses suggests that he cannot decide what to say.</i></p> <p>'I'm stuck in the middle' saying he doesn't see himself as 'good' or 'bad.' <i>'in the middle' suggests that he thinks that you should be one or the other but actually he is neither as 'noone's perfect' – accepts that he is not perfect but feels uncertain of his identity. 'Stuck' suggests that he doesn't feel that he is in control can't change things.</i></p> <p>He explains that he was good 'at most everything' and so others called him 'ACE' <u>But he prefers to be called his own name – why? Doesn't want to have the pressure of living up to externally imposed competitive perfection identity which ACE suggests??</u></p> <p><u>Others try to define him but he finds this too much pressure. P.5</u></p>
Accelerated childhood	<p>Anthony</p> <p><i>Talks about experience of being a young carer as 'sometimes very difficult.' Language refers to physical and emotional too? Trying to hide this? impact on him: 'it can drain you a lot, it will, it will, exhaust you, and it's, it's just hard, yes.'</i> Describing</p>

	<p><i>the hardship he has to endure.</i> Physical and psychological. 'just' belittling it? 'yes,' self affirming. P.2</p> <p>Describes the chores in the home. Sees it as '<i>a lot.</i>' No mention of emotional support.</p> <p>It is habitual, part of his life. 'I kind of rarely interpret it for her but shopping-wise it's I guess like twice a month. And chores is mostly every week. Yeah'. P.4</p> <p><u>Does not seem to get emotional support?</u> <u>Does more than would be expected of someone of his age, p.4</u></p> <p>His identity is associated with his cultural background – it is important for him to fit in but it is difficult – there is a pressure to 'stand out' to be 'one of the best' within the hierarchy. <u>The 'conflict' he mentions seems to be in the sense of something to work against. Something that is 'very hard.'</u> Impacted by caring role? Maybe conflict is related to promotion of himself is helping his mother.p.6 to have manners and to be able to really stand out from people, especially the Chinese community it's it's also kind of very hard because in the Chinese culture it's is like a conflict.' P.6</p> <p><u>Pressure to be the best in competition with others in areas of 'education', 'personality' and 'looks'. But there is no mention of the community being supportive or collaborative. Pressure of having to perform for others. Needing to perform well. All these things are external that others see. Relate to extrinsic motivation. P.7</u></p> <p>'it's quite hard and it is draining, yes, exhausting, but I guess that's the way it has to be like'. P.8</p> <p>'for Mentally is, is mostly, like trying to please the other family member, as the person you're caring for, and it's hard that you, you know, if you did all this stuff and then they don't appreciate it. Physically, maybe it's because of doing a lot of stuff, you know, you get tired. Describes caring as 'hard' 'you get tired.' P.8</p> <p>'school is a priority so I guess I just have to really put it aside first.' Says he makes school 'a priority' – but has to put it aside first – matter of fact. '<i>I just have to...</i>' <u>inevitable – no alternative – resigned.</u> P.11</p> <p>Because of his circumstances he feels that he has become 'an older person.' 'The type of situation' he is in – this is how he sees it – has caused him to 'become an older person....I've become more mature, yes.'</p>
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This appears clear to him – repeats, clarifies his identity the type of person he has become due to his circumstances. P.14

Sadia

She describes varied areas of help – ‘cleaning’ ‘helping out’ and ‘reading and stuff like that’. This participant is of Bangladeshi ethnicity so maybe parents don’t speak or read English well? Added area of help needed. Additional needs of families with parents who don’t speak English. But this sounds vague, could be evasive deflecting the real reason?? P.4

Salma

Remembers her childhood as a time when she was more active. Sports reminds her of her childhood. Likes to look back. Why? No longer sees herself as child? – Now mature, with responsibility? Just turned 18, but repetition of ‘used to’ implies things have changed - she no longer has much opportunity to pursue her interests or what she enjoys – there is a sense of loss, loss of her childhood? Loss of time without responsibility? when she was free to do things that she enjoyed??

‘used to love sports activities’ p.2

Also likes to spend time appreciating time to herself. *‘fresh, like, time out, with myself’ need to feel refreshed? Recharged? Opposite to fresh is wilted image of needing restoration. [Link with Anthonys reference to drained] [Implication for professionals - could check to see if this happens]. p.3*

Considers Y caring role as difficult for the younger ones under 18 ‘studying issues’ thinks it’s ‘really hard’ for them because she doesn’t ‘think they can handle education and chores and family within themselves.’

‘Within themselves’ – suggests inside – keeping difficulties inside lonely internalizing difficulties, confined to them – not shared. ‘handle’ questions them being able to manage – mental capacity? P.5

This reference to Younger carers – is it a reflection on her own earlier experiences of caring when she was younger? This method (of talking in terms of other younger carers) distances her from her own experience – so she can talk about it more easily. Indirect reference to her own hardship also acts as a privacy boundary? P.5

Education important but she feels important for younger carers to 'have their own little.... Freedom because it's not all about work throughout the day...especially if it's to manage household chores and education.'

Speaking of chores and education.

'*handling* both at the same time then it's going to....lead to depression and stress and then it's going to become *harder*.'

Suggestion that things are hard to handle. P.10

She thinks 'the younger carers might need professional support' – she suggests a carer to help the parents instead of the children always caring? Role reversal? P.11

Again, repetition of cultural expectations but here she is questioning them – not for herself but for other young carers?

'Children are meant to help parents' – and it can prepare then for the future but Salma feels 'it's not their time.'

She refers to when she started to care for her parents – 12 years old.

Talks about becoming 'more mature' at 12 years old. It's as if she had to become more mature and take on a particular caring role – doing research to identify their needs and support? P.11

Talks about becoming 'more mature' at 12 years old. It's as if she had to become more mature and take on a particular caring role – doing research to identify their needs and support?

'I became more mature at the age of 12 I tried to do the other things, researching everything, finding out about people's health and so on. Then it came to me that, oh my word, these people need help, so that's why after doing research I became so happy and then it was like I put my mind straight on my family and then education.'

It is only after doing research that she realized she had to help them.

Then she focused her attention on their care and her education is secondary. Family first then education. P.11

'In the past it affected me negatively because I couldn't concentrate on my studies.'

Talks about negative impact retrospectively. Easier to talk now? P.11

Farhan

Also in B 1 – positive identity. Farhan believes that being a carer has made him 'more mature..... I did have to grow up quite quickly (pause) so to adapt to the situation'. H feels that he has had to and has been able to adapt and become more mature.

But doesn't say this has been too quickly.

He sees caring 'in a good light' where it has 'matured' him and this has allowed him to do 'different things' talks about positive personal consequences – in terms of effect on him – positive reframing. P.7

But he recognizes that helping others helps him too: 'so trying to help them relieve the stress and in that sense it helps me relieve that stress as well.' This is where he acknowledges that he is stressed.

[Reflection: research has shown that helping others makes us feel good – eudemonic aspect of happiness. P. 15]

F wanted me to know that he is from a lone parent family and sees this as an added circumstance to manage: 'on top of being a young carer I do come from a lone parent family background.' Said this quietly – maybe embarrassed, sad about this?

Says that his Dad left a gap which he and his younger sister feel they need to fill to support their Mum. Feels responsible in his family as they are a lone parent family.

'so yeah, me and my older sister do make up for *that gap that my dad left*. So it's not that much harder but you've got that much *more responsibility* rather.'

Dad missing – left a gap, avoid? That needs filling – void of responsibility. Sees this as added pressure compounding the effects of being a YC.

P.18

Nadia

'I used to like help my dad get some medicines from the pharmacy, uhm, with my parents I used to go.'

Past tense, talks of past tense and present has her role changed?

Says she cleans the house helps her Mum to 'do the dishes and stuff and with my dad like needed massages and stuff, I used to comfort my dad and make him tea and stuff.

Emotional support 'comfort' P. 3.

'My dad has arthritis, which is uhm, like very hard for him to walk and everything so we always help him we always, uhm like, massage his leg or his foot and like we always make him food or uhm tea and like, always get his snacks and whatever he wants we do that, and like we always help him around the house.' Repetition of 'always', she does a lot for him, role reversal? [This is according to the role I assume for a child, in my culture, in my situation – My husband and I do everything for our children, but then we are not ill.]

'Very hard for him to walk and everything so we always help him.'

Describes how she helps her dad.

'massage his leg or his foot.... Make him foodget his snacks and whatever he wants we do thatalways help him around the house.' P. 6 Idealisation of her father?

we just run the bath for him and we get, like, what ever he needs, like if ...'

She runs his bath, Goes to the pharmacy 'me or my brother will go to the pharmacy and get' medicine.

Is she worried about the new baby and added work for them all especially her Mum?

She picks up her brother (from school or to hold?)

Younger siblings need help too

'my mum's really busy now, so we have a baby sister and she's expecting again now, uhm, in April though.'

'My mum's really busy so we're doing everything for my dad as well now'.

Helps with siblings and Dad as Mum busy. P. 7

Fabina

When she is asked what it is like being a YC she says 'it's kind of like a hard job

She refers to caring for brother and sister as a 'hard job' ... and 'like you have to uhm care for them enough to do stuff for them.'

