

**“WHO AM I?: AN EXPLORATION OF IDENTITY DEVELOPMENT OF YOUNG
ADULT CARERS IN THE UNITED KINGDOM AND UNITED STATES”**

by

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ABSTRACT

Young adult carers are those individuals aged 18-25 who provide unpaid care, support, and assistance to an ill or disabled family member. In the United Kingdom, there is a growing awareness of the experiences of young adult carers; conversely, the lives of young adult carers in the United States remain largely hidden from the view of researchers, policy-makers, and social care advocates. The very stark contrast in the position of young people with caregiving responsibilities between the United Kingdom and United Kingdom provides the contextual basis for this research study.

While it is understood that young adult carers play an important role in supporting their families, little is known about the effect providing care during youth and young adulthood may have onto a young person's development of identity. In contexts in which the social construction label of 'young carer' has been embedded into policy and community care practices, such as the setting in the United Kingdom, the ways the young carer label may influence, facilitate, or even exclude the receipt of formal support services is also unknown. In the contrasted context of the United States, in which the discourse of young caring is in its infancy stages of development, it is unclear how young people with caring responsibilities navigate their understanding of their identity, particularly in the absence of a socially constructed 'label' and additionally, the absence of formal support services.

Therefore, this doctoral research project sought to understand the potential impact that caring responsibilities may have upon the development of identity for young adult carers living in the United Kingdom and United States. The hidden nature of young caring in both country contexts called for a combination of sampling strategies to achieve its aims. There was a strong reliance on purposive sampling through gatekeepers, convenience sampling, and a small instance of snowball sampling, and a critique of the selected strategy, including an acknowledgement of the limitations of this research study will be presented. This comparative research utilized 55 qualitative semi-structured interviews from young adult carers in the United Kingdom (27) and United States (28). A thematic analysis was used to highlight themes connected to identity development.

As a small-scale exploratory study, this research project has produced rich data to further help raise further questions and explorations in future work. One major contribution of this work includes a multidisciplinary approach to its theoretical underpinnings, by drawing from developmental psychology, sociology, and sociolinguistic perspectives to better understand the identity development of young adults with caring responsibilities. Secondly, this work revealed the ways young adults with caring responsibilities opt to engage the socially constructed discourse on young caring through the complex use of language (and specifically, labels and codes). Through Foucauldian understanding of discourse and power, it was also observed that young adult carers/caregivers enact and perform and indeed *resist* the socially constructed identities that academia and social care policy and its practices has sought to impose upon them. This research supported previous understandings of ‘doing’ family life and its practices, whilst also advancing our consideration of young adults as active agents in their own lives and in their families. In all, this research study sets the stage for future work on the implications of the social construction of identities in low and advanced young carer awareness country contexts and the meanings it may have on the actual lived experience of young adults with caring responsibilities.

DEDICATION

I would like to dedicate this thesis to two groups of people. First, I would like to dedicate this thesis to my beloved family, for whom this work would not exist without their love, devotion, and sacrifice. Mother, Ferrell, and Granddaddy: your faith, selflessness, patience, and strength has enabled me to endure the unimaginable so that I could now experience the unimaginable. The best is yet to come.

I would also like to dedicate this thesis to the young people represented in this body of research. For those who participated in this research study, I am thankful for your vulnerability, openness, and graciousness. For the children and young adults with caregiving responsibilities around the world, this work is for you. It is you I kept in mind through the sleepless nights, the countless late night trips (and overnight stays) in the office, the many revisions, and the times I was not sure that I would finish this work. This is for you. For you too, the best is yet to come.

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LIST OF TABLES

Table 1.....	101
Table 2.....	102
Table 3.....	106
Table 4.....	107
Table 5.....	108
Table 6.....	109
Table 7.....	110
Table 8.....	111

LIST OF FIGURES

Figure 1.....	37
Figure 2.....	39
Figure 3.....	45
Figure 4.....	140

TABLE OF CONTENTS

Chapter 1: Introduction.....	1
1.1. Motivations for this research study.....	4
Chapter 2: Setting the stage: An introduction to young caring.....	6
2.1. Introduction.....	6
2.2. The profile of young caring.....	6
2.3. Cross-country context of the United Kingdom and United States.....	9
2.4. Our current understanding of young adult caring.....	12
2.5 Conclusion.....	18
Chapter 3: Sociological & Sociolinguistic understandings of care, ethics of care, & identity.....	19
3.1. Introduction.....	19
3.1.2. Rationale for the study of young adulthood.....	19
3.1.3. Young adulthood and identity.....	22
3.1.4. Social identity theory.....	31
3.2.1. The meaning of care.....	34
3.2.2. Family practices.....	36
3.2.3. The contested nature of care & young caring.....	41
3.2.4. Identity, care, & ethics of care.....	52
3.3.1. Introduction.....	57
3.3.2. Language & Labelling.....	57
3.3.3. Performance.....	64
3.3.4. Code-switching & Power.....	66
3.3.5. Discourse of young caring.....	69
3.3.6. Conclusion.....	73
Chapter 4: Methodology.....	74
4.1. Introduction.....	74
4.2. Research aim.....	74
4.3. Research paradigm.....	75
4.4. Epistemological positions.....	76

4.5. Rationale for international comparative research.....	77
4.6. Ethical issues.....	79
4.7. Participant vulnerability.....	79
4.8. Anonymity and confidentiality.....	80
4.9. Potential for harm or distress.....	82
4.10. Informed consent.....	83
4.11. Multiculturalism and diversity.....	84
4.12. Reflexivity.....	84
4.13. Researcher-participant relationship.....	85
4.13.1. Methods: Introduction.....	87
4.13.2. Ethical approval.....	87
4.13.3. Sampling strategy & rationale.....	87
4.13.4. Study settings.....	95
4.13.5. Identifying participants.....	97
4.13.6. Semi-structured interviews.....	99
4.13.7. Research questionnaire design.....	100
4.13.8. Pilot study.....	100
4.13.9. Main research study recruitment: Determining data saturation.....	102
4.13.10. Recruitment strategy.....	103
4.13.11. Main research study participants.....	108
4.13.11.1. Age.....	109
4.13.11.2. Gender.....	110
4.13.11.3. Sample composition.....	111
4.13.12. Data analysis.....	112
4.13.13. Selection of quotations.....	113
4.13.14. Conclusion.....	114
Chapter 5: Identification with the young carer identity in the United Kingdom.....	115
5.1. Introduction.....	115
5.2.1. The moment of discovery: You are a young carer.....	117
5.2.2. Care as a family role.....	125
5.2.3. Conclusion.....	133

5.3.1. Introduction.....	134
5.3.2. The acceptance of the young carer identity.....	135
5.3.3. Is the young carer identity beneficial?.....	138
5.3.4. When the experience of young caring does not lead to the receipt of services.....	142
5.3.5. When the young carer identity has negative consequences.....	149
5.3.6. Using the young carer label in certain contexts.....	152
5.3.7. On not identifying as young adult carers.....	162
5.4.1. The sibling perspective on the young carer identity.....	166
5.4.2. On not identifying with the young carer identity.....	167
5.4.3. On identifying with the young carer identity.....	172
5.4.4. Conclusion.....	175
5.5. Conclusion.....	176
Chapter 6: Identification with the young caregiver identity in the United States.....	180
6.1. Introduction.....	180
6.2. Identifying as a young adult caregiver.....	181
6.3. Using the young adult caregiver label.....	188
6.4. Understanding the value of the young caregiver identity.....	193
6.5.1. Introduction: The sibling perspective on young caring.....	202
6.5.2. The types of care providing by sibling young adult caregivers.....	203
6.5.3. Why sibling young adult caregivers may not identify as caregivers.....	204
6.5.4. When sibling young adult caregivers identify as caregivers.....	214
6.5.5. How sibling young adult caregivers receive support.....	218
6.5.6. Conclusion.....	222
6.6. Conclusion.....	224
Chapter 7: Conclusion.....	229
7.1. Introduction.....	229
7.2. Review of the thesis.....	229
7.3. New contributions to knowledge.....	235
7.4. Limitations to this study.....	237
7.5. Research findings not addressed.....	243
7.6. Implications for future research and conclusions.....	246

References.....	252
Appendix 1: Participant information sheet and consent form.....	287
Appendix 2: Recruitment flyer.....	292
Appendix 3: Research study questionnaire/interview protocol.....	293

CHAPTER 1: INTRODUCTION

This thesis is an exploration of the identity development of young adult carers in the United Kingdom and young adult caregivers in the United States. To date, there has been little academic scholarship on the way young people with caregiving responsibilities consider the formation of their identity. Furthermore, there is little existing research on the experience of identification with the young carer/caregiver identity for young people in the United Kingdom and United States. This current study adds to the knowledge on young adult carers/caregivers by examining how they may come to identify as young carers/caregivers, how they navigate that identification, and the impacts it may have on their sense of identity. This research study also offers a new perspective on the ways identity and identification for young adult carers and caregivers can be influenced across two different country contexts.

While there is a growing body of research on the experience of young adult carers in the United Kingdom, there is far less research in the United States on young caregivers and young adult caregivers. It is generally accepted that the United States is around 20-25 years behind the United Kingdom in the formation of young caregiver awareness, recognition, policy, and formal support services and interventions. There are only two national studies to date on the experience of young caring in the United States; these will be reviewed in Chapter 2: “Setting the stage: an introduction to young caring”. Only one national organization exists to provide formal support to young caregivers in the United States. There is also a lack of a common language to discuss young caring, and one may encounter several different words to describe young people with caregiving responsibilities. This adds to confusion and lack of understanding within the United States.

In contrast, the United Kingdom is positioned as the global leader in research, policy, and supportive interventions for young carers and young adult carers. Across the country, there are hundreds of non-profit organizations, *young carers projects*, that are dedicated to supporting children and young adults with caring roles. There is increasing legislative movement to strengthen the rights of young carers and young adult carers across the country. While research on the lives of young carers is largely focused in England, there is a steady and growing body of research on the experience of young carers in Scotland, Wales, and Northern Ireland. Compared to the United States, the public representation of young people with caregiving responsibilities is

increasingly acknowledged. However, the United Kingdom is far from a utopia for young carers and young adult carers. The period of austerity and cuts to social care services has meant that formal support for young carers and young adult carers has been negatively affected. Services have been greatly reduced and in some local authorities, formal support for young carers and young adult carers is non-existent. The cuts to disability support have also had a reverberating effect on children and young adults with caring roles, as it means that the family members for whom they provide care often find their formal support reduced. In some cases, this necessitates an uptake in the amount of care that young people may need to provide in their families. Furthermore, whilst it is not common for young people in the United States to refer to themselves as “young caregivers”—recalling that there is lack of language available in the United States—it is also true that young people in the United Kingdom may also be unaware of their status as young carers or young adult carers. Like their counterparts in the United States, they are deeply aware of the contributions that they make to their family, however, they may not refer to their action as “care”. This may mean that young people do not identify with the young carer identity because they are unfamiliar with such a label.

We not yet fully understand how young people come to identify as young carers or young adult carers within the contexts of the United Kingdom and United States. This research takes the view that the identification moment with the young carer/caregiver identity may have profound impacts on young people’s understanding of their sense of self. Part of this study’s uniqueness is its reliance on multidisciplinary approaches to understanding the lived experiences of young people with caring responsibilities and their development of identity. Therefore, this research seeks to explore how young people understand identification and identity as it relates to the positionality of young caring.

In the following chapters, I present the research study that emerged from the questions of identity exploration for young adult carers and caregivers in the United States and United Kingdom. This international comparative research study involved 55 semi-structured qualitative interviews with young adult carers/caregivers in the United Kingdom and United States.

Chapter Two will present an introductory literature review for the current understanding of young caring in the United Kingdom and United States. This literature review will begin with the profile and statistics of young caring in the United Kingdom and United States. It will follow

with a close examination on the reasons for such a discrepancy on the state of young carers and young adult carers between the United Kingdom and United States.

The third chapter holds the extensive theoretical literature review. It will begin by discussing the rationale for the study of young adulthood and theories promoted within lifespan research, namely the theory of emerging adulthood. It will present both supportive arguments and criticism for this theory. Finally, it will address the connections between the theoretical framework of young adulthood and the existing theories on identity development for young adults. An overview of the social identity theory will be presented. This will include a discussion of the relationship between identity and identification, as well as the concept of multiple identities and roles. The latter half of the chapter will engage critically with the notions of caring for and about within the context of multi-generational, interdependent caring relationships. Key terminology in this section will include sociological literature on family practices and the ethics of care. Close attention will also be given to the historical debate of the social construction of young caring and its controversial position in the disabled parents movement. The contested nature of care and young caring in the context of policy and practice in the United Kingdom and United States will be presented and examined. Finally, this chapter will draw upon post-modernist and post-structuralist theories, such as the work of Foucault, to discuss the intersections of labelling, code, performance, and power, in view of the ways young people negotiate the label of 'young carer'.

Chapter Four will present the methodology for this body of research. The research questions and aims will be presented. Next, this chapter will review the research paradigms and epistemological underpinnings of this research study. A rationale for why this research involved a qualitative, inductive, interpretive approach will be provided. The chapter will also address the ethical issues and informed consent process for the participants in this study. Next, the chapter will provide a detailed examination of the selected methods for this research study. There will be a significant discussion on the recruitment process for the participants to this research. Finally, the chapter will conclude with a reflection on the data analysis for this study.

Chapters Five and Six will present the major findings for this research study. Chapter Four will examine the identification process for young adult carers in the United Kingdom. Chapter Five will examine the identification process for young adult caregivers in the United States. It will discuss the close relation to identification and identity for young adult

carers/caregivers, and provide an in-depth discussion on how they come to identify (or may not) as carers/caregivers. The ramifications for their identification will be discussed in detail, including the impacts on their ability to access formal support as they transition to adulthood.

Chapter Seven will present the concluding thoughts on this research study. The major findings for this research will be reviewed, as well as a reflection on the limitations of this study. This chapter will also address major findings in this research study that the space limitations for the thesis did not allow to be included in this work. I will conclude with implications for future research and directions for practitioners.

In this chapter, I have provided an overview of each chapter to be presented. Before moving on to the introductory chapter to young caring, I will address my motivations for this research study.

1.1.MOTIVATIONS FOR THIS RESEARCH STUDY

Before I discuss the crux of this body of research, I feel that it is necessary to reveal my positionality to this research. I am a former young caregiver from the United States. When I was 11 years old, my mother had a spinal surgery performed incorrectly. This surgery left her in chronic pain and unable to return to work as a registered nurse. My older brother, who is seven years older than me, left his first year at university to come home to begin providing care for me and my mother. At 19 years old, my brother unexpectedly became a young adult caregiver. He obtained full-time paid employment to financially manage our home. He also became responsible for the care of our mother, including intimate personal care. In addition, he did the cooking, cleaning, and transportation needs for our family. Like many other young adult carers and caregivers, we did not have formal support. As I lived in the family home, I also helped to provide care for my mother. My brother, however, shielded me from the more negative aspects of caring, and consequently, caregiving did not prevent me from attending school or university. Our lives were forever changed. Because of the responsibilities associated with his caring role, my brother was not able to finish university. He has only recently returned to university and graduated this year with his Associate's degree. Throughout our family experience, it was abundantly clear that caregiving shaped both of our lives. For my brother, he expressed that caregiving had completely shaped who he was. However, it wasn't until recently through my own research, that we began to see ourselves as "caregivers". This was a new-found identity for

us. Our awareness as caregivers, along with the new knowledge of how prevalent young caring is in the United States, was a revelatory experience for us. It is through our experience of understanding how caregiving shaped our lives that this research is fueled. In the effort to maintain full disclosure as a researcher, I felt it necessary to provide the reader with my personal connection to this research. I will consider how my personal experience may affect the research study in the Methodology chapter. Now, I turn to the introductory literature review for this study.

CHAPTER TWO: SETTING THE STAGE: AN INTRODUCTION TO YOUNG CARING

2.1. INTRODUCTION

This chapter will present a review of applicable literature for this research's focus on identity development in young adult carers in the United Kingdom and United States. First, I shall begin with a profile of young carers in the United Kingdom and United States, as our understanding of the young carer identity is derived from the conceptualization of young caring during childhood. Most young carers become young adult carers once they reach adulthood (Becker, 2008) so a foundational understanding of the characteristics of young carers is wholly necessary. Next, this chapter will address the cross-national context of young caring in the United States and United Kingdom, as this will undergird the comparative nature of this research study. I shall then review the profile of young adult carers in the United Kingdom and United States, noting the paucity of research on the lived experience of young adult carers in both countries.

2.2. THE PROFILE OF YOUNG CARING

There are nearly 3 million children under the age of 16 in the United Kingdom who live with at least one family member who has a chronic physical or mental health problem, illness, or disability (Becker, 2008). Becker (2008) asserts that not every child living in a home with an ill or disabled family member will become a young carer because there may be other adult family members who shoulder most of the responsibilities for care, or the family may receive formal support through paid carers and other modes of assistance. For those children who do take on more substantial caring roles in the family, the term *young carer* has been used to describe their role.

In the United Kingdom, the label "young carer" has been used to describe those under the age of 18 who provide care for a family member(s) with an illness, disability, or health condition requiring care, support, or assistance. Whilst this term has been in use since the late 1980s (O'Neill, 1988), a definition of young caring was established by young carers scholar Saul Becker in the United Kingdom in the early 1990s and has become widely accepted (Aldridge & Becker, 1993). His traditionally cited definition established that young carers are:

children and young persons under 18 who provide or intend to provide care, assistance, or support to another family member. They carry out, often on a regular basis, significant, or substantial caring tasks and assume a level of responsibility which would usually be associated with an adult. The person receiving care is often a parent but can be a sibling, grandparent, or other relative who is disabled, has some chronic illness, mental health problem or other condition connected with a need for care, support, or supervision (Becker, 2000, p. 378)

This definition from Becker (2000) has been used as the defining standard for categorizing young caring for the United Kingdom and has influenced similar definitions in the United Kingdom and around the world (Rose & Cohen, 2010). Other definitions have included a focus on the impacts on the child, such as the definition offered by Cree (2003, p. 301), stating that young carers are those “whose lives are *affected* by the illness or disability of someone in his or her family”. Heyman and Heyman (2008) suggested that young caring definitions that focus on adverse effects have arose from a focus on risk factors in wider social work practice. Despite the lack of a completely verbatim accepted definition, there is now considerable agreement regarding the characteristics of young caring, particularly in regards to the levels of inappropriate care they may take on in the home and the experience of negative, adverse impacts (Aldridge & Becker, 1999). Previous national surveys in the United Kingdom have established that over half of young carers are from lone parent families and provide care for ill and disabled mothers (Dearden & Becker, 1995; Dearden & Becker, 1998; Dearden & Becker, 2004). Research has indicated that girls are more likely to be classified as young carers than boys, yet boys do act as young carers in significant numbers (Becker, 2008; Dearden & Becker, 2004). About half of the young carers surveyed in 2003 provide care for a family member with a physical illness or disability, followed by mental illness (29%), learning difficulties (17%), and sensory impairments (3%) (Dearden & Becker, 2004). It is also true that young carers may provide care for more than one person, if either parents, siblings, grandparents, or other family members have care needs. Most young carers engage in domestic tasks in the home, such as cleaning and cooking (Becker, 2008). 48% of young carers are involved in medicine administration and may give injections to their loved ones (Becker, 2008). A striking 82% of young carers provide emotional care and support; this may be characterized by sitting (or “keeping company”) with an ill family member, providing a listening ear, or helping a family member make decisions (Aldridge & Becker, 2003; Becker, 2008; Dearden & Becker, 2004). One in five young carers

engage in intimate care tasks, such as bathing, toileting, and helping their family dress (Becker, 2008). Young carers may also be involved in household responsibilities, translating for a family member (if English is not the first language), and aiding the family member to walk or stand if mobility issues are present (Becker, 2008). Because young carers can be involved in significant amounts of caring, often without support, there is concern of adverse negative impacts to their physical health and mental-well-being (Becker, 2008). Young carers are at risk of social isolation, depression, anxiety, physical pain from aiding their family member (e.g., back strains), educational problems such as chronic absenteeism, tardiness, and poor school performance (Becker, 2005). Young carers may also experience a number of positive effects from caring such as a close bond with their family members, enhanced sense of maturity and responsibility, and various life and social skills (Dearden & Becker, 2000).

The label “young carer” has served a variety of beneficial purposes, including group membership, aiding in public representation, garnering societal and governmental recognition, using a generally accepted/universal term across health and social care professionals, educators, and researchers. However, the term “young carers” may also occasionally be used by health and social care professionals to describe those between the ages of 18-25 years old. The term “young adult carer” is more typically used to indicate a carer between the ages of 18-25 years old. This research study will use both labels as appropriate.

In the United States, there is an absence of an agreed upon name for young caring in childhood and young adulthood (Kavanaugh, Kalipeni, & Stamatopoulos, 2016). Shifren and Chong (2012, p. 113) affirm this position: “Currently, no general consensus exists for the operational definition of young caregivers”. One may find the terms “young caregiver”, “caregiving youth”, or “young adult caregiver”, amongst others, used to describe children and young adults with caregiving responsibilities. Notably, the lack of an accepted language for young caring has proved to serve as a barrier for identification and recognition of young caring in the United States. Kavanaugh, Stamatopoulos, Cohen, & Zhang (2016, p. 30) defined caregiving youth as those under the age of 18 who are “providing substantial care, usually on a long-term basis, to dependent family members of all ages who have physical and mental health conditions, disabilities, fragility, and other problems”. This definition does not vary widely from the accepted definitions in the United Kingdom, although it notably does not mention inappropriate levels of care and impacts to the child as found in some definitions found in United

Kingdom literature (Cree, 2003; Heyman & Heyman, 2013). Kavanaugh et al. (2016) noted that the characteristics of young caring are not expected to diverge from the characteristics in the United Kingdom and in other countries in which young caring has a more advanced public representation. I suggest that in thinking of a *young caregiver identity*, we can look to the *young carer identity* found within the United Kingdom for an understanding of the lived experiences of young caregivers in the United States. In sum, I also surmise that the characteristics of young caring are similar between countries. This research is concerned with the variance that may occur with the receipt of formal support and its potential effects on identity development, as the absence of the opportunity to seek formal support is undoubtedly the most striking contrast in the young caring experience in the United Kingdom and United States. In addition, this research will examine closely the implications of an absent language to describe young caring, particularly in relation to the effects on identification and identity.

Next, I will examine the variance in contexts between the United Kingdom and United States in young caring.

2.3. CROSS-COUNTRY CONTEXT OF THE UNITED KINGDOM AND UNITED STATES

Leu and Becker (2016) created a cross-country classification scale to illustrate the level of awareness and policy responses to young carers. To be clear, Leu and Becker (2016) state that this scale addresses the systemic responses to young carers, rather than the characteristic profile of young caring. Leu and Becker (2016) suggest that the characteristics of young caring in advanced capitalist societies look similar despite the differences in country's welfare regimes. Nevertheless, the Leu and Becker (2016) classification scale is useful for providing the contextual differences of the United Kingdom and United States. According to the scale, the United Kingdom can be classified as *advanced*, which is the second tier from the top (Leu and Becker, 2016). Currently, the United Kingdom is the only country to receive an advanced classification, and therefore, is rightly considered to lead the world in young carer awareness and policy responses. Prior to the 1990s, academics, politicians, and social care professionals did not recognize young caring (Becker, 2008). With the advent of the first set of small-scale studies in the late 1980s on young carers, the profile of young caring in the United Kingdom began to rise. Becker (2008) highlights the extensive body of research from the Young Carers Research Group

at Loughborough University in England for leading to increased scholarly understanding of young caring. Through the 1990s and early 2000s, media attention and documentaries on the lived experiences of young carers also helped to raise the profile of young carers. National non-governmental organizations (NGOs) such as the Carers UK, the Children's Society, Princess Royal Trust for Carers, Barnardos, and Crossroads, further championed the needs of young carers through funding qualitative and quantitative research and dedicated advocacy work in practice and in policy (Becker, 2008). Within the United Kingdom, there has been a development of legislation to give young carers legal rights to assessments for formal support, the most progressive of these is The Care Act 2014 and the Children and Families Act of 2014 in England. As further proof of the United Kingdom's advanced status, they point to the existence of over 350 young carers projects around the United Kingdom in contact with around 30,000 young carers (Becker, 2008; Leu & Becker, 2016). However, the access to formal support can vary widely across the United Kingdom, and the time of austerity has made the threat of cuts to social services increasingly a matter of focus for dedicated young carers service provision. An Action for Children survey in 2011 found that almost a third of young carers dedicated services in the survey are expected to close or are at significant threat to do so, and nearly all expected to drastically reduce the amount of services they could provide (Action for Children, 2011; Heyman & Heyman, 2013). In Britain, continued parallelism with the United States has much to do with the "privatization of welfare, reduction of state services, and increasing emphasis on informal networks to support the care" of aging family members (Phillips, 1995, p. 45). The continued hidden nature of young caring, coupled with notions of the home as a private sphere, cultural understandings of intergenerational care, and stigma, often mean that children and young adults with caring responsibilities may not receive formal support services. Currently it is estimated that there are over 175,000 young carers under the age of 18 in the United Kingdom, and only 30,000 young carers may be in receipt of a formal support service (Becker, 2008). As indicated by Leu and Becker (2016), most young carers and young adult carers in the United Kingdom will not receive official identification or receive formal support in connection to their caring role.

Moving down the Leu and Becker (2016) scale, the United States has been placed three places below the ranking of the United Kingdom. Giving the United States an *emerging* classification, Leu and Becker (2016) argue that the United States has a growing public awareness of young caregivers with a small yet growing research base. Kavanaugh et al. (2016)

completed a scoping review of young caregiver literature in the United States, citing a total of 22 published peer-reviewed empirical papers. There are no specific legal rights for young caregivers or for young adult caregivers. There is one non-profit organization dedicated to supporting children with caregiving responsibilities, the American Association of Caregiving Youth. While influential in leading the national discourse on support for young caregivers, this organization's front-line work with young caregivers is largely focused in its base in the South Florida area. Their ability to expand nationally has been hampered by the limitation in resources common in non-profit agency work, in conjunction with the barriers in assessment outreach across school systems (Kavanaugh, Kalipeni, & Stamatopoulos, 2016). The only existing portrait of the national prevalence of young caring in the United States was completed in 2005 by the National Alliance for Caregiving—over a decade old. This research study used figures extrapolated from the United States Census to report that there is an estimated 1.3 to 1.4 million children with caregiving responsibilities in the United States. It is typically thought that the figure is a very low estimate, and numbers would be much higher in present time (Kavanaugh, Kalipeni, & Stamatopoulos, 2016). As with the United Kingdom, most young caregivers and young adult caregivers in the United States will not receive official identification or receive formal support in connection to their caring role.

Why has the profile of young caring ceased to reach widespread national attention in the United States? Leu and Becker (2016) argue that the strong reliance on the privatization of the health care system in conjunction with mounting structural inequalities has excluded many from participation in the “for-profit” care market. This exclusion has led children and young adults to serve as the safety nets for their families’ care provision, shifting them into significant caring roles at young ages. Leu and Becker (2016) also assert that the difference of perspective on children’s rights between the United States and United Kingdom may impact the way children’s unpaid care work in the home is perceived. The United States has not ratified the UN Convention on the Rights of the Child, one of the very few countries in the world to do so (Leu and Becker, 2016). Indeed, the United States is the only UN member country to have failed to ratify this treaty. The UN Convention on the Rights of the Child places children’s rights to relationship on the child, rather than on the parent or the state (Levesque, 1996). Previous research has argued that the United States devalues children’s rights in favor of parental rights, and the UN Convention on the Rights of the Child would demand greater protection of legal power to

children (Engman, 2015; Levesque, 1996). Levesque (1996) states that if the United States embraced the UN Convention on the Rights of the Child, this would radically transform American jurisprudence and academic discourse, a transformation that upholds children's personhood status to such an extent never been seen in the United States. The UN Convention on the Rights of the Child has critical application to young carers globally, as the rights afforded to young carers in the United Kingdom appear within the framework in the treaty (Kavanaugh, Kalipeni, & Stamatopoulos, 2016). As political rhetoric in the United States has been overcome with conservative fears of a loss of parental rights, this has had a detrimental effect to the development of recognition for young caregivers in the United States (Engman, 2015).

In addition, the lack of public discourse on young caring in the United States has cultivated a culture of misunderstanding about the nature of young caring within families (Kavanaugh, Kalipeni, & Stamatopoulos, 2016). There remains a concern that signs of young caring in families may be misinterpreted as problems of neglect and abuse by the parent(s), and there is a fear of social service involvement (Kavanaugh, Kalipeni, & Stamatopoulos, 2016). This is not unlike the setting in the United Kingdom, and fears of social service involvement remains a barrier in the identification of young carers hidden from social care support services (Aldridge & Becker, 1994). However, generally, with the addition of legislation such as the Care Act 2014 in England, it is becoming increasingly understood from a political standpoint that young caring in the home does not necessarily indicate parental neglect or abuse. Both countries, therefore, can make improvements in the education and awareness of young caring within their respective social care sectors.

A final note: this research study was not intentionally designed to make intra-country comparisons. Therefore, this research will only broadly compare the context of young caring for the United Kingdom, rather than drawing comparisons between England, Scotland, Wales, and Northern Ireland. Future research should examine the state of young caring in an intra-country context.

2.4. OUR CURRENT UNDERSTANDING OF YOUNG ADULT CARING

Becker and Becker (2008, p. 6) defined young adult carers as:

people aged 18-24 who provide or intend to provide care, assistance, or support to another family member on an unpaid basis. The person receiving care is often a parent but can be a sibling,

grandparent, partner, own child or other relative who is disabled, has some chronic illness, mental health problem or other condition (including substance misuse) connected with a need for care, support or supervision.