There is no mention of her mother here.

Adam

Sees being a YC as 'not easy' and 'hard' because there are other 'things on your mind such as schoolit's another thing to put on your shoulders and it's really tough.'

'another thing to put on your shoulders' – a burden? Something to carry? Weight? Bearing down from above? Another pressure - pressures from different directions.

'It is not easy, it's hard because, sa, like you've got, you've got other things on your mind such as school and that and if you're going for like GCSEs and that it's, it's another thing to put on your shoulders and it's really tough. So yeah' p.4

Difficult to fit in caring to timetable. '...if you've got to do homework and you've got a lot of homework and stuff it's really tough because then you've got to fit that into your timetable. Or like if you're helping your mum like you need to kind of

get that in. It's really tough.' Time pressures – competing priorities.
Repetition of 'It's really tough' this emphasises how he feels.
Hard to fit everything in? p.8

He feels support for younger YCs could be 'having one-to-ones, asking them about their week,finding out about them....such as hobbies or something like that and maybe.... getting them into it a bit more.'

It seems that Adam thinks more interaction with adults for the YCs would be supportive? He likes others to show interest in him? Is this because they are not really being cared for themselves – role reversal needs balancing? p.15 This is relevant for implications for the professionals.

Habib

Um well because um a couple of years ago there has been (pause) there has been like a sudden (pause) a sudden problem with her eyes then it's like she couldn't see properly, it's cloudy, so um she has eye drops so I help her take her eye drop, I clean the house and um make her breakfast sometimes in the morning.' P.7

Does describe with a little encouragement.

Lots of pauses and repetition could suggest that he is a little reluctant to say much about his Mum. Unsure how much he wants to say or is it because it is an emotional topic for him to speak about so best avoided??

One long sentence then describing in a very matter of fact way, his mother's issues and what he does to help out at home. It is one long story, it is list like, descriptive without any comment. He cannot comment.

Explains that he helps with medication

He cleans the house

Sometimes makes her breakfast. P.7

When asked if caring affected him he said 'um no, not really because as I said, it's just part of me.' P.8

Identity – he can't separate being a YC from himself. It is part of him now. Maybe he can't remember not being a carer?

Is he referring to being part of the group? Is this a shift away from describing the role of YC in terms of his caring at home to describing it as being part of a group, does this make being a YC easier to talk about? Easier to accept? Makes it more public, so that he can keep the private private. Shift in identity from private to a publically acceptable shared identity??] Is it a coping mechanism? A welcome support?

'I feel normal er I've been through it for a long time so I get used to it.'

	<p><i>'Normal' – like everyone else – normalizing the situation</i> <i>'get used to it' – language suggests that he has adapted</i> <i>'been through it' – suggests that he sees caring as something difficult to get through. P.8</i></p>
Isolation/Not fitting in	<p>Anthony <i>'It's just me and my mother' very short sentence, bare, barren – reflects isolation? Factual 'just' suggests not enough. More needed? P.5</i></p> <p>'stuck' – suggests cannot escape, tied, confined to a place. Suggests isolation – 'just with your mother'. 'Environment' – sense of boundary – enclosure – different place or circumstance to others. P.10 <u>'stuck in like an environment where it's just with your mother you, the person the person you are is, is a lot more mature than other people at school' p.10</u></p> <p>Makes it difficult to really fit into '....friends group', difficult to relate to friends. For example they don't get his jokes. Different form of communication 'like as a big person's joke.' <u>Doesn't explain how this difficulty to really fit in affects him. Again, the way he says this is very matter-of-fact – inevitable – unemotional resigned – can't be changed. Sense of acceptance.</u></p> <p>Big person – he means 'older' but not 'older'?? His communication skills have adapted to the situation he is in? Can't adapt to social communication with friends – would have been the case anyway – or due to upbringing? P.10</p> <p><u>Recognizes diversity in his community but doesn't think there is cohesion – sees that there is isolation 'we don't really get together.'</u> <u>Reflects his own feeling of isolation? Cultural and caring circumstances.</u></p> <p><u>Feeling isolated culturally too. Wants to change this – thinks he can make an impact here – again displacement of his impact? From mother/home to wider society. P.17</u></p> <p>Sadia Likes to have 'fun' with others even not of same age. Especially 'little kids' at Young Carers' group. <u>What about her peer</u></p>

group? Doesn't say that they 'have fun with each other'. More reciprocal rather than shared. P.?

She understands herself as a YC through involvement with the group. What she says about the group 'It's like we are meeting new people and getting along with new people that I don't really even know' suggests a lot of change needs to adapt. [But in the group there are mainly regulars - perhaps Sadia is only recently started to feel comfortable getting to know the others - I observed her when I attended the group sessions that she was involved with others]. I think she is referring to coming together with people not in her usual circles. Suggests isolation. P.3

Salma

Refers to herself as an 'individual' repeats 'individual' later on too. 'Likes to help'. Sees herself as different? P.2

Farhan

Also in C2? Likes to be different: 'I like to be different, I'll put that out there;', means he is OK to admit to this and to show others this quality. Not afraid to say this openly.

Knows he is different - but proud of this - come to terms with it.

Doesn't want to be someone 'kind of normal' 'I just want to stand out yeah.'

Believes that being different helps you stand out. Pleased to be different - rationalizes that he is different from others. A coping mechanism? Positive reframing? Who has helped him with this? P.3

Farhan saw that the YC's group offers him support and he gives support to other members of the group too - 'I can look at it both ways, from two sides really, that I come here and obviously meet up with other people quite like me and like obviously being one of the eldest..... you come here to help other people as well.' P.14

Nadia

Sees herself as 'I'm a bit different to everyone else coz I'm a carer for my dad, but that doesn't really affect uhm, anything coz I have my friends to talk and if anything happens.'

Corrects herself 'nothing really happens though, like if I have something to say I tell my friends and they always listen. Covering up?

Or normalizing her experience.

Has friends to support her, friends she can talk to.

Whole quote: 'I'm a bit different to everyone else coz I'm a carer for my Dad, but that doesn't really affect uhm, anything coz I have my friends to talk to and if anything happens. Nothing really happens though, like if I have something to say I tell my friends and they always listen so it doesn't' really affect me that much.' P.5

Fabina

Describes herself as an 'annoying person.'

This is curious. It is not clear why she has said this.

Who does she think that she annoys? Has someone told her this? Is it something she likes to do? For amusement? Or does she assume she is annoying to others?

[Reflexive comment: I could have explored this a bit more]

She laughs about this but has repeated this. Is this an admission of low self-esteem? Negative self-image? Do others judge her in this way? p.2/3

'Sometimes I'm shy and sometimes I'm loud.' Is her behavior inconsistent because she wants to fit in with others? To minimize her difference?

She's aware of how she can act differently at different times. P.3

Adam

Feels young carers need to know that there are other YCs like them to 'tell them they're not alone.'

When asked if there was anything more that could be done to help him he said: 'I'd say yes because some people like me feel that it's just them helping and that and I think that if people have to care for people someone should go down there and tell them they're not alone and that and just bring them to a club like this or something fun and then get it off their mind and relax them a bit more. And yeah.' P.13-14

Theme of isolation?

	<p><u>For those who don't already go to YC group Adam wants to pass on the importance for getting things off their mind and helping them to 'relax a bit more.'</u></p> <p>He doesn't feel he needs help but thinks about the younger carers – thinks they need 'just a bit more support.'p.14 'I'd say for a younger carer, younger than me, I'd say maybe a bit more support. Um yeah, just a bit more support.' P.14</p> <p>Habib</p>
<p>Reticence</p>	<p>Anthony</p> <p>Refers to mother's suffering. <i>Reluctant to elaborate – hesitant.</i></p> <p><u>Explains in a matter of fact way that his mother has mental illness – not emotional – not detailed or specific about the kind of mental illness. No mention of emotional support that his mother needs or that she gets from him – why? Is it difficult for him to talk about? Or does he not take on that role? P.5</u></p> <p>'Right, er, yeah I guess so. Uhm. Yeah, I try to... Oh I don't know, I try to, I try to er, Oh, I don't know, sorry. <u>'Maybe idea of coping not coping is irrelevant. No choice.</u> He seems unsure that he is coping – says he tries to but not sure he manages it. <u>Apologetic 'sorry' repetition 'I try to' unsure of success – repetition could reflect his continued efforts but might demonstrate how much he tries but not necessarily with success?? Maybe he's unsure it is about coping. P.14</u></p> <p><u>When Anthony could not answer the question he apologized saying 'I'm having a difficult day today, sorry. Yeah, er...(pauses) can I get back to that one?' Apologetic – for finding things hard – (guilt?) Doesn't know what helps him cope – but again perhaps the interviewer's assumption is wrong – he's not coping and so avoids answering the question. This could be another hint of emotional impact of being a YC/talking about it. P.16</u></p> <p>Sadia</p> <p>Says that being a young carer does not affect her in any way. Maybe reflects her lack of awareness – understandable –</p>

SEN, age. P.4

'no' Definite answer – trying to hide something? Afraid to say it does so? Reluctant to share?