Becker and Becker (2008) made a distinction from their earlier definition of young carers (see Section 2.2) as they recognized that 18-24 year old carers are at a different place developmentally than younger carers, possessing unique needs and experiences. Furthermore, young carers are legally *children*, whilst young adult carers are legally *adults*, falling under the remit of child and adult social services respectively (Becker & Becker, 2008).

Historically, the population of young adults with caring responsibilities has not received much scholarly attention, rather psychologists and social policy researchers have focused on their childhood and later adulthood caregiving counter-parts (Hunt, Levine, & Naiditch, 2005). The exact numbers of young adult caregivers in the United States is unknown; however, Levine et al. (2005) assert that the numbers of American caregivers between the ages of 18-25 years old are between 3.9 million to 5.5 million. As of the 2001 census, there were 229,318 young adult carers aged 18-24 living in the United Kingdom (Becker & Becker, 2008). Of these young adult carers, 29,128 provide care for 20-49 hours per week, and 26,941 provide care for more than 50 hours per week (Becker & Becker, 2008; Thomas & Dorling, 2007). Beyond pure statistical figures, there remains a shortage in portrayals of the lived experience of young adult carers in research. The only large-scale national study in the United States on young adult caregivers to date is the work of Hunt, Levine, and Naiditch (2005). In the United Kingdom, three seminal studies stand as our current basis for understanding the lives of young adult carers: the groundbreaking study of Becker and Becker (2008), and the work of Sempik and Becker on young adult carers in education and employment (2014). This research in both countries have served to shed light on the daily lives of young adult carers and caregivers. In this section, I will provide an overview of the profile of young adult caregivers in the United States, followed by the profile of young adult carers in the United Kingdom.

In the United States, recent caregiving scholarship has focused primarily on *Sandwich Generation* caregivers, and the experiences of women caregivers. Sandwich Generation caregivers refers to women who are responsible for caring for an elderly parent or grandparent in addition to their young aged children, all whilst juggling a career (Dilworth & Kingsbury, 2005). In the context of the United States, female caregivers, those with informal education

backgrounds, and those from first-generation immigrant families have been shown to provide the greatest amounts of care (Lahaie, Earle, & Heymann, 2013). Within a growing interest in the experiences of adult women caregivers, there is a very small body of research beginning to consider the experiences of those in young adulthood.

Research in the United States is beginning to emerge on the group of young people referred to as *Millennial caregivers*. Caregiving advocacy organizations in the United States are gradually beginning to recognize the participation of “Millennial caregivers” in the labor market, i.e., those caregivers born in the early 1980s to the early 2000s. Research from the National Alliance for Caregiving and the AARP Public Policy Institute in 2015 found that the “typical” Millennial caregiver is 27 years old and is equally likely to be male or female. Their research also indicated that the “typical” Millennial caregiver provides care for a middle-aged female, usually the parent or grandparent with a physical health condition (National Alliance for Caregiving & AARP Public Policy Institute, 2015). In addition, when compared with caregivers of other ages, Millennial caregivers are more likely to provide care for a family member with a mental illness (National Alliance for Caregiving & AARP Public Policy Institute, 2015). The “typical” Millennial caregivers are engaged in paid employment, and on average work 34.9 hours per week (National Alliance for Caregiving & AARP Public Policy Institute, 2015). In 2016, the AARP Public Policy Institute found that Millennial caregivers make up 29% of all employed caregivers, and 73% of Millennial caregivers (between the ages of 18 and 34) surveyed in their research study have paid employment (Feinberg, 2016). Of those Millennial caregivers, 53% work full-time (Feinberg, 2016). The AARP Public Policy Institute also reported that “millennials are more likely than caregivers ages 50 and older to report being fired from a job (7 percent v. 2 percent), or receiving a warning about their performance or attendance at work (15 percent v. 5 percent) for caregiving reasons (Feinberg, 2016, p. 4). Perhaps unsurprisingly, 69% of Millennial caregivers in their research study reported that they would support a ban on workplace caregiver discrimination (Feinberg, 2016). It is clearly evident that much of the current focus on younger age caregivers in the United States has featured primarily on their participation in the paid employment.

One of the issues in the paucity of young adult caregivers research in the United States is the lack of a consistent age range for determining who is a young caregiver and who is a young adult caregiver (Kavanaugh et al., 2016). This impedes the development of age-specific support

services in the United States, as nearly all state and federal social care services use age as a criteria for the entry point of service (Kavanaugh et al., 2016). This research takes the view that young adult caregivers are classified as those between the ages of 18-25 years old, however it is understood that some may consider part of that age range to fit under a young caregiver classification. Beyond the age discrepancy issue, there are also major gaps in the literature in the lived experiences of both young caregivers and young adult caregivers in the United States. In the young caregivers scoping review conducted by Kavanaugh et al. (2016), they identified a need for future research on social support impacts, physical health impacts, race and ethnicity issues, the impacts of a privatized health care system, and finally, large scale prevalence studies.

Similarly, there has been little scholarly attention to date on the experiences of young adult carers in the United Kingdom. What we do know about the lives of young adult carers can largely be attributed to the work of Becker and Becker (2008) and Sempik and Becker (2014). The age range of classification as a young adult carer has shifted in recent years; researchers and young carers project workers may consider young carers to be those up to age 25, whereas the Department of Health typically considers those under the of 18 to be young carers (Heyman & Heyman, 2013). The major characteristics of young adult caring do not drastically shift from those of young caring in childhood. Similar to their younger age counterparts, young adult carers engage in a wide variety of tasks, including domestic tasks, medicine administration, intimate personal care, transportation assistance, and emotional support (Becker & Becker, 2008). We also know that the rates of young adults providing care for ill or disabled family members tend to rise in socio-economically deprived areas (Thomas & Dorling, 2007).

Much of the recent work has sought to address the needs and experiences of young adult carers in paid employment and education. In the United Kingdom, our understanding of the experience of young adult carers in employment and education as they seek to balance caring responsibilities can be attributed to the scholarship of researchers Joe Sempik and Saul Becker. Their survey of 295 young adult carers in the United Kingdom reported findings on the experience of 77 young adult carers who had left school and were in paid employment or could be classified as “NEET” (not in education, employment, or training) (Sempik & Becker, 2014). Most of their respondents cared for parents with a physical disability, mental illness, or a long-term physical illness (Sempik & Becker, 2014). Those young adult carers who are NEET reported poorer physical health and greater likelihood of the presence of mental health problems

than those young adult carers who were involved in paid work (Sempik & Becker, 2014). Of the 39 respondents who were engaged in paid employment, 44% has chosen to take the job because of its convenient proximity to the person for whom they provided care (Sempik & Becker, 2014). 38% of the young adult carers in the survey reported that the flexibility of working hours factored into their decision in selecting work (Sempik & Becker, 2014). 30 of the 37 working young adult carers in the survey indicated that they informed their supervisor of their caring role, and 59% reported that their manager was supportive in response (Sempik & Becker, 2014). Working young adult carers also revealed that absenteeism and chronic lateness were characterized in their experience; on average young adult carers were absent from work 17 days a year and were either late to work or worked shorter hours 79 days a year because of their caring role (Sempik & Becker, 2014).

Setting educational goals and deciding to attend university is a common developmental task for many young adults, however, caring responsibilities have the potential to hinder their educational experience (Newman & Newman, 2012). Some young adult carers found that their care provision at home had negatively impacted their ability to perform well in school, which then diminished their opportunities for college and university education (Becker & Becker, 2008). Missing school was a reported problem, as well as learning disabilities that hadn't received proper attention because the carer attended school infrequently (Becker & Becker, 2008). With regards to college and university education, project workers in the Becker and Becker (2008, p. 34) survey communicated that young adult carers are often "not in education due to barriers that impede them, for example, low family income, no or few qualifications, low self-esteem, teenage pregnancy, inability to leave the cared for person, lack of motivation or time, insufficient support and guidance at school, and a lack of appropriate courses close to home". For those who do attend university, they are required to balance caring with their studies, by either returning home on the weekends to care or by living at home and commuting to their university (Becker & Becker, 2008). Nevertheless, young adult carers reported largely positive experiences in college and university when compared to school, because they found the environment in higher education to be more flexible, adult-oriented, and with more supportive staff (Becker & Becker, 2008).

The pursuit of interpersonal relationships, both romantic and friendly, serves as another task young adults engage in during this stage of psychosocial development (Newman &

Newman, 2012). The social experience of young adult carers is often impacted by their caring responsibilities in the family home: half of the young adults sampled said that they did not have enough time for themselves and spent excessive amounts of time with the family members to which they provide care (Becker & Becker, 2008). Lack of money also negatively influenced the young adults' ability to participate in social activities (Becker & Becker, 2008).

Becker and Becker (2008) emphasize that regular and sustained caring for a family member is not the norm for most young adults, rather young adulthood is the time for increasing independence from the family unit. Sullivan and Sullivan (1980) and Berman and Sperling (1991) found that "students who live at home while attending college tend to continue to be preoccupied by concerns and thoughts about their parents based on their actual daily interactions" (as cited in Newman & Newman, 2012, p. 393). If young adults who merely live at home and are not involved in care-taking roles may find themselves significantly attached to their parental unit, a young adult who provides constant care to a parent may understandably encounter difficulties in launching from the family home. This experience may cause strained relationships with their parents and families; indeed, over a third in the Becker and Becker (2008) sample reported negatively impacted relationships with the person for whom they provided care. Furthermore, leaving home is a decision often affected by the level of care needed by the family (Becker & Becker, 2008). Many young adult carers expressed that the close family ties that had developed as a result of caring also served as a barrier to leaving home. Finally, worry about either the health of the family member or the ability of the other family members (such as younger siblings) to provide care also influenced the young adult carer's decision to stay home (Becker & Becker, 2008).

A salient issue for 18-25 year old carers is the reality of financial strain (Becker & Becker, 2008). One project worker in the survey communicated that every individual seeking services had low income (Becker & Becker, 2008). Young adult carers may come to realize that they do not have their disabled parents as a financial fall-back, in contrast to their non-caring peers (Newman & Newman, 2012). Thus, young adult carers must become financially self-sufficient at an earlier age than their counterparts. Project workers have noted that while some carers attempt to find suitable paid work (even if related to the field of care), others don't see themselves ever escaping their caring role: "Sadly others have had no real aspirations for the future and can not see themselves ever being free from their real caring roles" (Becker & Becker,

2008, p. 43). Most young adult carers, when interviewed, expressed aspirations for the future, but recognized that the possibilities of the future would be largely dependent on “what would be expected of them at that time in relation to the needs of the people they support” (Becker & Becker, 2008, p. 49).

Through the seminal work of Becker and Becker (2008) and Sempik and Becker (2014), we can begin to fit together a profile of young adult caring in the United Kingdom. As the needs of young adult carers are distinguished from the needs from young carers, their unique position in the life course is brought to the forefront of research and policy concerns (Dearden & Becker, 2000). Young adult carers frequently express that they need different services from their younger, child counterparts and are typically pushed out of young carers projects once they reach age 18 (Becker & Becker, 2008). They may also not strongly associate themselves with adult carers because of their life experiences to date (Becker & Becker, 2008). This research study is undergirded by the understanding that young adulthood is a distinctive stage in life, and furthermore, the needs of young adults with caregiving responsibilities may significantly differ from childhood and older adults. A consideration of young adulthood as a unique period of time in the life span will now be discussed in the following section.

2.5. CONCLUSION

This chapter reviewed the current language used to describe young caring in the United Kingdom and United States, and provided an overview of the positioning of young adult carers and caregivers in their respective countries. This chapter sought to lay the contextual framework for the cross-country comparisons undertaken in the research study by examining the contrasts in public representation, recognition, and formal support in the United Kingdom and United States. In the following chapter, we will examine the theory of emerging adulthood as a way to ground the research study in an understanding of young adulthood in Western industrialized societies, supported by a review of the literature on identity and identity formation, and multiple identities and roles. The second half of the chapter will engage the notions of caring for and about in the context of multi-generational and interdependent care, the contested nature of care, and sociological and sociolinguistic approaches to discourse, labelling, performance, and power.

CHAPTER THREE: SOCIOLOGICAL & SOCIOLINGUISTIC THEORETICAL UNDERSTANDINGS OF CARE, ETHICS OF CARE & IDENTITY

3.1.1. INTRODUCTION

I will now address the rationale for the study of young adulthood and provide reasoning for why a dedicated consideration of caregiving during young adulthood is critical. In this section, I will review and critique the current theories on young adulthood, focusing primarily on the theory of emerging adulthood popularized within developmental psychology in the United States and increasingly, in Europe. I will then transition to a review of the literature on personal identity development in the life span, seeking to provide the reader with a foundational understanding of identity from a psychosocial approach. Within that section, I will address the theories of multiple roles and identities to aid our understanding of the young carer identity. The next section will briefly cover the theory of social identity, as this will prove useful in building our knowledge on the issues of identification for young adult carers.

This second major section of this chapter will provide a critical engagement of two areas of theoretical work: first, how do we understand caring (for and about) within the context of inter-familial relationships and practices; second, a theoretical understanding of the social construction of identities and how these are performed, negotiated, and represented. Both the sociological literature on family practices and the ‘ethics of care’ literature will be examined in detail, and particular emphasis will be given to its relevance to further understanding the lived experiences of young adults with caring responsibilities. Close attention will be paid to issues of normative family practices and its possible juxtaposition with the realities of everyday life in families in which young caring takes place. The contested nature of care, especially in the discourse of young caring, will be raised and examined in the context of the United Kingdom and more briefly, in the United States. In the subsequent section on sociological and sociolinguistic approaches, we will delve deeper into its interplay in understanding of identity and identification. Additionally, literature from poststructuralist and postmodernist perspectives will be presented, including Foucauldian approaches to discourse and power. In this discussion, the reader can expect to find an engagement with labelling theory and the concepts of stigma, language and code-switching, embodiment, performance and voice.

3.1.2 RATIONALE FOR THE STUDY OF YOUNG ADULTHOOD

Considering young adulthood as a separate stage in the lifespan is rooted in developmental psychology. A number of assumptions will guide this reflection on young adulthood. First, this perspective assumes that there is a social construction of relationships, roles, and identities along the life path. It also assumes that each life stage will affect the entire life course, and that individuals experiences multiple transitions through life as they move through life stages (Heinz, 2009). Heinz (2009, p. 3) notes that transitions from youth to adulthood are “fuzzy” and “less age-dependent” in modern times; transitions to adulthood are more determined by the individual and their perspective on what constitutes adulthood, rather than legality of age. The navigation of pathways has emerged as a theme of transitions to adulthood, as young people consider their constructions of social reality through interpersonal relationships, occupations, education, and more (Heinz, 2009).

In the United States, academic discourse on young adulthood in recent years has focused on the debate of the theory of emerging adulthood. The theory of emerging adulthood, as proposed by Jeffery Arnett, accounts for the relatively recent demographic changes in the lives of 18-25 year olds in Western industrialized societies, as now, the completion of those tasks is commonly postponed, even in the late twenties and early thirties (Arnett, 2000). It is typically distinguished from adolescence and young adulthood as an in-between stage of life, characterized by an exploration in work, new friendships, romantic relationships, and religious, moral, and political beliefs (Arnett, 2000; Harter, 2012). Nearly 50 years ago in industrialized societies, once young people reached the age of 22 or 23, they were expected to have married, found stable employment, and had conceived at least one child (Arnett, 2006). The other alternative, particularly for wealthy males living in England, was an expansive tour of Europe before coming back to England to settle into adulthood (Arnett, 2006). The difference between yesteryear’s wanderlust and today’s is that the period of exploration and delay of adult responsibilities is now considered customary for both women and men (Arnett, 2006). In industrialized societies, the median age for marriage and first childbirth is now in the late 20s and early 30s (Arnett, 2006).

Criticism of the theory of emerging adulthood lies in the assumptions of social mobility, educational attainment, and paid employment participation within young adults in Western industrialized societies. Some criticism has pointed to the theory of emerging adulthood as a marker of social class and cultures (Douglass, 2007). The perception of one’s ability to leave

home for university, for instance, can be seen as hallmark of social class that may not be generalizable to all young people living in Western societies. Heinz (2009, p. 7) asserted that emerging adulthood in the United Kingdom and elsewhere is significantly determined by social class as social class “opens or restricts access to pathways which support young people to act according to the criteria for being adult”. Côte (2000) promulgated the term *arrested adulthood* to capture the experience of those whose circumstances, such as lack of available paid employment within one’s local area, meant that they were socially excluded and hindered from participating in the paid labor market, and therefore delayed in reaching adulthood. Thus, it cannot be assumed that young adulthood is a period in which young people feel that they are in control of their life paths, as conversely, some young people may feel that their life paths are considerably restricted by circumstances outside of their control (Heinz, 2009). This certainly may be true for young adults with caregiving responsibilities. Researchers have also debated whether emerging adulthood is present within the context of Europe and specifically the United Kingdom. Since the 1970s, there has been a general shift in the norms of young adulthood to one that emphasizes individualization (Douglass, 2007). This has been viewed as a time in which fertility rates have dropped, marriage rates have decreased, and women’s participation in the labor market have increased across Europe (Douglass, 2007). Other research has pointed to the influence of university enrollment in shifting the patterns of “launching off” for young adults in Britain (Stone, Berrington, & Falkingham, 2011). In the United Kingdom, while traditionally, young adults left home earlier and in greater numbers than other European young adults, this may be changing due to increased home prices, the recent global recession and subsequent market insecurity, and decreased welfare support under a time of austerity (Stone, Berrington, & Falkingham, 2011). Furthermore, cyclic patterns have emerged in young adults leaving home, either for paid work or university, and returning home due to the completion of education or the inability to secure employment (Stone, Berrington, & Falkingham, 2014). It is true that in congruence to one major facet of emerging adulthood theory, the large majority of young adults in Britain do not marry (Thomas & Dorling, 2007). Nevertheless, some research in Europe has given weight to the theory of emerging adulthood in regards to its notions of young adulthood as a special time for young people to make decisions, explore options and life paths, and is complex with stops and starts (Billari & Liefbroer, 2010). I present the theory of emerging adulthood as a perspective that may not be generalizable to all young adults in the United States and United

Kingdom, but may offer some value in understanding their navigation of their entry into adulthood.

To be clear, the theories of emerging adulthood to explain the unique position of young adults in present-day Western industrialized societies such as the United Kingdom and United States is not without its criticism. Indeed, I caution against using the theory to generalize across all young adults in the United States and United Kingdom, particularly in regards to race and class. I assert that theory presents a useful perspective on the notions of exploration and identity development for young adulthood, and may help shed light on the experiences of young adult carers and caregivers seeking to explore their world and their identities. I also believe the concept of emerging adulthood can help address the in-between time of young adulthood, as young people transition from childhood to adulthood. Moreover, this concept may give further reassurance that young adult carers and caregivers should be placed in a different grouping than their youth and adult counterparts and therefore require different needs-based services. Thus, the assumption that young adulthood is a time of exploration, identity development, and transitions will guide the rest of this research study.

3.1.3. YOUNG ADULTHOOD AND IDENTITY

As this research study seeks to explore the identity development of young adult carers and caregivers in the United Kingdom, this literature review will now transition to a consideration of young adulthood and identity development.

Wilson, Ruch, Lymbery, and Cooper (2008, p. 166) suggested that adolescents may need to navigate the following tasks as they transition to adulthood:

- *Establishing a new personal identity*
- *Achieving a new level of closeness and trust with peers*
- *Acquiring a new status in the family*
- *Moving towards a more autonomous stance toward the wider world.*

Those tasks are interconnected, as a new status in the family and closer relationships with peers can impact upon one's personal identity. For this research, we are most concerned with the way young adults establish their identity as they begin to approach adulthood. As 18-25 year olds are increasingly defining adulthood as a time when one takes personal responsibility for actions, makes independent decisions, and obtains financial independence from parents, many may feel

as if they have not quite yet reached that stage in life fully (Harter, 2012). McAdams (2013) calls the navigational process of emerging adulthood a state of becoming an author of one's own life. This is a time in which it is thought that the emerging adult is free to create a narrative identity, i.e., the story of one's life (McAdams, 2013). As noted in Section 2.4, every young person will not feel "free" to create their own identity, particularly if they are hindered from exploration because of financial restraints, child-rearing, or in our focus—providing unpaid care for an ill or disabled family member. Nevertheless, young adulthood is encapsulated by transitions, uncertainty, and instability. A general sense of uncertainty regarding the direction of one's life is allowed and in some instances, even encouraged as an acceptable part of this time period. Furthermore, Arnett (2000) describes the late teenage years through the mid-twenties as the most volitional time in of all life stages. Because of this freedom of choice, the most constant uniform characteristic of emerging adulthood is its explorative and instable quality. Harter (2012) suggests that this age group is afforded the freedom of choice because it is assumed that they have not yet taken on the salient responsibilities of adulthood (e.g., commitment to a career, financial independence from their parents, marriage, and parenting).

Emerging adulthood provides the opportunity for temporary role commitments, a type of "trying on" of identities related to interpersonal relationships, work, and worldviews (Harter, 2012). The years spent at university are seen as the quintessential experience to "explore and adopt, as well as shed, various possible selves" (Harter, 2012, p. 137). This period of time mirrors Erikson's (1968) concept of moratorium in which the adolescent is allowed (by society at large) a delay of adult commitments to engage with different roles and identities. Erikson (1968) believed that each society and culture allows for such a period of exploration for the young person on the verge of adulthood, and has been encapsulated in terms such as "wanderlust" and "lost youth" (p. 157). While emerging adulthood is recognized as a period of exploration, there exists a tension between reality and idealized dreams (Harter, 2012). As much as the emerging adult is encouraged to explore multiple aspirations and identities, the reality remains that the emerging adult will be forced to reconcile with the constraints of life and commit to an identity (Harter, 2012). The danger, Erikson (1968) warned, lies in young people committing to an identity too soon because either circumstances demanded a commitment or those in superior positions, such as the young person's parents, forced a commitment upon them.

Identity is concerned with who one is and how one defines oneself (Marcia, 1993). The formation of one's ego identity encompasses the conglomeration of childhood proficiencies, beliefs, and values into a coherent sense of wholeness that allows the young adult to experience connection with the past and direction for future (Marcia, 1993). Psychoanalyst Erik Erikson formulated a groundbreaking theory on psychosocial development and ego identity that addressed the various stages of growth taking place within an individual's cognitive, psychological, and physiological being (Erikson, 1968). Erikson's concept of ego identity was considered unique and original because he placed the concept of identity within the framework of human growth and development (Marcia, 1993). Identity is not a "free-floating construct", but rather "an integral part of a larger developmental scheme" (Marcia, 1993, p. 5). His theory was strongly influenced by classical Freudian theory yet without the strong focus on the unconscious and the sense of the individual fighting forces in the outside environment that is traditional in classical psychoanalytic theory (Marcia, 2007). Instead, Erikson placed greater focus on an individual's healthy adaption to his/her milieu within a supportive social context (Marcia, 2007). While he approached ego development with a less confrontational view of society than his predecessors, Erikson recognized that a conflict exists between optimal growth and the failure to grow at each life stage (Marcia, 2007). Erikson and his colleagues referred to this conflict as an "identity crisis" (Erikson, 1968, p. 16). They rejected an overly unfavorable outlook towards the term *crisis* in favor of a more neutral view towards change, an approach that sees an identity crisis as a crucial marker for a period of transition (Erikson, 1968). His eight stages of psychosocial development reflect this tension: basic trust versus basic mistrust, autonomy versus shame/doubt, initiative versus guilt, industry versus inferiority, identity versus identity diffusion, intimacy versus isolation, generativity versus stagnation/self-absorption, integrity versus despair (Marcia, 2007). Each task must be successfully resolved before moving onto the next developmental stage (Marcia, 2007). With an acknowledgement of the tension that exists within each developmental stage, Erikson advised against an "either-or interpretation" (Marcia, 1993, p. 5). Instead, he championed that a proper resolution of a crisis should manifest itself in a predominance of the optimal characteristic, for example, a person experiences a greater sense of autonomy than not (Marcia, 1993).

James Marcia offered the first operationalization of identity formation in the adolescent and young adult in 1966 (Schwartz, Mullis, Waterman, & Dunham, 2000). Marcia construes

identity as a self-constructed structure, and without active development, he believes individuals will need to use external sources to determine their values and beliefs (Waterman, 1988). Marcia (2007) argues that the formation of identity is most often considered at adolescence because it is the first moment in which numerous individual and societal elements that are crucial to development occur simultaneously. The adolescent individual has reached a stage in growth in which sexual maturation, cognitive development, and the yearning for autonomy are present (Marcia, 2007). Concurrently, society expects that the adolescent will begin to reason and determine the suitability of various occupations, make decisions that are characteristic of adulthood, while society is required to give the space to foster such exploration (Marcia, 2007). Furthermore, Marcia (2007, p.4) asserts that adolescence is the time that the individual changes from “being a recipient to being a provider”.

Marcia posited that two components exist in the theory of identity formation: exploration and commitment (Schwartz et al., 2000). Exploration refers to the active trying on and off of possible identities with the goal of a “more complete sense of self” (Schwartz et al., 2000, p. 505). Commitment is related to the concept of decision-making, in that an individual has chosen an identity (made up of beliefs, goals, and values) to follow and engage in throughout day-to-day life (Schwartz et al., 2000). Marcia (2007) operationalized identity formation in the adolescent and young adult through his theory of four identity statuses: identity achievement, identity moratorium, identity foreclosure, and identity diffusion.

The theory of multiple roles and identities is used to explain the multi-faceted parts of self often described by individuals. We may see ourselves as one body and a whole, but in the context of our identity, one word rarely fits all. The ways we define our self-concept are infinite: the things we do, the groups by which we associate, our relationships with other individuals, our personal characteristics, our hobbies and interests, our personality features—truly, the means of self-identification are limitless. During the developmental period of young adulthood, individuals continue to determine their self-concept through a variety of factors, both internal and external. For those young people with caregiving responsibilities, caregiving can be represented through both the act of caregiving itself, the relationship with their family member, and the personal attributes influenced or gained from caregiving. Caregiving can be a role that exists amongst many, or it could be *the* role by which all other parts of the self are defined. The belief that carers/caregivers occupy a caregiving role in addition to other social roles has been a facet of

research since the 1990s (Barnett, 2015; Franks & Stephens, 1992). Since the early 2000s, research, largely from the United States, has focused on the health impacts, both physical and psychosocial, from the various roles adult family caregivers may have throughout life (Marks, Lambert, Jun, & Song, 2008; Williams et al., 2008). This research typically excludes the experience of young adult carers/caregivers, instead focusing on middle-age carers/caregivers. In addition, there remains a gap in knowledge regarding the connection of multiple roles and identities to a young adult carer/caregiver's self-concept.

Identities are the meanings that define who we are in the context of our social roles (Berger & Bzostek, 2014). Identities are created and evolved as a result of social interactions with others. Thus, when we focus on the formation of our identity, we must also consider that our identities are derived from our various social roles and group memberships. Identity theory typically takes at least two foci: roles-based identity or group membership-based identity (Hughes, Locock, & Ziebland, 2013). Roles-based identity approaches the concept of identity from the perspective that our social roles ("what we do") help define who we are, whereas group-membership-based identity suggests that we are defined by our group belonging (Hughes et al, 2013). The two approaches have significant overlap, as it is true that we can occupy roles and those very roles place us into certain groups. A roles-based identity approach may be more applicable when studying the lives of young adults with caring responsibilities, as particular attention is typically given to what they *do*.

Because young adults with caring responsibilities also occupy other social roles, e.g., student, son, lover, the concept of multiple identities is both relevant and necessary when addressing their identity. Noor (2004) suggests that because we have many roles, we therefore have many identities. The concept of self-complexity, as a facet of identity theory research, argues that most individuals possess multiples roles and identities as they navigate throughout life (Settles, 2004). Theories of multiple roles and identities exist as a part of a trend in psychological research to view the self as a complex and multi-faceted entity, rather than a homogenous, unified whole (Koch & Shepperd, 2004).

Identifying as a daughter, father, or employee, for example, allows us to engage socially with others, maintain a sense of belonging, and provide us with a set of guidelines for behavior according to social norms. As Lawler (2008, p. 2) succinctly writes, "Identity, then, involves *identification*." When we identify ourselves, we are often associating ourselves with a wider

category, e.g., identifying as female now associates us with *women* and thus a *female identity*. At the same time that we identify with someone or something, we are often required to simultaneously dis-associate ourselves with another identity. Identifications tell us who are *not*, sometimes, as much as who we are, which in turn, allows us to more expansively describe our self-concept. Woodward (2004) suggests that identity is marked by similarity with others but also difference from others. Furthermore, some identities are not necessarily chosen by us, but are placed upon us by external structures and other individuals. For instance, the color of one's skin may lead others to align an individual with a group of like-colored skin, believing that she/he would identify with that group. The person may or may not identify with the group but nevertheless, that is how society views and recognizes the individual. It stands to reason then that identity is a concept involving both objectivity and subjectivity, the internal and the external (Woodward, 2004).

In a discussion of identity, it would behoove us to recognize that the issues surrounding the concept of multiple identities are neither universally agreed upon nor understood. Firstly, there is an on-going debate whether multiple identities are beneficial for well-being or detrimental. Other research focusing on *self-concept pluralism*, the theory that the self is defined by multiple parts (personalities, identities, and roles) rather than an "amorphous whole" suggest that multiple aspects of the self may contribute to healthy well-being and psychological adjustment (Campbell, Assanand, & Di Paula, 2003, p. 118). Linville's (1987) work on *self-complexity* found that a high degree of self-complexity acts as a buffer against stress. Further research has found that multiple identities are associated with lower levels of depression and anxiety (See Gara et al., 1993; Menaghan, 1989; Brook, Garcia, & Fleming, 2008). Moen, Dempster-McClain, and Williams (1992, p.1634) assert that multiple roles may improve an individual's "social network, power, prestige, resources, and emotional gratifications". Satisfaction in one's multiple roles, rather than the mere existence of multiple roles, is likely a distinctive factor in contributing to one's overall well-being (Moen, Dempster-McClain, & Williams, 1992).