Clear answer - certainty about this p.4

Not specific about parents' 'illness'. She remains superficial, aloof. Why? Maybe sees this as private, too difficult to talk about, maybe doesn't really know? Vague, reticence. P.4

When asked if there is anything which someone could do to help, she pauses and says 'no'. Cannot think of anything she needs from others to help her. Or will not say. Why does she pause? Thinking about it or deciding whether to say? P.6

Reticent again when speaking about role as carer at home – why? Too emotional? Accepts caring role in the home as part of a norm?p.7 OR is reticence a coping mechanism??

Salma

When asked about the disadvantages about being a YC she says here that 'there is nothing bad going on.' She has assumed the question is about something 'bad going on.' She does not see any disadvantage about being a Y Carer, or does she just say this? Any denial? Reframing? Hiding the truth? P.5

BUT (in Accelerated childhood section) Considers Y caring role as difficult for the younger ones under 18 'studying issues' thinks it's 'really hard' for them because she doesn't 'think they can handle education and chores and family within themselves.'

'Within themselves' – suggests inside – keeping difficulties inside lonely internalizing difficulties, confined to them – not shared. 'handle' questions them being able to manage – mental capacity? P.5

This reference to Younger carers – is it a reflection on her own earlier experiences of caring when she was younger? This method (of talking in terms of other younger carers) distances her from her own experience – so she can talk about it more easily. Indirect reference to her own hardship also acts as a privacy boundary? P.5

P.7 Dad's not really 'physically unhealthy' – how then? What support does he need? More to do with cultural expectation of daughters?

	<p>But mentions that Dad has heart condition. [I didn't pursue this to find out how restrictive are their conditions, does she help them every day or as and when? – I felt it was a sensitive issue and that because she hadn't volunteered this I did not want to push for further information.] Mum has high blood pressure p.7</p> <p>But she considers 'younger carers' 'younger than 18' she thinks 'they would need help.'</p> <p>Younger carers need to be able to focus on education. Important for Y carers to take time out from the family – 'looking after a family 24 hours' harder for younger carers 'a lot harder for them than for me.' Is this reflecting how she felt when she was younger. Externalising the problems she used to face. Distancing it for herself. Preferring to talk indirectly about difficulty – so as not to betray her family??p.10</p> <p>Speaking of chores and education. '<i>handling</i> both at the same time then it's going to....lead to depression and stress and then it's going to become <i>harder</i>.' <u>Suggestion that things are hard to handle.</u></p> <p><u>Is she referring to how hard she has found it? Indirectly without betraying her own situation and parents. P.10</u></p> <p>P. 12 She talks of teachers asking her if she was OK. She knew they suspected that things were not Ok.</p> <p>She acknowledges that 'I used to look a bit depressed.'</p> <p>But she hid the truth 'I just used to say everything's finebecuase I wouldn't say it to the teachers otherwise they're going to put Social Services in, or somet, but I is fine.'</p> <p>Fear of being reported to social services. Therefore she said nothing? But there was something to say?</p> <p>Concludes, 'but I was fine' <u>trying to convince herself? P.12</u></p>
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	<p>Fear of being reported to Social services no longer exists as she is over 18! 'because it's like I'm 18' Suggests that previously didn't seek support – afraid to reveal/afraid of social services and being taken into care. See over yes she states this previous fear.</p> <p>Previously afraid to seek professional help? 'before it was a bit worrying' p.13</p> <p>Farhan</p> <p>Nadia</p> <p>Describes herself as a 'chatterbox' 'I talk too much. Other people say I talk a lot.'</p> <p>Why does she talk too much? What might be behind this? Friendly? Nervous? Wants to evade something? Prevent topic of conversation reaching a place she finds difficult? Is this good for her? Can she process what she is going through? P. 4</p> <p>Also in A3 Sees herself as ' I'm a bit different to everyone else coz I'm a carer for my dad, but that doesn't really affect uhm, anything coz I have my friends to talk and if anything happens.'</p> <p>Corrects herself 'nothing really happens though, like if I have something to say I tell my friends and they always listen.</p> <p><u>Covering up?</u></p> <p><u>Or normalizing her experience.</u></p> <p>Has friends to support her, friends she can talk to.</p> <p>Whole quote: 'I'm a bit different to everyone else coz I'm a carer for my Dad, but that doesn't really affect uhm, anything coz I have my friends to talk to and if anything happens. Nothing really happens though, like if I have something to say I tell my friends and they always listen so it doesn't' really affect me that much.' P. 5</p> <p>Fabina</p> <p>'I just need to look after him and that's it, and help my Mum.' Fabina describes that she 'just' looks after her brother and 'that's it.' But she also helps her Mum. 'She uses the word 'need' as if it is not her choice. 'just' playing down her role – making it sound small. P.5.</p> <p>When asked if being a carer has affected her she says 'sometimes....they like...' but then stops herself and says, 'actually it doesn't really affect me.' It is as if she wanted to talk? But stopped herself? Who are 'they'? What did she want to say? Started then stopped herself – guarded? Why? I think that I realized that there might be more that she wanted to say this but did not want to push her. P. 5</p> <p>Fabina said that she would not talk to others about her situation 'if it's personal stuff like proper personal then (she) wouldn't say it, if it's like OK to say it (she) will' and wouldn't mind.</p>
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	<p>She is guarded with others – is she being guarded with me? She keeps barriers up, limited disclosure to others. P. 9</p> <p>Re thoughts about the future, I tried to explore why she does not think about the future but she was reticent: She couldn't say why. 'No, I just don't.' p.10 She has plans after all? Now just passing the time? She thinks that she may 'probably be in college.' P.10</p> <p>Adam</p> <p>When asked if YCaring affects him he said, 'Um in ways it does, because sometimes I feel like I'm the only one, which I'm not obviously, but you just feel like it's really tough, cos, cos like, cos you're young and that you're not really open minded about stuff and you tend to think that it's just you and stuff but it isn't. Sometimes Adam feels like he's 'the only one' in this position – no one else. P.7 'It's really tough' Isolation. Feels isolated? p.7 Mentions age 'Open minded' – It think here he means experienced – knowledgeable. He thinks that when 'you're young' 'you tend to think it's just you and stuff but it isn't.' Adam has learnt that he is not alone and wants other younger carers to learn this. He shows concern about other YCs. Adam says that you don't have to feel 'that it's just you' – 'there's loads of help out there to help you.' Isolation. P.7 Adam explains that YCs can feel different and isolated from others, 'like mentally you think I'm the only one and stuff'. <u>Does he see this as 'unfair' Doesn't say it's unfair but perhaps feels this? Raising issue of support. P.7</u></p> <p>Habib</p> <p><u>When asked about any other important characteristics about him:</u> <u>'No, not really' suggests that there are other important characteristics about him but he doesn't want to talk about them??</u> Reticent about himself and self-identity. P. 5 Reticent about caring for Mum – doesn't volunteer information about her or his relationship or his caring role, when asked, needs to be encouraged. <u>Wants to keep this private? Too personal? P.7</u></p> <p>When asked if there is anything that someone could do to help him, he replies 'No, it's all right'</p>
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	<p>This short answer to the question suggests there is but 'it's alright' as it is. He is resigned as opposed to happy about the way things are. Acceptance of things as they are. Or reticence? P.10</p> <p>Again it seems there is but he doesn't want to talk about it – doesn't say just 'no.' 'no, not really.' P.12. It is hard for him? He is too young for the depth of questioning?</p>
	<p>Discussion – is reticence a symptom of the 'hardship' and or a coping mechanism? Boundaries important. May be they need containment – separate place where they can talk about thoughts and feelings YC group goes a long way but maybe within school more could be done? E.g. like Farhan had. EPS could give support via schools.</p>

Superordinate Theme 2 Benefits of Caring Role	Evidence from participant accounts
Positive self-identity	<p>Sadia</p> <p>Says she sees herself as 'caring' 'friendly' 'happy' <u>in a positive light. Appears to have a simple outlook. 'That's kind of it.' Doesn't look too deeply? Or only wants to talk about the positive? She talks of positive characteristics that others can observe and appreciate 'caring' 'friendly' 'happy'. 'that's kind of it' what about her? How does she feel about it? What about underneath what people observe? I am curious about what she doesn't talk about. P.2</u></p> <p>Sadia says that what's good about being a carer is that she likes to help. 'I like to help' But she hesitates and thinks for a moment 'uhm' <u>Doesn't say any other reason. Justifies it as good because it suits her personality? Caring seen as good. [I could have asked her what if she did not like to care?]</u>p.5</p> <p>The jobs she would like to do are all related to helping others: 'nursing,' 'TA' or a 'teacher.' <u>Is this because of the caring role that has been adopted as part of identity?</u> p.6</p> <p>Salma Describes herself in terms of helping others "I am a very lively outgoing individual who liejs</p>