In contrast, other research has found that multiple identities may negatively affect well-being and are correlated with higher levels of depression (Brook, Garcia, & Fleming, 2008). Goode (1960) asserts that role strain and role conflict caused by multiple identities can be overly demanding and difficult to navigate (see below for a more in-depth discussion on Goode's

seminal theory of role strain). *Identity interference*, in which the obligation of living out a single identity interferes with the ability to perform another identity, can occur (Settles, 2004). The extent of identity inference may depend on the importance an individual places on a particular identity, i.e., *identity centrality* (Settles, 2004). According to Settles (2004), there is an even greater likelihood that identity interference will occur when an individual has multiple central identities. Settles' research on the female identity and the identity of "scientist" (2004) found that multiple identities in themselves did not solely cause depression, but that higher rates of depression were reported when either or both identities were salient. Other researchers, such as Martire, Parris Stephens, and Townsend (2000) and Pleck (1985) have found that role salience has a direct effect on well-being, yet the work of other researchers, e.g., Thoits, 1995, has produced contrasting evidence. It has also been argued that role salience may actually serve as a moderator influencing role strain and psychological wellness. Brook, Garcia, and Fleming (2008) found that multiple identities may either help or conflict with each other, and that possessing a greater number of identities leads to either a higher or lower well-being depending on whether the identities have a sense of harmony with each other.

Consequently, it remains apparent that multiple roles have the ability to influence psychological well-being both positively and adversely. This is a useful foundation from which to frame the approach to the experience of young adult carers/caregivers, as it recognizes that a multiple roles perspective can account for the diverse and individualized influence upon young adult carers/caregivers. In short, each young person experiences the presence and continuous shifting of multiple roles uniquely. Some may find the various roles and identities at play in their life to serve as a buffer from stress, and others, through the experience of role strain, may find their multiple roles to have a causal relationship with emotional distress.

Within the debate on the utility of multiple identities, there is a gap in literature regarding multiple identities in the context of young adults with caring responsibilities. Previous research from the United States has focused on older adult carers and their relation to the identity of "carer", with significant evidence that those with caring responsibilities do not identify as a "carer" (Henderson, 2001; Hughes et al., 2013). In the United Kingdom, Bowen, MacLehose, and Beaumont (2010), in their study of carers of those with advanced multiple sclerosis, found that many of their participants did not identify as a "carer", preferring instead to be recognized by their *family role* to the person requiring care, e.g., wife or husband. Bowen et al. (2010)

suggested that in consideration of such a significant rejection against the term “carer”, that was likely that the disassociation prevented the family members from accessing carer support services. The access to service issues potentially caused by the terminology of identification could have enormous consequences, in view of the perspective of Molyneaux, Butchard, Simpson, and Murray (2011, p. 425) in which they assert that the term “carer” remains the “gateway” into which support services are accessed. Taking an admonitory position, Molyneaux et al. (2011, p. 424) conclude that the term “carer” is “no longer effective”. For those individuals who receive care from the person to which they care for, the term “carer” may be too simplistic, too broad, and ignores the relational and reciprocal nature of care (Molyneaux et al., 2011). For example, a person may receive emotional support for their mental illness from the person who has a physical disability that requires care. The experience of mutual care may not be adequately explained by the terminology of “carer”. Working within the perspective that mutual care is common to all, the label of “carer/caregiver” may be increasingly ill-suited. Furthermore, the complexity of mutual caring relationships merits special consideration in view of the ways in which individuals perceive their multiple identities as “carer” and “cared-for”. It is likely that their multiple identities consist of blurry boundary lines, if there are distinct lines at all. O’Connor (2007) suggests that conceivably even the language of “roles” is imprecise when describing the identity of individuals providing care. Rather, O’Connor (2007) advocates for the use of “position”, in place of “role”. Positioning, she argues, creates space for the dynamic shifting, renegotiating, and contextual aspect of our social interactions. O’Connor (2007) points to the hesitancy of her participants to self-identify as a caregiver in the earlier period of time during their caregiving experience; as time moved on, her participants were more willing to view themselves as caregivers, particularly as the health of the family member for whom they provided care deteriorated and required more substantial caring activities.

Recent literature in the United States has attempted to encapsulate the process of caregiving in the “caregiver identity theory”, which posits that the caregiving role is birthed out of an existing familial role (Montgomery & Kosloski, 2009). The caregiving role identity is subject to the various changes that take place during the course of one’s caregiving experience, e.g., the changes in the health of the cared-for. The caregiver’s identity is also shaped by society’s existing social norms and expectations, particularly with regards to gender performance (Montgomery & Kosloksi, 2009). Cultural norms and ethnic backgrounds are included in a

caregiver's identity and may also guide the family's expectations towards the duty to care. Montgomery and Kosloksi (2009) assert that each family develops its own caregiving beliefs, ideals, and customs unique to their family experience. It is within this caregiving ethos that families determine which member takes up caregiving, which activities performed, and how support and assistance from external sources are negotiated. Once the level of care required changes, the caregiving role identity shifts as the caregiver changes both their actions and the way they view their role in relation to the cared-for.

For young adult carers/caregivers, a distinctive factor in determining whether a young adult identifies as a "carer/caregiver" may present in their age and relationship status to the family member. In previous research from both the United Kingdom and United States that concludes that the term "carer" is an inappropriate label, the participant sample consists significantly of those in middle adulthood and those caring for a spouse. It is possible that their experience is perceived to be *more* "normative" of their age and relationship status. Indeed, there is a level of cultural expectation from society (external) that the adult child will take care of the aging parent, and similarly, an expectation (internal) that the vows taken in the context of marriage allude to the duty to support the spouse "in sickness and in health". Arguably, young adults caring for a parent or other family member may not perceive their experience as normative for either their stage in life or their role in the family structure. The unusual nature of their caring experience may then permit the young adult to view himself/herself as a "carer". Conversely, young adult carers report that their motivations for providing care include love and devotion to the family member, therefore, they may view their caring activities with same perspective as their older and married caregiving counterparts (Becker & Becker, 2008). The beliefs surrounding love, duty, and devotion may extend to all ages of those providing care, and those factors may influence the caring identity in a similar manner to age or relationship status. Additionally, children providing care for a family member frequently report that they do not see themselves as "carers", but rather, "sons, daughters, siblings, and grandchildren who 'help out' at home" (Smyth, Blaxland, & Cass, 2010, p 146). The sentiment that "I am just helping out" is a common one found when interviewing young carers, and many view themselves as family members with simply more responsibilities than their other peers. Therefore, a variety of reasons exist to explain why some young adult carers/caregivers may or may not recognize themselves as a "carer/caregiver". A nuanced understanding of the issues surrounding identification is

imperative to better comprehend the experience of young adult carers/caregivers and address them appropriately, but also for their positioning in society at large. In the policy work of young carers in the United Kingdom, a defining label has been beneficial in protecting their rights as a socially recognized group (Smyth et al., 2010). Thus, there is a danger if the term “young carer” is relinquished, those young people may remain unrecognized, hidden, and at risk for service and governmental policy omission.

The criticism of the term “carer” is more than surface semantics, it potentially uncovers a nuanced layer of the “carer”/“caring” identity—an identity perhaps not best encapsulated by terminology but by role, behaviors, and emotional feelings. At the very least, it again brings up Lawler’s (2008, p. 2) assertion: “Identity, then, involves *identification*.” The complexity of understanding the experience of identity formation in the young adult carer is further deepened by the notion that “carer” may not be an identity in which they identify with at all. An exploration of the concepts of role conflict, role overload, and role strain may help make sense of the ways in which a young adult providing care may self-identify.

As Marks and MacDermid (1996) argue in their research explaining the theory of role balance, the self is both capable and responsible for organizing its multiple roles as one navigates through life’s various circumstances. According to Marks and MacDermid (1996), this is an unconscious and continual self-organization process, but one that allows various roles to gain prominence in consciousness as the situation requires them. If this research study reveals that young adult carers/caregivers identify with their familial role most of the time, but when specifically asked, they unhesitatingly identify as a “carer/caregiver”, the assertion of Marks and MacDermid (1996) on role prominence may help explain this finding.

3.1.4. SOCIAL IDENTITY THEORY

A consideration of social identity theory is useful in the consideration of the identity development of young adult carers and caregivers because I assert that the young carer/caregiver identity is not simply an identity, but also a distinct social group. Previous research has advocated for a view of young caring as a distinct social group (Aldridge & Becker, 2002; Becker, 2008). Indeed, a social group perspective has helped to fuel supportive policy for young carers, as the perspective encourages society to view young carers as a group with needs, rights, and power. Furthermore, a view of young carers as a *vulnerable* social group has enabled society

to enact policy to protect them from harmful, inappropriate levels of caring and to preserve their childhood. This view of young carers as a vulnerable social group emerged within the adoption of family-focused policy in the New Labour decade prior to 2007 (Heyman & Heyman, 2013). While the classification of young carers and young adult carers as a social group has proven beneficial for the adoption of supportive policy, there is a paucity of research on how young people experience that group membership. We know from previous research that young carers typically find the bestowment of the young carer identity, i.e., the moment that they are officially recognized as a young carer by another individual, as a new revelation about their identity. Young carers understand they are contributing to their families in significant, valuable ways, but they typically do not have a label to describe their distinct role in the family. The young carer identity can give them a language to describe their role, and as we have seen in previous research, it can give them a social group of which to claim as their own. Therefore, we can accept that young carers can be seen as a distinct social group, but we understand little beyond knowing that this is a new, revelatory discovery for them. We do not know whether young carers readily accept the identity or if they contemplate whether it fits for them. We do not know if young carers feel that the identity only fits them in some instances and not in others. We do not know whether young carers feel pressured to take on the identity of young carer, recognizing that the receipt of formal support services is the direct result of identification as a young carer. This research sought to explore these questions. To help guide our understanding of young caring and identification, we will now review the theory of social identity.

Whereas the work of Erikson and Marcia on personal identity was grounded in developmental psychology, social identity has its roots in social psychology. Social identity theory is the idea that individuals are a part of distinct social groups and categories, and individuals can construct meaning about themselves from their group memberships (Hogg & Abrams, 1988). The seminal work of Polish social psychologist Henri Tajfel (1972, p. 31) defined social identity as “the individual’s knowledge that he belongs to certain social groups together with some emotional and value significance to him of the group membership”. British social psychologist John Turner (1982, p. 15) was also a prominent scholar in this field, and he defined social groups as “two or more individuals who share a common social identification of themselves or, which is nearly the same thing, perceive themselves to be members of the same social category”. Groups may have different language, behaviors, expectations, values, beliefs,

and norms from other groups—the possibilities are endless. Group membership can also have an influential role in the construction of an individual’s identity (Hogg & Abrams, 1988). Hogg and Abrams (1988, p. 2) assert that group membership can develop a person’s sense of self, their understanding of “who they are, of what sort of people they are, and how they relate to others”. The understanding that one belongs to a group is a “*psychological state*”, meaning that one becomes belongs to a group partly because they *think* of themselves as a member of a group (Hogg & Abrams, 1988, p. 3). Social identity, therefore, exists when individuals not only share characteristics of a group, but also think of themselves as belonging to the group. Hogg & Abrams (1988, p. 17) tend to refer to the social identity approach as “the group in the individual”. This means that within individuals, there exists the notion of belonging to multiple groups. This rightly connects with our earlier discussion on multiple roles and identities, as individuals consist of multiple roles, identities, and groups. The young carer identity, therefore, can exist as one role, identity, and group, out of many.

Therefore, I agree with the assertion of Becker (2008) that young carers and young adult carers can be rightly seen as distinct social groups. It is commonly accepted that young carers and young adult carers share a set of similar characteristics, as reviewed in Section 2.2 of this chapter. One is viewed to be a young carer if they experience an assortment of those characteristics. Previous work has featured the debates of researchers and practitioners in deciding what constitutes a young carer identity (Cree, 2003; Heyman & Heyman, 2013). There is little existing work on how a young carer perceives of this identity once it is conferred to them. A young carer’s perception of these characteristics can shape their conceptualization of their identity, both as an overall sense of identity, as well as their specific identity as a young carer. Throughout this work, I encourage the reader to remain reflective that young carers do not typically self-identify with the young carer identity. While this research will examine the possibility of self-identifying as a carer, this may not be the norm for most children and young adults with caregiving responsibilities in the United Kingdom or in the United States. In most cases, this is an identity that is conferred to them by someone else. In this discussion on social identity and social group membership, it follows that the young carer identity is a *group membership* that most young carers did not self-elect to take part in. The young carer identity is not an identity that was *chosen* by them. In this instance, choice in young caring can be viewed in two ways: firstly, the choice to become a young carer, and secondly, the choice to accept or

reject the title of “young carer”. The former refers to the question of duty, obligation, and agency in young caring: do young people elect to take up caring roles in their families without explicit, verbal negotiation in their families? In this research, I am primarily concerned with the latter: how do young people feel about having a new identity bestowed upon them? Is this label an accurate embodiment of their identity? Crisp and Hewstone (2006, p. 3) assert that social identifications have an inherent element of choice: “we can both choose to be categorized, or categories can be chosen for us”. It may be true that young carers and young adult carers experience both; they may not make the initial choice to be identified as carers, but they may subsequently choose to accept the young carer identity. This research seeks to explore these issues and generate new understandings from the perspective of young adult carers.

At this juncture, I will now shift our examination of young adulthood, care, and identity from a developmental psychology perspective to one of a sociological and sociolinguistic perspective. In many ways, we will see how this research is truly multidisciplinary, as it can draw from several theoretical understandings to better capture the lived experience of young people with caring responsibilities. Overlapping themes will emerge, for example, the notion of social groupings from a social identity approach has significant parallels with the social construction of young caring taken from a sociological perspective. It is hoped that this in-depth review of multiple disciplines will bolster our analysis and draw out the rich nuances of this research study’s data.

3.2.1. THE MEANING OF CARE

We will first consider the meaning of care. Care, according to Noddings (1984, p. 12), is both entrenched in complexity and open to the subjective perspective of the individual. Noddings (2003, p.9) believes that definition of “care” consists of a conglomeration of the traditionally held views of what it means to care. She asserts that “to care” means that a person possesses a burdened mental state regarding the cared-for, or a particular *regard* for the cared-for, or alternatively, a duty to look after the well-being of another (Noddings, 1984, p. 9). Joan Tronto also devoted much of her work to the definition of care, and she identified four sub-elements of care:

- Caring-about: the awareness that there is a need for care

- Taking care of: the assumption of the responsibility to respond to the need for care
- Care-giving: the competence to take action and skillfully meet the need
- Care-receiving: the responsiveness to care (Sander-Staudt, 2011)

Tronto also highlighted the numerous ways in which women and people of color tend to provide care to those who possess “privileged irresponsibility”, i.e., those who can afford to buy the caring services and avoid the burden of care (Sander-Staudt, 2011). This tendency is a result of the power dynamics of political and ideological structures in place by the dominant group (Sander-Staudt, 2011). In Tronto’s (2015) view, care relations do not exist in a vacuum, but are influenced by the private and public spheres.