	<p>to help uhm, people.” P.2</p> <p>Farhan</p> <p>Sees himself as mature p.7</p> <p>‘I think it’s made me more mature if I put it that way....’ P. 7</p> <p>Nadia</p> <p>V quiet</p> <p>Defines herself as a YC for her Dad – this is in answer to qun ‘tell me about yourself.’ ‘I am a young carer for my Dad’ Proud of this? P.2</p> <p>Describes herself as ‘happy, smiley person, I like to smile a lot.’ These are observable behaviours, on the surface, are they hiding anything? P.4</p> <p>Fabina</p> <p>When asked if there is anything good about being a YC she says ‘no’ there is nothing good about being a carer. Doesn’t see any benefits of caring. Opp to others. P.6</p> <p>When asked if caring for her brother has effected how she sees herself Fabina says ‘uhm, (pause) I haven’t really noticed.’</p> <p>She sounds unsure but admits to not having really noticed if caring for her brother has affected how she sees herself. OR doesn’t really consider herself? P.7</p> <p>Adam</p> <p>Sees himself as ‘nice’ ‘bubbly’ and ‘a nice person to talk to’</p> <p><u>Positive view of himself – positive self-identity. P.3</u></p> <p>When how he feels about being a YC he replied; ‘Um good and bad. Good because you know you’re helping people and that it builds your confidence up in looking after people and that, but no because you don’t get enough time to go out or do what ever you want and stuff. It’s really tough.’ P.9</p> <p><u>Adam can see the good and not so good aspects of caring.</u> Says he feels ‘good and bad’ about being a carer. He feels it is</p>
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	<p>'good because you know you're helping people and....it builds your confidence up in looking after people.' But he feels less good about it because 'you don't get enough time to go out or do whatever you want..... It's really tough.' <u>Time pressure. Time for yourself p.9</u></p> <p>Adam feels caring 'is a good thing because you're helping obviously and because there's people out there that are less able to do certain stuff you're able to help them so in a way it's good.' P.10</p> <p>Sees the good he is doing – this makes it/caring feel good. P.10</p> <p>Caring helps Adam not to be lazy – as he thinks he is. <u>Caring means 'then you're not lazy like what I am, like it tends to like to get you up and you doing stuff and that. He thinks it is good as a carer as 'you're basically active most of the time.'</u></p> <p><u>Is this a divided self? Implies that this is not me.</u></p> <p><u>Brings out the best in him? Prevents him being lazy which he thinks he might be.</u></p> <p><u>Sees himself 'as a good person' because he helps others 'family members, friends sometimes...' p.10</u></p> <p><u>Adam feels a sense of achievement?</u></p> <p><u>Adam feels 'confident' about himself – likes to 'go out there and show people that (he) can do it.'</u></p> <p><u>Feels he can prove himself to others p.13</u></p> <p>Habib</p>
Positive feedback	<p>Sadia</p> <p>Sadia sees herself as a 'caring person.' <i>Repetition of caring/care and 'really' gives emphasis to this.</i> <u>Trying to persuade herself or me? Where does this come from? Her caring role? Or is she justifying her role as something that fits with her anyway?</u></p> <p><u>Her role as carer defines her? What she gives to others important: 'people hurt and I care for them.' 'They have fun with me'. She sees herself responding to others, responding to the needs around her. Therefore she sees herself as a caring person? P.1</u></p> <p>Farhan</p> <p>Describes himself in terms of how others see him as he doesn't like talking about himself (<u>modesty</u>) 'I'm going to kind of</p>

	<p>run on what other people would say about me rather than what I'd say about myself, because I don't, I don't like speaking about myself a lot so taking it from people like the young carer adults that they see me as a leader, ' he respects the views listens to them; obviously gets positive encouragement from the the YC's youth workers. Says others see him as 'a leader, someone who's enthusiastic and a good communicator.' Therefore aware of his strengths - does this help him? P.3</p> <p>Says his views about himself are 'mainly it's a lot of views of myself are based upon what other people see as,' He shows awareness of this. Psychological theory related to this. Based on things he does at home and at school etc, 'the stuff I do at home, the work like I do at school and stuff like that...'</p> <p>Others highlight his individuality and strengths: 'people do say oh, you're not like this person or like that person etc. ' He says he gets recognition from other people 'so people do give me that recognition.' Seems to enjoy and value the recognition. So externally motivated to care as well?? He takes this on board and isn't afraid to let others know about this 'So I kind of take that on board and obviously put it out there.' P.4</p> <p>Also C5 awareness of strengths section. Refers to his maturity and how a lot of people say he has 'good time management as well, which kind of helped me towards my exams and stuff like that. ' which has helped him with his studying for exams as well. Generalised his skills as a carer to other areas of his life, strengths have helped him – pointed out by others. P.9.</p> <p>Nadia</p> <p>Fabina</p> <p>Adam</p>
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	<p>Refers to the fact that sometimes the help given is not appreciated, p. 8.</p> <p>Several of the Young Carers do not talk of positive feedback from others at all. In fact Anthony reluctantly states that, hypothetically, one can feel disappointed if hard work is not appreciated by the person who he cares for. 'It's hard that you, you know, if you did all this stuff and then they don't appreciate it,' (Anthony, p. 8).</p> <p>Habib</p>
Generalising skills	<p>Sadia</p> <p>Describes herself as a young carer in terms of being part of the group – not in terms of her role in the family/society. <u>Is this how she sees herself or how she is able/wants to articulate it?</u></p> <p>Says she cares for 'the people here' at the YC's project.</p> <p>Sees her role as a Young carer going beyond her family – <u>generalized to other areas of her life. Therefore has it become a major part of her identity? P.3</u></p> <p>She says she cares for her 'Mum and Dad' and 'brother and sisters' at home <u>- so the caring role is generalised at home too. P.3</u></p> <p>Salma</p> <p>YCs group 'very exciting' as she has recently become a 'volunteer youth support worker' Previously a Young carer but just a month ago once turned 18 became a helper. P.9</p>

	<p>'It's like trying to learn from what I've learnt from Health and Social care from that, advancing my knowledge to the extent that I know exactly how to handle people, even though its not going to be a family member, it might be someone else like my grandparents or an elderly person in the street,...'</p> <p><u>Wants to continue what she's learnt so far in her studies</u> – Health and Social care.</p> <p><u>Wants to continue learning taking it beyond her personal experience to help others.</u></p> <p><u>Wants to extend her experience of caring role to be able to</u> 'handle people, even though it's not going to be a family member.' Now part of her self-identity. 'I am able to help them with their holistic needs.' Feels experienced, empowered to help others in the ways she wanted others to support her??? Transference??</p> <p>Wants to be able to help others 'with their holistic needs.' (Salma, p. 14)</p> <p>Farhan</p> <p>Farhan saw that the YC's group offers him support and he gives support to other members of the group too – 'I can look at it both ways, from two sides really, that I come here and obviously meet up with other people quite like me and like obviously being one of the eldest..... you come here to help other people as well.'</p> <p>Farhan listens to others 'like their backgrounds and what they're going thorough and stuff.....you feel quite sad for them, so in that sense you kind of like you come here to help as well.'</p> <p>Farhan shows empathy for others 'you feel quite sad for them'– is this is a strength which has developed as a result of his own experience. <u>Generalising his caring role to beyond the family? Does this take away from his own sadness? Deflection??</u> p.15</p> <p>Nadia</p> <p>Wants to be 'a detective or a doctor..... I want to be someone who would help people, because I've been helping my dad and my dad said you can be whatever you want to become, so I is thinking of doing something that would help people like nursing in (like) homes...' P. 10.</p> <p>Fabina</p> <p>Adam</p> <p>Habib</p> <p>He again equates his YC role/identity with his role/identity as part of the YC group rather than his role at home looking after his Mum. Is this like transference? Is this easier to talk about because it is more public and less private – less</p>
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	<p>possibility of talking about his Mum and his relationship with her and how caring for his Mum impacts his life? [As an EP these thoughts would have been going through my mind – formulations and therefore it may have meant that I did not want to get him to talk more about an aspect of YC that he wanted to avoid talking about][Or is his identity as a YCarer firmly fixed /associated with the YC project group since his caring at home for him is normalized?] p. 10</p> <p>‘we have to look after the younger ones’ is this something that has been encouraged by the youth workers of is this linked to self-identity of being a carer and looking after others? P.10</p>
Preparation for future life	<p>Sadia</p> <p>Salma</p> <p>Being a YC means ‘helping parent’ ‘it’s about becoming who you are later in the future – <u>like molding yourself for</u> ‘later in the future’ <u>preparing for the future, identity-forming?</u> – <u>have her parents told her this? Is this her way of accepting the role? Positive reframing? Coping mechanism?</u></p> <p><u>Seeing benefits of caring for the future</u> ‘... as in the future it would help us when we’re older, it would help us understand how we are meant to be.’</p> <p><u>‘meant to’ repetition and suggests the right way to be, the correct way to act. But who or what determines this? Where have these ideas come from? Religious beliefs? Cultural expectation? P.4</u></p> <p><u>Suggests that it has been hard but benefits are now coming to fruition.</u></p> <p>Now ‘ready’ for ‘the future’ when she will ‘get married’ p.5</p> <p>YC role helps her being ready for future whens she gets married and leaves her parents. Future – marriage being ready for this is important to her. Caring role prepares for this so that she will be ‘ready’.</p> <p>Refers to idea of reaching an age 18 whens she is ‘going to be leaving my parents behind’ (says this v quietly) Doesn’t really want to or doesn’t really want to admit to this – guilt? Uncertainty. P.4</p> <p>Salma talks about specific female ‘us females’ role ‘to build up for the future procedure of the future generation’. ‘future procedure’ = <u>idea of circular tradition – circular</u> reciprocity. Separate female role. Sees YC as part of gender expectations. ‘as for my Mum it’s basically house chores which enables us females to build up for the future procedure of the future generation.’ P.8</p> <p><i>The word ‘procedure’ - showing teaching how things work how things are done carried out how things function. Passing on of knowledge. P.8</i></p>