Care, in its modern conceptualization, is thought to be relational, political, and ethical (Williams, 2018). Whilst care functions on a macro-level in terms of global justice and economies, care is also deeply personal (Williams, 2018). Care can take place on a paid, transactional basis on a global scale; entire people groups migrate from one part of the world to another to enact paid caregiving in private (e.g., homes) and public spaces (e.g., eldercare homes and hospitals), and subsequently, care is gendered, classed, and racialized (Olson, 2017; Williams, 2018). Recent, feminist approaches to care consider the nature of unpaid caring activities and roles, in either domestic or workplace environments, and the ways unpaid care can rehearse inequalities across an intersection of identities. Thus, we understand that care takes on many forms and is operated on macro, meso and micro scales in our current world. In our present study, we will focus on the unpaid care that young people in the United Kingdom and United States undertake in their households and within their families in which disability, illness, substance abuse, and other health-related conditions are present. For these young people, care is practiced intergenerationally and mutually, which this chapter will examine in its nuanced forms. In drawing attention to this particular practice of care, I do not wish to intentionally neglect the ways young people enact care in other ways, reflecting especially on paid care labor, care given to the environment and within social justice approaches, and unpaid caring relationships with other important individuals in their lived experience (e.g., romantic partners, friends, co-workers, and so forth). Certainly, such care intersects constantly in their lives. In the lives of young people, care, in all its executed forms and operations, is an essential and worthy examination.

Nevertheless, the particular interest of this research and the space limitations of this thesis will demand a refined scope of study, and it is my belief that this research, although small-scale and exploratory, will continue to guide and deepen our thinking about the practice of care by young people.

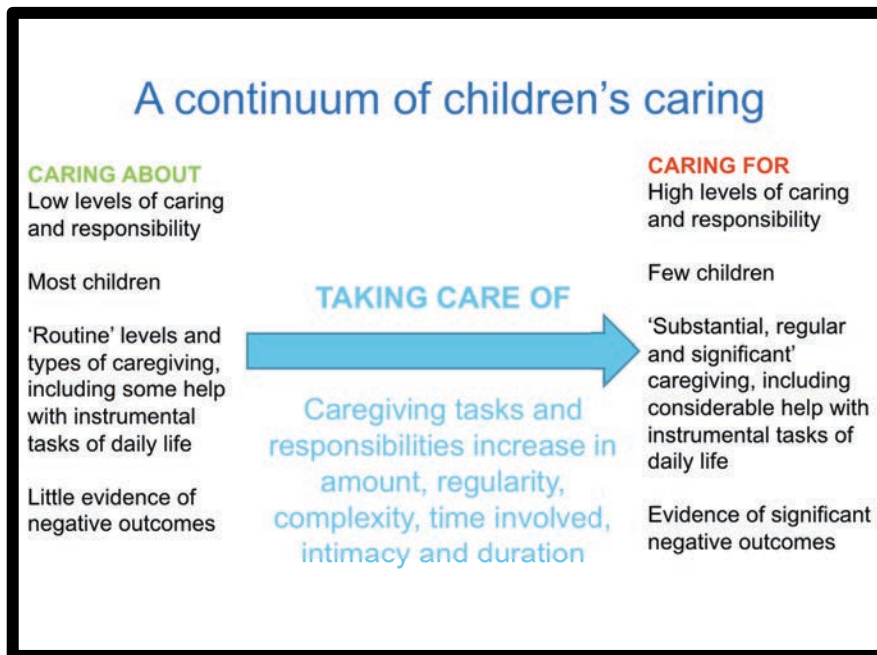
3.2.2. FAMILY PRACTICES

According to Williams (2018, p. 551), care involves “complex interpersonal, emotional, and physical encounters between care giver and recipient”, and I suggest this is particularly true for young people in consideration of their family practices. It may be helpful to think about the term ‘family practices’ as an observation of what individuals in their families *do*, rather than what they *are* (Morgan, 1996; Williams, 2004). Developed by sociologist David H. J. Morgan, family practices promote the idea that the concept of family is “actively created” by its members (McCarthy & Edwards, 2011; Morgan, 2011). In a radical shift from previous theoretical understandings, under Morgan’s (1996, p. 186) approach, family “represents a quality rather than a thing”. In its nature, family practices are the changeable, daily interpersonal relations with others, not bound by traditional notions of marriage, blood, legal ties, or shared residence (Williams, 2004). Such a commitment to this broad and fluid view led Finch (2007) to prefer to use the term “family relationships” rather than use “family” as a noun, as notions of family are not fixed. In this present study, I affirm the perspective of Morris (2012) that ‘family’ can mean anyone in importance in the extended network of the young person without necessitating familial ties. Finch (2007, p. 69) makes clear that the question ‘Who is my family?’ is actuality a statement on relationship—“Which of my relationships has the character of a ‘family’ relationship?”. The concept of family practices is meant to challenge the narrative offered by policy, the media, and even historical traditions in academic research of a “normative family”, one that is white, heterosexual, two married parents, with a male breadwinner (Williams, 2004). What families ‘do’ is often a center of debate in society through the determination of what are moral, good, or dysfunctional family practices (McCarthy & Edwards, 2011). The regular, daily activities of the family articulate meaning about family life on a wider, societal scale. Such meanings have critical ramifications for families, as the work of Morris, White, Doherty, and Warwick (2017) provides evidence that the narrative of ‘vulnerable families’ in the United Kingdom has strongly influenced social policy and its practice. We are tasked with negotiating and centering the actual, lived experiences of “family”, especially for families facing disabling

societal factors, and are oppressed, marginalized, and pathologized in the gaze of the ideal, normative family.

This moves us to a consideration of normative versus lived experiences in for young people whose ‘family’ includes those with illnesses, disability, and other health-related conditions. Historically, the narrative of family, and subsequently, the notion of the ‘normative’ family is one in which all of its members are healthy and able-bodied, and ‘care’ extends from parent-to-child through typical, developmental stages from birth through the legal age of adulthood (Williams, 2004). Nevertheless, it is increasingly viewed that care is universal, mutual, and intergenerational in the experience of childhood and youth. Care is not an ‘either or’ dichotomy but rather exists on a continuum. In the following model offered by Becker (2018), children’s caring is observed as the “caring about” performed by the majority of children to the “caring for” performed by those deemed ‘young carers’:

Figure 1



In this model, most children “care about” their family members and practice routine levels of caregiving, which can include daily household tasks. This might be what some think of as “normal” tasks for family membership, like household chores, running occasional errands for another family member, assisting or ‘baby-sitting’ younger siblings. Becker (2018) indicates that this type of “caring about” does not usually correlate with negative psychosocial impacts. As

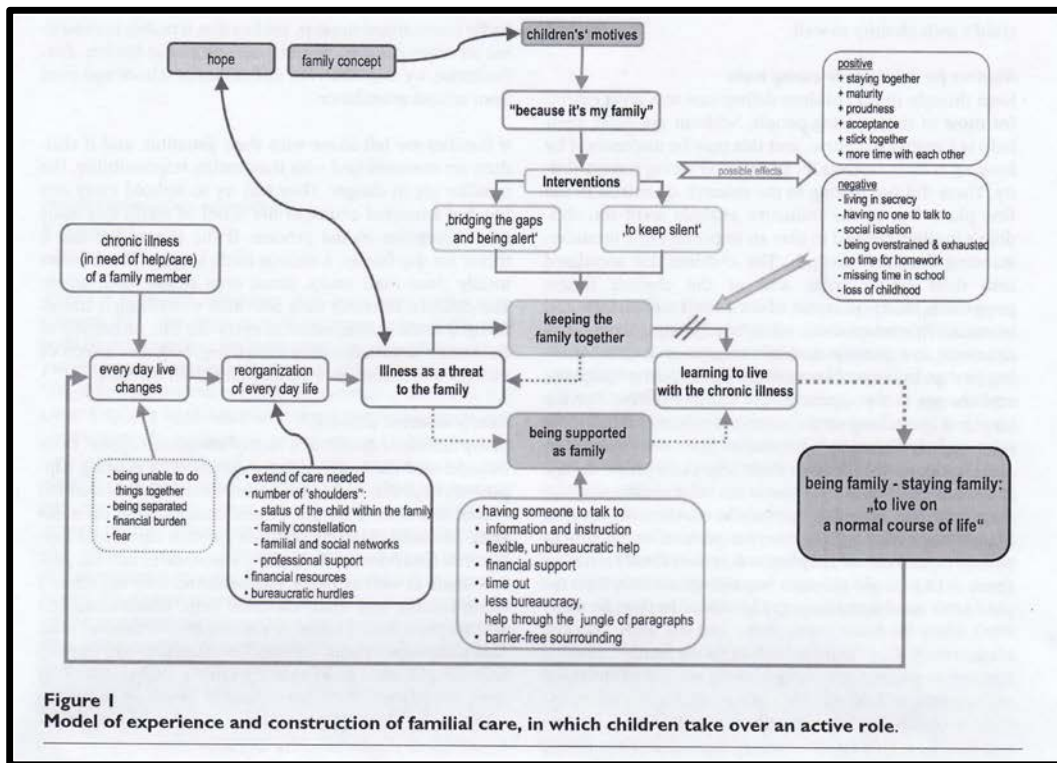
children begin to engage in more substantial, regular tasks, their “caring about” gradually shifts into “taking care of”. When children have high levels of caring and responsibility in the home, which significantly fewer children do, their position becomes known as “caring for”.

For families with illness, disability, or other health-related conditions, systematic and complex factors may determine whether the children and young adults in the family find it necessary to undertake substantial caring tasks for the maintenance of the family. This is an important distinction to emphasize, as Becker (2018) reminds us that every child and young person living in families with chronic physical or mental health problems, illness, or disability will *not* become what we have defined as a ‘young carer’. In the United Kingdom, for example, there are 3 million children currently living in households with chronic physical or mental health problems, illness, or disability (Becker, 2018). There are 360,000 children in the United Kingdom who have parents who misuse substances (Becker, 2018). Of those numbers, the 2011 census has estimated there are 215,000 children deemed ‘young carers’ in the United Kingdom (Becker, 2018). How do children and young people live in families in which there are chronic health problems or impairments, yet do not fit the Becker (2000) definition of young caring? This thesis has already set forth the issue of hiddenness and invisibility for young carers and their substantial absence from focused academic research and specific policy (the variance in context between the United Kingdom and United States has already been noted; see Chapter 2). Thus, we bear in mind that statistical figures of young carers may not capture the full scope of young caring because researchers have simply not reached them. However, in this present instance, we consider the reality that every family with health issues will not be a family in which young caring takes place. Factors such as lone parenting, poverty, social exclusion, unavailable or unwilling family members or friends, and a lack of either paid care support or government-sponsored formal services can contribute to the necessity of young caring (McDonald et al., 2010; Metzger-Blau & Schnepp, 2008).

Even as family practices theorists such as Fiona Williams advocate that we challenge and re-think the notions of normative families, they also acknowledge that the normative family ideals and the lived experiences of family influence each other (Williams, 2004). Our idea of normal can play a strong role in shaping our views on how our families *should* like and do, even if it is very different from our reality. Research involving young carers continues to provide evidence that young people with caring roles grapple themselves with the construction of

“normal family life” and how their experiences fit within that framing (O’Dell, Crafter, de Abreu, & Cline, 2010). The work of Metzging-Blau and Schnepf (2008) with young carers in Germany highlight two phenomenon in the family practices of young carers. First, young carers seek to negotiate ways to keep their family together, i.e., maintain their sense of a cohesive family unit with as little disruptive to daily life as possible (Metzging-Blau & Schnepf, 2008). Second, children sought to “live a normal course of life” in the midst of the family’s changes and adaptations (Metzging-Blau & Schnepf, 2008). In the following chart, we see what Metzging-Blau and Schnepf (2008) have constituted the model of experience and construction of familial care, when children engage in caring roles:

Figure 2



As young carers mark that their lives are filled with change due to the nature of their family’s health condition, they enact strategies to reorganize their everyday life. They step in and take responsibility for tasks that in times of need, and Metzging-Blau and Schnepf (2008) found that those children experienced their lives in states of constant alertness to what needed to be done to maintain the family’s daily functioning. This finding was also complimented by the work of McDougall, O’Connor, and Howell (2018) with young carers in Australia: they reported their

need to always be vigilant and available. This became their understanding of ‘normal’ for their family, even though they were acutely aware that their lived experiences were different from their peers whose families had an absence of illness or disability (Metzing-Blau and Schnepf, 2008). This phenomenon was also observed in the lived experiences of young carers in New Zealand; young carers reported that their caring tasks evolved in the face of the support needs, the availability and capacity of other family members to care, and the availability of external support services (McDonald, 2010). Their reflection of their family practices, even in the midst of flux, were also marked by an acceptance that this was a natural part of their life and care was something they became used to (McDonald, 2010). Similarly, the young carers in the McDougall et al. (2018, p. 576) study expressed that care was something you “do for family” and accepted their role as the way their lives were to be. Such adaptation became so embedded that when asked to state their unmet support needs, the young carers reflected little desire for change, as they had become accustomed to their state of affairs (McDonald, 2010). Certainly, gained competencies can be surmised as children perform care tasks repeatedly over a period of time, especially for children who had been caring for several years into their adolescence. Thus, these research findings show that when engaged in regular, substantial care tasks, some young people recognize that they feel different to other young people and other families; additionally, young people also exhibit adeptness in maintaining normalcy in their families—in whichever way they have come to interpret ‘normal’.