	<p>Farhan In terms of his career, Farhan says he has a few things in mind: Teaching 'Sports doctor' 'Sports lawyer' <u>Related to his interests and helping others.</u> 'So I'm still looking into what I would study but for now I'm still thinking.'p.17</p> <p>Nadia Wants to be 'a detective or a doctor..... I want to be someone who would help people, because I've been helping my dad and my dad said you can be whatever you want to become, so I is thinking of doing something that would help people like nursing in (like) homes...' p. P.10. Also in Generalising skills</p> <p>Fabina</p> <p>Adam</p> <p>Habib When asked if there is anything about him which helps him, he said: um my inspiration for being a pilot um because pilot, you have a lot of pressure on your shoulder. When you transport people from country to country in planes and that's what we're doing here, we have to look after the younger ones and makes sure nothing really goes wrong with them so um they don't get into trouble with no fights. And so far it's bee so good.' This suggests that being inspired about possible future careers helps him. He can see that his current experiences will help him with 'pressure' in a future career – such as being a pilot. Does he mean responsibility instead of pressure here? Does he se responsibility as pressure therefore? P. 9.</p>

Superordinate Theme 3 Managing Impact of caring	Evidence from participant accounts
Support from others	Anthony

Suffering – he acknowledges explicitly for the first time?

Likes to meet others who have '*kind of suffered the same*' as he has. At YC's group

He can 'share' 'experiences' and help the younger ones.

There is the suggestion of him liking to impact/help others – this is important to him. Why? Helps him connect with others? Creates cohesion – later it is clear that this cohesion in society is important to him. Maybe at home he does not feel that he makes sufficient impact? Is this transference? He does not talk of impacting/helping his mother at home in this way. Maybe he feels he can't change situation with his mother. [The researcher acknowledges that is how she feels about caring for her parents- being an EP is a kind of transference and a coping mechanism? P.12

Helping others helps him. Acknowledges that coming to YC's project ('here') helps him – important to do '*other stuff*' but put as a hypothetical 'if I do other stuff' Does he do other stuff?? Recognises he needs to do other things to relieve stress – he's not sure what. 'I guess coming, coming here is a help. Maybe also I I do other stuff, other things maybe that can sort of release some stress.' P.16

Sadia

In answer to question what is important to you in your life she says 'My family and my friends, who I'm related to and who are important people.'

Family and friends (relationships) are important to her. Is there a hierarchy of people who are important to her? People who are important are important to her? Sense of duty? Cultural expectation? Family and relations come first.p.2

She understands herself as a YC through involvement with the group. What she says about the group 'It's like we are meeting new people and getting along with new people that I don't really even know' suggests a lot of change needs to adapt.' [But in the group there are mainly regulars - perhaps Sadia is only recently started to feel comfortable getting to know the others – I observed her when I attended the group sessions that she was involved with others]. I think she is referring to coming together with people not in her usual circles. P.3

Salma

Is YC identity linked to/seen as being part of the YC group or the role? P.4

Likes to meet 'new people and new other carers' p.9

They 'talk about how they are coping' and 'the ways that we can help each other out in situations like this.' Mutual support.

'Share opinions' and talk about 'ways to find positive and negative ways in helping our parents..' Mutual support.

	<p>Enjoys interacting with others who she can talk to. 'So I really enjoy it' p.9</p> <p>Farhan</p> <p>'I don't think it affected my friends or, coz at the end of the day if they say for instance I do have to be home by a certain time to be able to take my sister home so obviously it, for instance if my friends were like oh, how come you cant stay after school and they'd moan about it then I don't see them as being my friends, my friends are people that accept that and understand that and sometimes they'll come with me in that sense. So it hasn't really affected me in that way and school hasn't affected me either and in terms of like a job or whatever, no. It's more, mentally wise and stuff like that. '</p> <p>Being a carer didn't affect his friendship, in spite of constraints on his freedom (see A1) - his friends understand is situation and 'sometimes they'll come with me.' Friends supportive – with him not against him.</p> <p>He has to 'be home at a certain time to be able to take his sister home'</p> <p>If his friends moaned about this - didn't support him- he wouldn't consider them as his friends. V mature outlook.</p> <p>Protective factor.</p> <p>His friends are those who support him - they accept his situation, understand and sometimes they help him and go with him. P.8</p> <p>In terms of school – F says 'they've been... a lot through the exam period my sister was in and out of hospital and the school <i>kind knew about that.</i>' Appreciated the support at school. Teachers just knowing about what is happening at home and what he was going through was supportive.</p> <p>'because I'm quite close to my teachers and my head of year etc. like the help was put in place, so in that sense I was helped there and I didn't really move to college because I didn't want that kind of support system to go away'.</p> <p>Close relationship with teachers meant help is put in place.</p> <p><u>Talks explicitly of a support system – learning from his a-level subject to relate to his own life?</u></p> <p>Decided not to change school at yr 12 – 'because then (he'd) have to <i>build that whole relationship up again</i> and then the <i>trust</i> and so on, but if it's still the same school then that's still there, everyone still <i>knows you</i>.</p> <p>He recognizes the importance of his relationship with teachers at school – building up the relationship, trust and the fact that everyone knows him is important. <u>Helps him have a sense of belonging – school acts as a protective factor to support him.</u></p> <p>[Reflexive comment: Implications for other YCs and for professionals involved.]. P.13</p> <p>Farhan talks about the kind of help/support he got from school – flexibility 'they gave me extra time' 'when I is running</p>
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late.' He explains that if he had gone without breakfast 'a lot of teachers would go and buy me some.' Kindness shown by teachers helped him. He is v appreciative of them. P.14

[Reflections – I can relate to the significance of this – in UEL the tutors are very supportive and understanding- if I've been a little late to lectures sometimes, M Fox knows that on these days I was wanting to take my children to school at the price of being 20 mins late to lecture (wasn't able to take them when on placement). I was trusted to make the right judgment. I appreciated this. However, there were some other students who didn't understand and made insensitive comments/jokes... if I couldn't go out with them after lectures or if I was occasionally late, and sometimes this made me feel stressed/upset. But I learnt to forgive them and put it down to their ignorance and insensitivity to people who are not in the same position as them. To balance this there were several students on the Doct were very supportive (some in the same situation of caring for elderly parents and or children who were sick); we supported each other through difficult times and knew when it was appropriate to make jokes. Like Farhan I know who my friends are and I focus on them. People making comments or joking about people being different is a form of bullying and perhaps this is an area of support for YCs who feel different because their circumstances are different. I think this is an important aspect of diversity. Implications – helps schools think about the support they give YCs even if it is acknowledgement of what they are going through but ideally building a positive relationship of support and trust – perhaps it should be a policy that schools set up a meeting with YCs and their teachers to address their needs within school – EPs could facilitate this or input psychological knowledge to this effect].

'like a lot of my friends, they understand the situation, they respect that and help out when they can.' P.14

Nadia

Also in A3&4 Sees herself as 'I'm a bit different to everyone else coz I'm a carer for my dad, but that doesn't really affect uhm, anything coz I have my friends to talk and if anything happens.'

Corrects herself 'nothing really happens though, like if I have something to say I tell my friends and they always listen.

Covering up?

Or normalizing her experience.

Has friends to support her, friends she can talk to.

Whole quote: 'I'm a bit different to everyone else coz I'm a carer for my Dad, but that doesn't really affect uhm, anything coz I have my friends to talk to and if anything happens. Nothing really happens though, like if I have something to say I tell my friends and they always listen so it doesn't really affect me that much.' P.5

YC's group helps Nadia 'because at home I always help my dad and now I come to this youth club and it's like the people, ...we have fun and let loose and just enjoy ourselves.' Have fun, feel free, enjoyment at the Y C's group which she sees as a 'youth club' Club suggests a sense of belonging. P. 9.

Fabina

Has been coming to YC's group since she was 8 years old. She says she likes the YC's group because she likes 'Just making friends and just letting time pass.' This shows that friends at YC's group are important to her. *'just letting time pass,'* is an odd phrase. What is she waiting for? Time for herself? Doesn't really talk about support. P.8 But she likes the trips and the fact that there's like a special occasion they have a party.' P.9

Adam

Mentions people as being important to him – family, and close friends because they support him. 'the most important people in my life I'd say is my family and close friends because they really likes support me.' P.2 Mentions people as being important to him – family, and close friends because they support him. 'the most important people in my life I'd say is my family and close friends because they really likes support me.'

He feels that the YCs 'like this club, it gives you a lot of support and it brings you up.' Does he mean that the group helps with socialization or does it help YCs to feel lifted up? Does this suggest that he can often feel down – or did so before attending the project? Implies he needs lifting at times.

Adam says that YCs are important to him because 'it supports me' 'it gives me timeout of caring, to have fun' and he sees other people 'who are similar to' him. This helps with the idea 'of mentally thinking that you're alone, it kind of opens your mind to see that there's other people out there that are the exact same as you.' P.11

'So going back to the point of mentally thinking that you're alone it kind of opens your mind to see that there's other people out there that are the exact same as you. So I think the club's nice thing. . p.11

Adam likes the YCs group – sees it as a 'club' – membership, belonging, part of a wider identity. P.11

Adam feels that the club 'motivates' him, 'gets me up and going. It's a kick start in other words.' P.12

People at the club who work here and family members and friends as well, they're a really big support to help me.' P.13
Others support him also

Feels young carers need to know that there are other YCs like them to 'tell them they're not alone.'

When asked if there was anything more that could be done to help him he said: 'I'd say yes because some people like me feel that it's just them helping and that and I think that if people have to care for people someone should go down there and tell them they're not alone and that and just bring them to a club like this or something fun and then get it off their mind and relax them a bit more. And yeah.' P.13-14

Theme of isolation?

For those who don't already go to YC group Adam wants to pass on the importance for getting things off their mind and

helping them to 'relax a bit more.'

He doesn't feel he needs help but thinks about the younger carers – thinks they need 'just a bit more support.' p.14 'I'd say for a younger carer, younger than me, I'd say maybe a bit more support. Um yeah, just a bit more support.' P.14

Adam wants to pass on his wisdom re caring to those who may not belong to a group 'cares out there, you're not alone, there's other people out there to support you and lead you through the tough times and yeah.'

He refers to 'tough times' as if he is speaking from experience. P.17

Inevitability of tough times?

Habib

He says that friends are important to him 'keep me going though life' [Here I should have asked him how they help him going through life – what does he need help with in this life to help him get through? Is it a figure of speech and not literal?]

He values long-term friends, 'especially the ones (he has) known for a long time.'

'keep me going' repeats again on next page – he feels that he needs others to keep him going... p.3

He says that family are important to him but he hasn't volunteered much information about his family except that he lives with his Mum. Wants to keep this private? P.4

Distracted by interruption – didn't continue about family. P.4

Family important to him – 'they've been keeping me going through life.' He is hoping they will always be there for him: 'I hope er they'll keep me going until I die.' *But is he unsure about this or worried about this?* Or is this a figure of speech and not literal? 'until I die' could mean always rather than literally until he dies.

Again repeats 'keep me going' has already referred to this and here he repeats it also. P.4

'A young carer, part of being in this project is like, it has, it's like it's a part of me, coming here, enjoying to see people, friends, having a nice time, two hours of every Xday spend it with friends away from family. But some people here, er friends, I consider them as family, yeah. P.6

He associates being a YC with being part of the YC project group – why? It has become part of him 'it's a part of me'. He enjoys seeing people, 'friends, having a nice time, two hoursto spend it with friends away from the family.'

Needs/likes to be away from family.

	<p>He says that some of his friends are like family 'some people here, er friends, I consider them as family, yeah.' <u>This suggests that he sees the YC's group as a family - feels at home with them? P. 6</u></p>
Normalizing the role	<p>Anthony Says that interests and hobbies are not affected but perhaps he has not had the chance to consider this before – <u>maybe wants to give impression that all is OK? 'I don't think' suggests uncertainty about this – wants to normalize his situation 'same' – but same as what? Everyone else? Same as it has always been? P.12</u></p> <p>Sadia Unsure but says she sees no disadvantages of being a Young Carer – <u>maybe because she is not aware what it means?? Or because she has normalized it in her life. It is part of her life and she does not know any other way to compare? Example of acceptance? P.5</u></p> <p>Salma Learning from parents <u>Is she saying that things in life are circular? 'Things that go around in life.' Reciprocal? Duty? 'we learn from our parents as our parents teach us a lot of things that go around in life.' P.4</u></p> <p>Learning from others outside the family too – 'our second socialisation' 'I think being a young carer is showing us of who we are meant to be and how we are meant to look after our parents' p.4 Secondary socialization 'is our school, college, outside people and organisations that are working with us.' 'outside people' Idea of boundaries – family and friends and those outside of these realms. P.4</p> <p>She recommends that the Younger ones 'should give it their best shot, like education like how (she) did when (she) was younger.' p.5</p> <p>She sees the role as influential as it has allowed her to live up to cultural and religious expectations. 'Being a young carer has influenced me in many different ways as in like traditionally it's we like in my culture and my religion is that we look after our parents no matter what stress they are going through, no matter what pain'.</p>

	<p>Shows an awareness of different separate cultures ‘my culture’ ‘traditionally’ how it has always been. Is she saying that the cultural expectations of caring is already there Inevitability. ‘my’ repetition– suggests pride ownership of her ‘culture/religion’ p.6</p> <p>Personal use of 1st person – suggests ownership of this. ‘we, I – this self correction emphasis her personal belief and commitment to her culture and religion. She wants this known as she is proud of it. Religious beliefs – ‘we are meant to look after our elders.’ <u>Sense of duty due to religious beliefs.</u> Wanting to do what you are ‘meant to do’ ‘we’ those who are part of her culture? Caring for parents shows ‘respect.’ ‘It’s like we show respect to them’ ‘not meant to put them down.’ <u>Suggests hierarchy?</u> ‘Meant to’ = doing the right thing. ‘Not meant to hurt them....meant to make them happy and feel that we still value their experience because our parents have taught us a lot through our younger age until as soon as we leave home.’ Responsible for parents’ feelings e.g. ‘happiness’. Again this suggests sense of duty related to culture and religion. No mention of love. <u>No mention of love. Why? Too personal? Not the reason for the caring? Or is not made explicit? More about reciprocal duty?</u> <u>No use here of personal pronouns – ‘we’ ‘us’ generalized – distancing – privacy?</u> ‘because our parents have taught us a lot through our younger age.’ ‘Because’ justification for obligation to care for parents. Importance of learning from parents who have taught her through childhood – obligation to give respect and appreciation. P.7</p> <p>[Reflexive comment: No mention of love – If I talked about my parents I would refer to love and reciprocal love not duty I want them to be well looked after and cared for because I love them and they deserve to be looked after well.] p.7</p> <p>Salma obeys requests of her Dad ‘if my father asks me to do something I will do it’ Does house chores for her Mum [Refelexive comment – in my own culture and as a parent I try to do as much as possible for my children and they do very little for me – I need to be aware of this bias and how it may influence my interpretation of what is fair on the YCs] p.7</p> <p>Farhan Also in A3. Likes to be different: ‘I like to be different, I’ll put that out there,’ means he is OK to admit to this and to show others this quality. Not afraid to say this openly.</p>
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	<p>Knows he is different – but proud of this – come to terms with it. Doesn't want to be someone 'kind of normal' 'I just want to stand out yeah.' Believes that being different helps you stand out. <u>Pleased to be different – rationalizes that he is different from others. A coping mechanism? Positive reframing? Who has helped him with this? P.3</u></p> <p>Farhan's meaning of being a young carer relates to 'religion' 'In a good sense I have to refer back to my religion that when someone like a family or anyone like that is given a child with a disability it is more seen as a good thing than a bad thing...' When a family is 'given a child with a disability' he says 'it is more seen as a good thing than a bad thing.' <u>Given – by whom? God? When you are given something you take it/accept it? Given like a gift??</u> The quote helps him? P.10 Farhan refers to a quote that he remembers – 'that God won't burden us more than it can carry.' Clarifies that 'burden' is not quite right but this is how quote is phrased. P. 11 Farhan explains that 'if he's (God's) given you a trial....He has obviously given that for a reason.' <u>Caring is seen as a trial = test. 'Heaven' is a place 'up there'</u> <u>Trial to see if he is worthy of heaven? P.11</u> Farhan goes on to say that if a person treats 'that child with a disability right, may be a way you can get into heaven. It's what you do to that child, which kind of after she, my younger sister came out, that's how I like think, that if I do this for my sister, if I did that for my sister, then maybe I'll make my way up there.' Heaven. <u>Relates to his idea that he has had to think about his actions/behaviour. Others/ and god are watching him and seeing do these good acts.</u></p> <p><u>Farhan rationalizes/reframes his sister's disability as a positive challenge which could benefit him ultimately – extrinsic motivation? P.11</u></p> <p>Doesn't see caring as a burden 'No....no' V definite about this – repeated 'no' Burden has a negative connotation, and also something a person can't manage. [Reflexive comment: perhaps I am making a comment here – judgement – but I am doing it to build rapport?] P.12</p> <p>Also C2 Refers to 'love' 'coz I love my sister more so...' Unlike other pp 2 and 3 and 1? More than what? But he goes on to refer to other siblings. Talks of loving her more because of her disability 'I think my.... 'my mum, if this makes sense, loves her more than she loves us because it's just like she's got a disability so she's that much more <i>special</i> than we are'. Farhan's disabled sister seen as 'special' an 'angel' in comparison to the other siblings who are seen as 'normal' Whilst his younger siblings might be 'jealous' it is accepted by Farhan.</p>
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	<p>'Because we're kind of seen like <i>normal</i> and she's yeah, she's like an <i>angel</i> or whatever. So, yeah.' P. 12</p> <p>Nadia Doesn't think caring affects her as she feels she can achieve what she wants to in life. 'My dad's always telling me uhm, whatever you want to achieve just go for it and make sure nothing gets in my way, so nothing gets in my way'. This idea is repeated on p. 11 is it her attempt to reverse the role reversal back to her Dad being her Dad. Or does it show that he does try to reverse if himself? P.7 <u>Wants to normalize her experience of caring for dad.</u> Feels normal – 'I feel quite normal.' 'It's not like very big, coz my dad's the same like how any other girls would see their dad, it's like, it's just like helping around and that's it really, it doesn't really affect me now.' <u>'Now' ? did before? P.9</u></p> <p>Fabina 'I just need to...' Feels the need because it is her job? Or the parent see it as her job? Cultural expectation? 'just' minimizing it. Playing down the role which she takes for granted? p. 4</p> <p>Adam</p> <p>Habib When asked if caring affected him he said 'um no, not really because as I said, it's just part of me.' P.8 Identity – he can't separate being a YC from himself. It is part of him now. Maybe he can't remember not being a carer? Is he referring to being part of the group? Is this a shift away from describing the role of YC in terms of his caring at home to describing it as being part of a group, does this make being a YC easier to talk about? Easier to accept? Makes it more public, so that he can keep the private private. Shift in identity from private to a publically acceptable shared identity??] <u>Is it a coping mechanism? A welcome support?</u> <u>'I feel normal er I've been through it for a long time so I get used to it.'</u> <u>'Normal' – like everyone else – normalizing the situation</u> <u>'get used to it' – language suggests that he has adapted</u> <u>'been through it' – suggests that he sees caring as something difficult to get through. P.8</u></p>
Boundaries	<p>Anthony <u>Separates 'home' and 'outside of the home environment'</u> Sees himself as different in different environments – kinder outside of the home.</p>