Because this present research study is focused on identity development in young adults with caring responsibilities, it is important to draw attention to the sentiment expressed by the young carers in McDougall et al.’s (2018) research: the label of “young carer” was often refused by young people because they felt the label disrupted their understanding of normalcy in their family practices. Not only was the label of “young carer” associated with stigma and connected to mistreatment from others, but the label served to highlight their “atypicalness” and harmed their efforts to “maintain a ‘normal’ family dynamic” (McDougall et al., 2018, p. 576). Furthermore, they sought to “hide” their family circumstances from their peers in an attempt to appear normal, even to the point of declining formal support services in connection to their caring role (McDougall et al., p. 576). The young carers in Metzing-Blau and Schnepf’s (2008) work also expressed that they would stay “silent” to protect the image of their family’s normalcy. Compounding upon these perspectives, the work of Morris (2013) with families deemed highly

vulnerable in the United Kingdom found that some families sought to perform their perception of “normal” family practices in the view of social care professionals, to combat the threat of negative social service involvement, some even to the point of providing false accounts to professionals. We can understand that these families are forced to navigate the oft-judgmental ‘gaze’ of outsiders and the very real threat of resulting negative consequences, however as Morris (2013) indicates, when intentional hiding of family circumstances from professionals takes place, it can have a damaging effect to the children of the family by continuing the harmful environment. I must stress that I draw attention to this aspect of the work of Morris (2013) not further pathologize families in which young caring takes place, and especially problematize disabled parents. Rather, I believe it provides useful reflection onto the complexities facing the decisions of young people to engage with the social constructed ‘young carers’, keeping in mind their efforts to avoid ‘othering’ their families. These findings add a nuanced layer to our consideration of the social construction of “young carer”. We can weigh the purported benefits of the distinct social group of young carers (and caregivers) in bolstering the fight for rights, formal recognition, and access to state-sponsored services, against the potential harmful effects of the young carer/caregiver labelling: stigma, discrimination, and an affront to their conceptualization of normalcy and maintenance of their family practices. If some young carers/caregivers wish to think of themselves as “normal”, it may be possible that for some young carers/caregivers, the benefits of the label are not outweighed by its negative effect on their perception of their identity and their family identity.

3.2.3. THE CONTESTED NATURE OF CARE & YOUNG CARING

In the midst of the surrounding discourses on care, it must be understood that the subject of care remains contested and unsettled (Evans & Thomas, 2009; Williams, 2018). First, the sheer phenomenon of children and young people ‘doing’ care continues to baffle Western society (Olson, 2017). The denial of the existence of young people with substantial caring roles in the family has served to render young caring invisible in both the United Kingdom and United States, although arguably the political recognition of young carers in the United Kingdom has diminished their invisibility to a lesser degree than their counterparts in the United States. The question of whether young people engage in care roles in their families acts as a major factor in its contested nature: does young caring even exist? Beliefs in the non-existence of young caring can lie in its cultural and gendered manifestations as embedded family practices, e.g., ‘this is

what family members do' or 'this is what female family members do'. It can also be observed in the false beliefs that young people are too narcissistic and self-centered to offer anything of altruistic value to their families. I consider that this belief is grounded in the current discourse on Millennials and youth culture that calls them 'lazy', 'spoiled' and overly protected (Bergman, Fearington, Daveport, & Bergman, 2010; O'Connor & Raile, 2015). It likely also stems from the persistent notion that children and young people functions as 'takers' of care, rather than 'givers' of care (Cockburn, 2005; Smyth, Blaxland, & Cass, 2010; Williams, 2004). The social construction of 'young carers' and its formal recognition in policy and practice serves as an acknowledgment that children and young people have agency to care. Such a position is one that Williams (2012) argues is unprecedented, as historically, the West tends to view children as recipients of both familial and government-sponsored care. More recent research on childhood has tended to assert that children are active agents in their own lives, their family life, and in schools and communities, which has significant ramifications for children and young people who provide care in families with illness or disability (Cockburn, 2005; Williams, 2004).

One area of contention regarding the theory of care lies within the disability rights movement in the United Kingdom. At this present juncture, I will acutely focus attention on contested issues surrounding care within the discourse of young caring in the United Kingdom, rather than the United States. Whilst there may be some parallels to draw upon within the disability rights movements in the United States and the United Kingdom, especially in regards to the notion of disabled people as a 'burden' to their family members and the state and also the notion of dependency, the utter lack of traction in viewing young caregivers as a distinct social group in the United States will prevent us from holding a deep discussion of the American context of social policy, 'care', and young caring (Parker & Clarke, 2002; Switzer, 2003). I am hesitant to embark on a discussion of any possible tensions between the disability rights movement and the advent of 'young caregivers' as a constructed social group because I do not feel there is sufficient evidence in literature to articulate such a view and give it the nuanced critique it deserves. The lack of evidence, in my view, exists partly because the idea of 'young caregivers' as a social group is relatively new and has not yet entered into a politized space, at least not in the same manner as it has in the United Kingdom. However, I will briefly articulate a supposition of how care could be viewed as contested in the narrative of young caring in the United States later in this section. Thus, the following section will solely focus on the contested

issue of young caring within the disabled people's movement in the United Kingdom, as I feel there is an established historical timeline to follow to guide our understanding.

Strong proponents of the disability rights movement, such as the work of Jenny Morris, have argued for a social model of disability in which language becomes of critical importance. In the social model of disability, the term "disability" refers not to impairment, but to the "disabling barriers of prejudice, discrimination, and social exclusion (Morris, 2001, p. 2). Therefore, "disabled people are those people with impairments who are disabled by society" (Morris, 2001, p. 2). It is the disabling factors found in society (e.g., discrimination, negative attitudes, and inaccessible environments) that have served to "disempower and segregate" disabled people (Morris, 2001, p. 2). Such a view is meant to help destroy notions that disabled people are incompetent, powerless, or pitiful tragedies because of their impairment (Morris, 2001). Put simply, one's impairment is not the problem, but rather the problem lies in the way society enacts and reinforces barriers that limit, restrict, and exclude. Unfortunately, as Morris (2001) argues, the popular narrative in society is one that impairment needs to be cured and treated. In Morris' view, it is an act of oppression that disabled people have not been in control of the narrative of impairment and disability. Rather, non-disabled people maintain and promulgate society's assumptions of disabled people, and this has allowed for misconceptions and prejudices to persist. Consequently, the disability rights movement seeks to change a disabling society (Williams, 2012). In relation to this study's present focus on young people with caring responsibilities, it behooves us to understand the framing of young caring within the disabled people's movement, particularly in respect to false narratives and prejudices. We can achieve this by shifting our examination to the perspective of disabled mothers and the language of young caring.

Morris (2001) points to the rise of the language of "carers and their dependents" and its debate in the 1980s and early 1990s in the United Kingdom as evidence for the othering and invisibility of disabled people, especially disabled mothers. Parker and Clarke (2002) suggest that the term of "carer" first came into existence in the disability work of Blaxter in 1976 in her description of a family member assisting a disabled individual (Blaxter, 1976). The politicization of carers in the United Kingdom arose during this time, through the campaigning of carers organizations such as the Association of Carers, now known as Carers UK, and now House of Lords member Jill Pitkeathley (Parker & Clarke, 2002). According to Williams (2012), the

carers' movement exists to make visible the care given within families in the home and push for financial and practical support as they provide care. Their successful campaign took the issues affecting carers from a place of inconspicuousness to a centered spotlight (Parker, 1994; Parker & Clarke, 2002). As the push for carers rights became increasingly embedded into social policy and community care practice, disabled people and particularly disabled parents expressed a *de-centering* of their rights and campaign for their legally entitled support (Parker & Clarke, 2002). Indeed, it was felt that the introduction of the socially constructed group of "carers", its subsequent politicization, and the adoption of the term "carers", facilitated a public discourse that disabled people were dependent and immature (Parker & Clarke, 2002). According to Keith and Morris (1996) and Morris (2001), the social construction of the children of disabled mothers as "young carers" further led to create a narrative of diminished capacities within disabled parenting. Keith and Morris (1996) critique the early work of Aldridge and Becker, firstly, by disapproving their creation of a term that children did not create themselves—"young carers"—and secondly, by rejecting the even the slightest notion that young caring creates a role reversal in parenting, i.e., the child takes responsibility for the disabled parent. Keith and Morris (1996) argued that when researchers claim that children provide help with personal care tasks and furthermore uptake responsibility intended for the parent, such as the view they argue lies within the work of Aldridge and Becker, it leaves too much room for the false assumption that children are "parenting" their parent. Morris (2001, p. 7) rejects the language promoted by the popular media of the day, calling children of disabled parents "little angels" because they "neglect their schoolwork and friends" to provide care for their parents. Additionally, Keith and Morris (1996) emphasize that disabled parents possess the same love and care for their children as non-disabled parents, and that their impairment does not affect their ability to want the best for their child, even if they may not be able to do all of the same tasks as other non-disabled parents. The major view that Keith and Morris (1996) wish to promote is that disabled parenting should not be problematized, rather fault-finding attention must be paid to the way in which society has enacted barriers in the lives of disabled parents. They bring attention to societal barriers such as inaccessible facilities, issues of poverty (Morris (2001) views poverty as the most important factor), and lack of formal support (Keith & Morris, 1996). They bolster their view with the words of social care academic Gillian Parker (1994): "While it seems true that children of disabled parents sometimes find themselves carrying a level of responsibility in excess to that of

their peers, they do this because their parents are inadequately supported, not necessarily because their parents are disabled”. When Aldridge and Becker (1993) stress that social care professionals are not addressing the needs of young carers during consultations in which only the parents’ views are asked and heard and are further silencing the voices of children, Keith and Morris (1996, p. 43) assert that they believe that only the views of parents *should* be taken, as disabled parents remain both “willing and capable” of making decisions affecting the whole family (in the majority of cases). Additionally, in the early 2000s, there were reports that disabled parents were forced to make claims for their government-sponsored support through their children’s needs as carers, rather than through their own merit (Goodinge, 2000; Wates, 1997). It follows then that those positioned within the disability movement were concerned about the ways that the discourse of young caring can serve to create false assumptions about the capacity of disabled people’s ability to parent their children. In essence, they proclaim that children are not their “carers” and that children “do not parent us”, and the social construction of young caring defines disabled parenting as inadequate (Keith & Morris, 1996, p. 43). Morris (2001) presents the following resolution: apply the social model of disability to children of disabled parents. In the following chart, we see that Morris (2001) presents a series of statements that she believes consists of disabling attitudes on the left column. In the right column, Morris gives alternative responses in view of the disability rights perspective.

Figure 3

<i>Disabling attitude</i>	<i>Disability rights perspective</i>
People who need help with the physical tasks of daily living are dependent.	Independence is not about doing everything for yourself but about having control over how help is provided.
If your child helps you put your shoes on, this involves a reversal of roles—you have become the child, and your child becomes your parent.	The need for help with daily living tasks does not undermine your ability to love and care for your child.
We need to recognize the role of “young carers” so that we can support these children in their “caring responsibilities, experiences and needs.”	Disabled parents should not have to rely on our children for help as we have statutory rights to “practical assistance in the home” and to the adaptations and equipment we require.

Here, we focus our attention on the final row in her chart. In the left column, Morris (2001) affirms that a disabling attitude is one that attempts to recognized the role of young carers and that more should be done to support them as they care for their parents. In the right column, Morris (2001) seeks to remind that disabled parents are already entitled to rights that should ensure their full participation in society, and therefore disabled parents should not need to rely on their children for support. Come full circle, Morris (2001) argues that the social construction of “young carers” is unnecessary because through the application of the social model of disability, focus should instead be on the disabled parents’ need to receive their entitled formal support (which they currently do not receive fully).

Morris (2001) suggests that the conceptualization of care by feminist ethics of care can help move us away from her view of a problematic notion of care. To Morris, the meaning of “care” has been misconstrued to mean to *take responsibility for* another individual (Morris, 1997). Such an interpretation of care implies that disabled people (or specifically, disabled parents in our present study) have relinquish control and choice (Morris, 1997). As articulated earlier, the perspective that disabled people need ‘care’ is oppressive (Parker & Clarke, 2002). Shakespeare (2000) offers that the notable principle of care ethics—mutual interdependence within relationships—can help us think differently about “care”. Because of the relational aspect of care, an understanding of the ethics of care is warranted. The theoretical approach to an ethics of care has its foundation in Lawrence Kohlberg’s moral development theory and subsequently Carol Gilligan’s feminist critique of Kohlberg’s work (Allmark, 1995). Williams (2018, p. 557) asserts that care ethicists “reconceptualize autonomy, reasoning, justice and equality in relational terms”. If we view care as universal and ethical, we raise the value of care, and in doing so, protect those who are at most risk of marginalization (Williams, 2018). Noddings (1984) believes that the nature of caring is defined within the relation between the one-caring and the cared-for (p. 9). To care and be cared-for, Noddings (1984, p. 7) believes, is a part of the universal human experience. In a deeper sense, we have a *longing* to care, as we crave the relational aspect between the one caring and the one cared-for found within the dynamics of caring (Noddings, 1984, p. 5). Her view on the human desire to care supports Deci’s (1995) view that the need for relatedness motivates people to care for others. We are relational creatures, and caring helps to fulfill our need for connectedness, with the added benefit of doing good beyond the confines of

the self. Relationship, in Gillian's (1993) view, cannot exist in the sphere of simple communion with other, but with interrelatedness that still maintains "voice" and agency.

In response to the critiques offered by disability rights academics and advocates, Aldridge and Becker sought to refute some of the claims that in their view felt misunderstood. Cogan (2004, p. 315) calls Aldridge and Becker (2003)'s work on young carers of mentally ill parents an improvement from earlier work, because of its clearer and explicit attention on the structural and social factors (namely, "poverty, marital discord, lone parenthood, absence of extended family and low levels of social support") in place to cause disability and the subsequent uptake of caring roles from children. Furthermore, Aldridge and Becker (1996) emphasize that their work on young carers was intended to record the experiences of children, especially their recounts of their emotional and filial lived experiences to determine what support is needed to prevent harm. They challenge that the disability rights movement is more concerned with *why* children care, rather than what happens *when* children care, i.e., their lived experiences. Whilst Aldridge and Becker (1996) agree that if disabling factors were addressed and support given to disabled parents, this would help reduce the instances of young caring. However, they caution an oversimplification of the context of young caring, asserting that disabling factors do not take into account the realities that the health conditions of family members may require care and support, and additionally, that some children practice agency by *desiring* to care for their families. Finally, they articulate that social care professionals must "don their 'young carer spectacles' to address the fears of children and their families of social service involvement in seeking support (Aldridge & Becker, 1996, p. 69).