He likes 'to take the initiative,' to lead, likes to motivate others – in the subtext is this because he gets a response from others? 'hopefully that will motivate the other people.' Likes to make an impact on others to 'influence them'. But this is outside of the home and contrasts with his comment – at home 'I am not that nice to my parents.' Why does he feel this? If no one is going to take part he'll try to step in first' Importance of people joining in – so they are not left out? Isolated? Transference ?? of what he experienced? P.3

Starts off in first person and refers to his mother – *matter of fact*
Then after doesn't talk using personal terms – not in first person, and 3rd person is plural – not directly referring to himself or his mother – generalizing/distancing his experience 'you' not 'I' and 'they' 'them' not 'my mother.' Why does he do this? To distance himself emotionally? Or to make it less about his situation so that he is not revealing information he considers private – to protect his mother's privacy? Showing respect for his mother? P.4

Oh, yeah I guess that's a bit confidential, p.9 Understandably wants to keep this private. Doesn't wish to talk about this. Why? Too painful? Doesn't want to betray mother's privacy? Doesn't want to talk about her to others? Wants to protect her privacy and his own? Fair enough. Or does he not know? Not discussed openly with him? P.9

Because of his circumstances he feels that he has become 'an older person.' 'The type of situation' he is in – this is how he sees it – has caused him to 'become an older person....I've become more mature, yes.'

This appears clear to him – repeats, clarifies his identity the type of person he has become due to his circumstances.

Circumstances have created dual environments – home – lonely he's been influenced by this and this in turn influences the relationship with his other environment – outside friends. P.14

Didn't want to talk about all aspects of the future. Boundaries – 'personal' aspects of his future wants to keep private. Maybe he's referring here to how looking after his mother will fit into his future? p.18

Sadia

Not specific about parents' 'illness'. She remains superficial, aloof. Why? Maybe sees this as private, too difficult to talk about, maybe doesn't really know? P.4

Reticent when speaking about role as carer at home – why? Too emotional? Accepts caring role in the home as part of a norm? p.7

	<p>Salma</p> <p>She separates out her time – when at college - education unable to help at this time. Education is a priority. 'As soon as' she goes home – takes over the responsibility 'the duty of both (my) parents' p.7</p> <p>Farhan Nadia Fabina Adam</p> <p>Habib <u>He says that family are important to him but he hasn't volunteered much information about his family except that he lives with his Mum. Wants to keep this private? P.4 Distracted by interruption – didn't continue about family.</u></p>
Making sense through knowledge	<p>Salma</p> <p>She refers to 'primary' and 'secondary socialization' – terms learnt in her studies? – <u>her studies maybe relevant for supporting her in her caring role. Helping her understand and come to terms with her own life and situation? Is this helping her process her situation and reframe it in a positive light? P.4</u></p> <p>(Also in Accelerated childhood section)'I became more mature at the age of 12 I tried to do the other things, researching everything, finding out about people's health and so on. Then it came to me that, oh my word, these people need help, so that's why after doing research I became so happy and then it was like I put my mind straight on my family and then education.' <u>It is only after doing research that she realized she had to help them.</u></p> <p>Farhan When asked what it's like being a young carer he talks about his sister – starts at the beginning when she was first diagnosed. He was 'quite young then' 'I was ten then' At that time his family: 'at that point' his 'family near enough hadn't come across disability before....'</p>

	<p>He lists in order of maturity each family member to emphasise that none of them knew about disability – starting from scratch in their knowledge base. He is practical, orderly about this. <u>Has the practical orderly approach been a coping mechanism?</u> <i>Repetition emphasizes the impact it had on all of them. 'hadn't' repeated word to highlight how none of them knew anything in the beginning.</i></p> <p><u>Found the discovery that his sister had a disability understandably difficult – describes</u> it 'like walking into a wall, perhaps.' <i>This metaphor suggests something sudden, a shock, wall – like a barrier to be surmounted/to get over. Hard hitting, impenetrable...</i></p> <p>But he says he read books to help him understand his sister's disability; when he was 11 and 12 – as an aside he jokes that at that young age he 'loved reading books.' He read a lot of books by different professors and stuff how to deal with it,'</p> <p>Talks about how he now remembers what he read and still applies what he learnt now. Says 'you have to <i>prepare yourself</i> when you do have someone in your family ...like that.' <u>Practical reaction to aid emotional response, preparation for his input, all he could do action – a coping mechanism which helped him?</u></p> <p>'Obviously' inevitability. Preparation important and necessary.</p> <p>Taking something 'on board' – coming to terms with it, P.5.</p> <p>He is very articulate when explaining that his sister has Rett syndrome and what this means for her – her development has been significantly effected and he explains the issues she has. This sounds well-practiced description. <u>He has no doubt explained this many times before.</u></p> <p>'She's got Rhett syndrome which is a mutation in the brain which it it kind of sets back everything so up until the age of one they progress normally so in terms of like crawling..... So she can't stand up by herself, she can't walk. She can't talk but she will like say random phrases like my name, my mum's name, calling my Mum stuff like that....' P. 6.</p> <p>Relates his studies to his situation 'sorry for using that term, we just used that in sociology today.' <u>Linking studies to his own life situation – resourceful. P. 18</u></p> <p>Nadia Fabina Adam Habib</p>
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Awareness of strengths	<p>Anthony <u>Prepared to take the lead – taking charge- being influential. Aware of strengths p.3</u></p> <p>Salma</p> <p>'I am a very lively outgoing individual who likes to help uhm, people, when it comes to my personalities which are helping, understanding, loving, caring and other sorts of uhm, personalities that there is.' Is this a result of being a YC? Or is it a justification to herself that being a YC is OK as it suits her 'personalities.' Refers to personality in plural – is this because she sees herself spit in some way? P. 2</p> <p>Says she likes to accept challenges when they come her way 'to show that I'm a very worthy individual' <u>in comparison to others?</u> 'not like, not like someone who would just stay around at home.' Personal construct 'active.....lazy. <u>Positive approach to challenge helps her feel worthy. Does she particularly need to help herself feel worthy?</u> 'worthy' to show – prove to herself or to others that she is worthy. Why does she need to prove she is worthy? Cultural/religious expectations? What does she mean by worthy? [Reflective comment: I could have explored this more in my questioning]p.2</p> <p>Farhan <u>Age significant to how he sees himself</u> = 'me being one of the oldest.... I've got to lead the group whether I like it or not but they say I'm good at it, so...' Who says? Duty? Unspoken sense of duty? <u>Feels some obligation to lead as 'I've got to lead the group...'</u> Modest about his strength but seems he agrees with and <u>wants to live up to what others say. P. 3</u> Doesn't think that being a carer has affected his school work and 'in terms of like a job.' He thinks that things can still be normal for him. But says it has affected him more 'mentality wise' psychologically. 'It's more, mentality wise and stuff like that.' But this is 'in a good way, not in a bad way.' P.8 Farhan thinks that caring has not affected how he sees himself but more how he acts 'it's not how I see myself it's more how I act.' <u>He has had to adapt his behavior. P.9</u></p> <p>Refers to his maturity and how a lot of people say he has 'good time management as well, which kind of helped me towards my exams and stuff like that. ' which has helped him with his studying for exams as well. Generalised his skills as a carer to other areas of his life, strengths have helped him – pointed out by others. P.9.</p>
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	<p>Nadia Fabina Adam</p> <p><u>Sees his strengths/personal qualities as 'helping' 'football'</u> <u>'Helping' – others</u> <u>'Football' - something for him</u> <u>Sharing out his strenghts/balancing self and others helps? P.12</u></p> <p>Habib</p>
Focus on the future	<p>Anthony Upbeat and certain that he thinks of the future. <i>Repetition = certainty. Enthusiasm about his aspirations.</i> But remembers that he hasn't explained. He wants to become a police officer. Explains his aspiration to help create a 'stable, cohesive community.'</p> <p><u>Police officer – enforcement to promote cohesion? Why an officer to create community? Perhaps is it about having authority, power control to create a world he would like to live in. having control where he feels he has none? Or does he see the police as people who serve the community?</u></p> <p>He demonstrates a sense of purpose for the future – where he can make a difference in society. Wants to make a wider community function better. Cohesion= stability. P.17</p> <p><u>He has a goal – to impact society and others, thinking about the bigger picture beyond his own world – but perhaps parallels his own experiences? In the future wants to see diverse community cohesive.</u> Hopeful about the future – that he will achieve his aspiration of becoming a police officer. P.18</p> <p>Didn't want to talk about all aspects of the future. <u>Boundaries – 'personal' aspects of his future wants to keep private. Maybe he's referring here to how looking after his mother will fit into his future? P.18 Of course there is some stuff but I might keep that personal.'</u></p> <p>Worries he will lose confidence. <u>Or is it that he worries about his ability to fulfill his future hopes?</u> <u>Police officer – a symbol - wish for someone who would tackle his situation? Lack of belonging? Father figure?</u></p>

'maybe sometimes my confidence with kind of (pause) kind of fail on me, because to become a police officer, it's really hard to get in and I'm just thinking to myself, you know, would I become a police officer and if I did how would I tackle situations within a community.....my worries, how can I keep myself alive.' P.19 Worries he will lose confidence. Or is it that he worries about his ability to fulfill his future hopes?

Police officer – a symbol - wish for someone who would tackle his situation? Lack of belonging? Father figure? P. 19

Wondering if he will get into the police officer training. not sure he would be able to tackle the things that are important to him in the future.

Recognizes that the job – police officer- is potentially dangerous – worried about staying 'alive!' Sees this as important.

Needs to be around to help others?

Uncertainty that things will be OK. Emerging theme – trying to give himself self-assurance in order to cope? P.20

"oh yes, yes. I guess, I guess what helps me cope is er (pause), I guess saying things to yourself like 'maybe it's going to be okay' p.20 But says he has 'never thought about that'

Repetition

Sadia

Has aspirations of getting a job when she grows up. 'I'd like to do nursing or a TA or a teacher.'

Aspires to working or going to university.

Has a simple plan with alternatives *Language is simple and straight forward* no complexities or elaborations as no complications perceived? 'I think' – slight uncertainty but this is understandable. P.7

Salma

Doesn't feel she needs help now because of her age – just turned 18 – proud of this. Does this suggest that she had needed it before? Was afraid to say so? *Mentions it several times and at the beginning of the interview.* Age determines the fact that 'soon I'm going to get married.' Therefore she's 'OK.' Why because she has a legitimate way out? P.9

Now thinks the experience has influenced her positively. *Now no fear of hassle from authorities 'because no one's going to hassle you'*

Feels in control of her future 'it's like you have your own future.' Does this suggest that she did not feel in control before?

	<p><u>Past is not her own? Hassled? P.12</u> Possibility to ask for professional help – counseling advice to help her help her parents so it won't interfere with education. She now feels free to get the support from professionals?? Because of her age? P.12 P. 13 Sees future as brighter than the past, 'My future, I think it's going to be brighter than how it used to be in the past' this suggests that it has not been good in the past - why?</p> <p><u>This is because she is hopeful to go to university. 'Or maybe doing an apprenticeship in the NHS because the main thing is that I wouldn't leave my parents, even if they are healthy...' p.13</u></p> <p>Farhan Identity - what is important to Farhan relates to his age and being a student at college. Also refers to what he wants to be in the future – wants to 'get into teaching, or medicine and stuff like that.' <u>Helping professions.</u> Relates to his activities = plays football – and coaches 'on the side'. 'I like playing football.' P. 2 He says he thinks 'I think everything is fine as it is for now, yeah.' 'yeah' <i>Convincing me and himself?</i> Laughing nervously? <u>I interpret that he is aware of the unpredictability, uncertainty. Not really focusing on the future here. P. 15</u> When asked about his hopes for when he is 21... 'going to uni, probably still be there or just came out, I'm not sure, because I'll be 18 when I leave college so yeah, I'd still be at uni. By then, yeah.' <u>Wants to go to uni after school. So fairly optimistic about the future but sounds a bit unsure.</u> <u>Wants what is usual for others.</u></p> <p>Nadia Thinks about the future - in terms of what she 'want(s) to become' when she is 'older and stuff. Yeah...but....' <u>However she trails off, giving the impression of uncertainty.</u> 'Probably I'm going to be in college. I'm not sure what I really want to become but I have some ideas.' In future wants to go to college <u>Not exactly sure what she 'really want(s) to become but (has) some ideas.'</u> <u>It is important to her to go to college and work hard.</u> 'yeah, so go to college and be working hard...and...yeah.' P. 12.</p> <p>Fabina When she was asked about the future she said that she didn't really think about it. 'Hmm, (pause)I don't really think</p>
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about the future.' Unlike other YCs she is not focusing on the future. P. 10

Re thoughts about the future, I tried to explore why she does not think about the future but she was reticent:

She couldn't say why. 'No, I just don't.' p.10

She has plans after all? Now just passing the time?

She thinks that she may 'probably be in college.' P.10

When asked if she had any ideas about what job she would like to do she said 'no' and did not want to explore. 'I haven't thought of anything yet.' P.11

Adam

Adam's thoughts about the future: He says he sometimes thinks about the future, about 'what will happen in the future, because you never know what's going to happen in the future.' He recognizes that the future is uncertain and it seems he feels that it is beyond his control. P.15.

But uncertainty of the future. P.15.

He resigns himself to what the future brings. Thinks that you have just got to get on with things 'sometimes you've got to take stuff by the hand and just carry on with it.' P.16 This is especially in respect to the future.

The uncertainty is related to his brothers and family' because I don't know how my brothers will turn out to be in the future or my family so I've got to wait and see from there.' His future is to a certain extent dependent on things beyond his control and linked to his caring role. P.16

Adam is hopeful about his education. 'maybe get a job or do (his) dream job which is being a footballer.' He has *dreams...* 'maybe' Why maybe? Only maybe? Why only maybe? Perhaps he thinks that caring will get in the way? Might need to carry on caring.

He has used the word hopefully three times – repetition means emphasis – he lives in hope. But he accepts that he 'may have to just carry on caring' if he 'needs to'. If he is required to, he will continue. But is hopeful for other outcomes in his future.

He hopes he will have his driving license - practical – laughs- at the idea of being fully grown up?? Having hope in spite of Uncertainty. P.16

Habib

He becomes more energized when talking about the future. 'yeah' p. 10

	<p>He believes he has several 'multiple choices of jobs'</p> <p>He looks to the future to see what he wants to be – does this mean he is not what he wants to be now?</p> <p>He's pleased with his ideas for the future. Yeah, lots of ideas' p.11</p> <p>Highlights his main ideas, he wants to be 'an inventor, an engineer, a pilot.' P.11</p> <p>In five years' time he sees himself as 'a successful student' and a successful person in the future getting good levels and getting a good job.'</p> <p>Says he 'thinks of his teachers' previous successful students to inspire him. I clarified what he meant by his teachers looking down at him. 'they remind me of some of their um, some of their older children that used to be with them when they were younger and I see myself as a successful person in the future getting good levels and getting a good job.' P. 11</p> <p>This relates to relationships and support from others!!</p> <p>I think he means that his teachers motivate him and compare him (probably the whole class) to previous students who did well and are 'now really successful' due to their 'hard working' ethic.</p> <p>He doesn't talk of any barriers to his education. P.12</p> <p>Gain links back to support and relationships.</p>

Appendix P: Ethics Approval Letter.

From: Mark Finn Sent: Friday, March 28, 2014 4:30:15 PM
(UTC) Dublin, Edinburgh, Lisbon, London To: Helena
Bunn Cc: Psychology Ethics; Karen WADEY Subject: RE:
Chasing ethics -

resubmission _____ Than
ks for the revised application Helena. The application is
approved. Karen - please regard this email from me as
evidence of approval (and attach it to your submitted thesis).
And wishing you all the best with your research. Shaila -
please record this application as approved and file the approved
application form Thanks, Mark

CD Containing recordings of all interviews