The work of Parker and Clarke (2002) have championed a view that the disabled people's movement and the carers movement do not have to sustain a polar oppositional stance. They emphasize that even in the midst of the increased prioritization of carers' rights in the social political sphere, carers themselves have reported that their needs are not being met fully by the social services (Parker & Clarke, 2002). This is congruent with reports from disabled people that they also are not receiving the support that they are legally entitled to obtain (Parker & Clarke, 2002). Therefore, Parker and Clarke (2002) insist that energy could be better directed towards challenging current policy rather than perpetuating fissures within the interests of carers and disabled people. Their way forward is three-fold: first, social policy must embed and practice the position that "disability is socially created"; secondly, acknowledgement must take place that

“women, people from black and minority ethnic communities, frail older people, those who are ill as well as disabled—may have their disability created in different ways”; and thirdly, whilst both the disabled people’s movement and the carers argue for the state to fulfill their legal obligation in support provision, the reality remains that some people will prefer for family members and friends to provide their care (Parker & Clarke, 2002, p. 357). I recognize the usefulness of Parker and Clarke’s position. To this present day, Clarke (2018, p. 172) acknowledges that there remains a “schism” in community care practices and academic research involving carers and disability rights. Similar to the views purported by Aldridge and Becker, I do not believe the social movements of disabled people, disabled parents, carers, and young carers have to be diametrically opposed. I believe Parker and Clarke did well to acknowledge that different people will have different views and therefore different agendas to champion. This feels especially true for individuals possessing other marginalized identities in society and where the theory of intersectionality offered by Kimberlé Crenshaw feels most useful. Briefly, Crenshaw’s (1991) work, based upon the overlapping oppression and discriminatory experiences of black American women, coined intersectionality to address the intersection of one’s identities across race, class, and gender lines. I agree with Clarke’s (2018) position that “structural impacts” caused by racist, disablist, and sexist attitudes and practices embedded into society must be centered into any discussions of the lived experiences of disabled parents and their children, including those young people who provide care. Finally, as much as I maintain the state must fulfill its legal duties to support the needs of disabled people and carers, I understand that the reality exists that disabled people and their family members and friends may decide amongst themselves that care would be better negotiated and practiced within their personal relationships, away from the involvement of the state. All parties within the relationship may determine that the care offered by social care services would not be adequate to meet the needs of the family. For example, Ornstein-Sloan’s (2016) doctoral research in the United States championed this view that the complexities of formal care services coordination outweighed any potential benefit to the disabled or ill family member, and therefore, some families elected to decline the services of paid caregivers. Disabled or ill family members may feel more comfortable due to their personal or cultural practices for care, and especially intimate care, to be provided by someone they know well. There is a risk, of course, in the influence of the gendered expectations that exist within families’ personal ethos and their embedded culture, for women to be seen as the primary

giver of care (and again, especially with intimate care). Furthermore, I assert that a complete reliance and expectation on the state to provide care may not be realistic, as I draw upon Williams (2012, p. 104)'s view that family and care policies frequently reveal the 'ought' of policies and the 'is' of how people actually rehearse family practices. Finally, I support Cockburn's (2005) realization that some children may, in actuality, *wish to* care for their families. Just as he admits the tension to respect the dignity of such children's views, I too acknowledge that our desire to center children's wishes as active agents in their own lives can feel at odds to our championing of children's rights. Cockburn (2005) further articulates that children's desire to care can highlight the complexities in our understanding of care ethics, especially in regards to the "cared-for" relationship.

The notion of "cared-for" and "carer" may also be further blurred within the relationships young people have with their disabled or ill family members. As previous research has established that young adult carers are at risk for serious mental illness, it may be that young adult carers themselves have needed or will need care from their disabled or ill family members. Other research has also indicated that young people may experience back strain from lifting disabled family members. To be clear, I do not bring attention to the health needs of young adult carers to lay blame at their disabled family members. I assert that within a social model view of disability, one would agree that any fault is not with the young people or their disabled family members, but rather, the breakdown of the state to provide sufficient and appropriate services to the disabled family member. I highlight the likelihood of young adult carers having their own health needs to demonstrate that care is continuously practiced in families in a variety of ways and in differing levels. It may be that in families where there are disabilities that young people engage in significant care tasks (e.g., practical, emotional, and intimate care) for longer, sustained, and more pronounced periods of time than families without disabilities.

Most recent research with adults with learning disabilities who provide care for disabled family members serves to bring attention to both the complexity and diversity in care conceptualizations. Baker, Johnson, Virgo, and Ward (2012) found that adults with learning disabilities were reluctant to use terminology "carer" because they did not want their child to be labelled as their carer. Baker et al (2012) also found that they were often rendered invisible in the eyes of social services and rejected from receiving a carers allowance because of the assumption that their learning disability meant that they could not also have a caring role. Those adults

expressed that they desired societal understanding of the ways they could have needs of their own because of their disability whilst also having needs as a “carer” to someone else (Baker et al., 2012). The principle of reciprocity in caring relationships has strong relevance in this present discussion. In her other work with adult carers with learning disabilities, Ward (2015b) identifies the importance of trust within reciprocity in their caring relationships. Reciprocity in this instance does not mean a ‘tit for tat’ transaction, but rather, reciprocity refers to the understanding that we have all been dependent in the past and will be dependent in the future. There is trust built within one’s relationship that care will be given whenever the need arises. Baker et al (2012)’s research, although focused on adults, highlights the issues of mutuality in caring that is also present amongst the lives of some young adult carers.

This chapter has already sought to establish that mutual interdependence in care is a normal facet of human life. I do not seek to contest this view in my present work. I further agree with Kittay’s (1999) perspective that our needs for care ebb and flow throughout the course of lives, highlighting dependencies inherent in the human experience. However, I hold that there may be times in one’s life that care feels more pronounced. I suggest that young people with caring responsibilities engage in what Ward (2015b, p. 167) calls “explicit enactment of mutuality” in which people exist in both “cared-for” and “carer” roles at the same time, because of their young age. For children under the legal age of adulthood, this is perhaps more clearly apparent. Normative expectations of childhood would allow that children need care—emotional, physical, and intimate—in various capacities, with different elements of care becoming more or less pronounced as children age. It follows that young caring subverts the expectations of normative family practices and children’s roles (Evans & Thomas, 2009). For children whose family circumstances necessitate their involvement in care for a disabled or ill family member, they may especially engage in “explicit enactments of mutuality”, as their needs due to their young age require care from their family, simultaneously as they provide care for their family members. I argue that explicit enactments of mutuality can also be observed with young adults and their families, although it may seem less obvious. Recalling our earlier examination of the theories of emerging adulthood, if young adults presently function in a state of prolonged adolescence, their youth, despite their legal age of adulthood, means that they too have needs that warrant fulfillment from their families. Note, that one’s need for care does not cease once past the age of 24 or 25 years old. The need for care, and indeed diversity in the type of care needed

will remain through one's entire life. Rather, I call rely on the developmental psychological approach that young adulthood (or, emerging adulthood) presents occasions for guidance and support that may feel similar to adolescence, than middle adulthood. As Evans and Thomas (2009) affirm that Western notions of childhood uphold youth as a period of carefree living and innocence, the theories of emerging adulthood also promote that the young adulthood years are specially designated for freedom and autonomy. Caring roles can serve to challenge those notions (Evans & Thomas, 2009). The existence of "explicit enactments of mutuality" can also feel more pronounced in young adulthood if the health condition of their family members change, such as a worsening of their health or a new diagnosis. Additionally, the work of McDonald, Dew, and Cumming (2010) with young carers in New Zealand found that change and adaption was critical part of families with disabilities or illness. The presence of family members or friends—and their absence—could mean that the uptake in a young person's caring tasks was dependent upon the availability of other family members or friends (McDonald et al., 2010). In particular relevance for the state of young carers in the United Kingdom, McDonald et al. (2010) also found that adequate external support, such as provided by state social care services, would led to a decrease in the amount of care that young people needed to provide. This finding has particular relevance for young carers in the United Kingdom, as we consider the influence the austerity period and continued cuts to social care funding and services will have to the formal support services available to both disabled and ill family members *and* young carers. Indeed, social care policies may "freeze" the identities of carer and the cared-for into place (Williams, 2012, p. 106). I assert that the current social political landscape in the United Kingdom certainly will have a detrimental impact to the level of care that children and young people will need to take on, particularly if there is not adequate services in place for their family members.

Within the context of the United States, I uphold the view that care is contested for young caregivers on the question of its actual existence. Caregiving literature in the United States often quotes former First Lady (and former young caregiver) Rosalynn Carter on the universality of care: "There are four kinds of people in this world: those who have been caregivers; those who currently are caregivers; those who will be caregivers; and those who need caregivers" (Schulz & Tompkins, 2010). In this popular quip, children and young adults are not typically thought of as the 'current' caregivers, but rather, future caregivers once they reach middle-aged adulthood (Olson, 2017). We observe further exclusion in scholarly research in the United States. When

research published from the National Research Council Committee on Health Care names the groupings of caregivers, young people are excluded (Schulz & Tompkins, 2010). This absence is supported by the lowered classification on the Leu and Becker (2016) country young carer awareness scale. Olson (2017, p. 6) affirms that the term “youth caregivers” is an “impossible anachronism” to social care professionals and academics alike, because of the sheer invisibility of young caring in the United States. In the context of the United States, the child continues to be seen as a dependent and recipient of care, furthering rendering young caregivers unseen (Olson, 2017). On this subject, Olson (2017, p. 5) offers a critique of the ethics of care approach, acknowledging that its focus on middle-aged and elderly caregivers has overlooked and ignored young people as agents of care, as they are seen as a “trope of care dependency”. This narrative of children as *needing* care has had significant effects in current social policy in the United States. We are reminded that the United States has yet to ratify the United Nations Convention on the Rights of the Child. As we understand that the social construction of young caring in the United Kingdom was bolstered by the politicization of young caring by the carers movement (even if rather recent in the movement’s timeline), the United States will also need to uphold a children’s rights agenda if it is to recognize young caring in American families. If American society begins to acknowledge the existence of young caring, they must also recognize that children and young people are active agents in their own lives and in their families. If this recognition can take place, the responsibility follows to support and champion children and young people’s right to justice.

3.2.4. IDENTITY, CARE, AND ETHICS OF CARE

At this juncture, I seek to transition our thinking to back to a discussion on identity, care and ethics of care. To guide our discussion of identity and care ethics, we will closely examine the work of academic Nicki Ward, whose focus on ethics of care, intersectionality and social care has particular relevance for my present study. The practice of care ethics offers critical framing for an understanding of identity as “relationally constructed” (Ward, 2015, p. 59). As Turner (1999) suggests, a social construction of identity takes the view that identity is fluid, changeable, and influenced through one’s relationships with the world. A post-structuralist, sociological perspective would further purport that identity is constructed through labelling and perceptions—both perceptions created by the self and perceptions pressed upon by others (Ward, 2015). Through a Foucauldian understanding of the way discourse is generated through social

relations, identity, as socially constructed, can be thought to exist as a discourse. Knowledge and power are embedded into discourse, and it certainly follows that the labels and assumptions associated with identity can also produce both knowledge and power. With the belief that care ethics possess a relational ontology, the relationships we participate in produce and enact power (Robinson, 1999). Our care relationships are included in this view, and care ethics can highlight the “creation and reification of those social power relations” (Ward, 2015, p. 59). Ward (2015, p. 59) argues that a social construction of identity may indicate individuals’ “needs for care and their roles within relationships of care are either given credence, marginalised or, in some cases, rendered invisible”. It has already been established that identities can be positioned in differing levels of status; it is additionally true that the identities we possess *within* relationships can also rehearse and reinforce operations of power (Sindic, Barreto, & Costa-Lopes, 2015)). A critical approach to ethics of care would consider the positionality of the constructed identities of the “cared-for” and the “carer” in the context of the caring relationship. We may think the identity of “carers” and the “cared-for” as social groupings, generated by the carers rights movement in the United Kingdom (Barnes, 2006). Ward (2015) argues that those identities have become embedded into social policy and practice in the United Kingdom, and furthermore, the possibility exists that individuals can be either included or excluded in society by their identities. The prevailing discourses can allow for the marginalization of individuals but also those very same discourses can define the boundaries of social groups and the right behavior within those groups (Davis, 2006). It is in this manner that identities (and the people possessing those identities) can be rendered invisible. Again, Ward (2015) argues that we see this most strongly in the politicized identity of the “carer” in the ways that individuals’ status as “carers” can determine their ability to access state-sponsored resources, such as a carer’s allowance. Ethics of care allows us to critically examine the discourse of the “cared-for” and the “carer” as care ethics would declare that those identities can transverse back and forth in different context and periods of time in one’s lived experience. Additionally, the notion of mutual interdependence in caring relationships blur the lines of demarcation between “carer” and “cared-for”. Social policy, therefore, has the ability to facilitate exclusion, as it functions to determinate who is eligible to receive formal support services. It is within this framing that Ward (2015, p. 66) argues that both “carers” and the “cared-for” “need to position themselves in particular ways” as a means of receiving support.

We can observe this phenomenon with young people deemed “young carers” or “young caregivers” as well. Previous literature in the United Kingdom has already suggested that the terms “young carer” and “young adult carer” have been articulated as a distinct social group (Aldridge & Becker, 2002; Becker, 2008). The relatively recent—in comparison to the timeline of development in the United Kingdom— adoption of the terms “young caregiver”, “caregiving youth”, and “young adult caregiver” in the United States amongst researchers can also arguably be seen as the stimulus to view young caregivers as a social group (Levine et al., 2005; Shifren & Chong, 2012; Siskowski, 2006). In view of Ward’s (2015) work, we can use care ethics to critique the ways that the prevailing discourse on young caring can serve to inform the development of social policy and its practices. More generally, ethics of care can help us understand that intergenerational care in families is interdependent. The diversity and complexity in caring relationships can be seen when older generations provide care for the young, and in the relationship of which this research is concerned, when the young provide care for the old. The discourse of young caring has helped to establish an understanding of who young carers (or caregivers) are and who they are not. The definitions offered by the seminal work of young carers researchers such as Aldridge and Becker (1993; 1999) suggest that young carers are those who provide care for those with health-related conditions or disabilities. As early research samples typically consisted of children who provided care for parents solely, children who provided care for parents with substance abuse problems were excluded in the interpretation of the young caring definition by social care professionals. The threat of social service involvement in such families likely also functioned to prevent the willingness of families to be identified. Even as the definition of young caring has expanded to include those young people, tension remains as in the view that children caring for parents with substance abuse problems should be considered neglectful, dangerous, and a reason for social service involvement. Siblings who provide care in conjunction with other family members, for instance, a parent or grandparent, have also faced exclusion in accepted understandings of young caring. The definition of young carers in common usage within the United Kingdom has been expanded to include siblings of those with a condition requiring care (Children’s Society, 2013). Despite this inclusion, Meltzer (2017) and Newman (2002) accurately recognize that most young carer focused research has primarily focused on children who are providing care for their parents, so there remains a dearth in knowledge about the position of children and in particular, young adults who provide care for

siblings. It should be noted that academics such as Aldridge, Becker, and others have traditionally included both sibling carers and children caring for those with drug or alcohol problems into their definition of young caring, but rather, those in key positions to identify young people as “young carers” for access to formal support services may not have perceived those young people to fit the definition. Even if academics possess inclusionary intentions, the popular narrative that does have exclusionary elements can win out.

The current focus on health-related conditions, disabilities, and substance abuse problems in the popular discourse of young caring may arguably exclude other young people with caring roles. Young people who take on caring tasks in their families for reasons other than the health-related conditions, such as military absence, divorce, or language barriers, tend to be omitted in definitions of young caring. Literature may discuss these reasons but only in conjunction with health conditions, for example, a young person may uptake significant caring tasks related to their disabled sibling because of their parents’ divorce, leading only one parent to live in the family home. Children who take on caring responsibilities solely because non-health-related reasons are typically viewed as children with potential needs or even vulnerable, but not young carers. This exclusion in turn affects the way social policy has been informed, as national policy definitions on young caring, such as the one found in the Children and Families Act of 2014, do not mention those young people explicitly.

There are two current, ongoing examples of the way the existing discourses on young caring can affect critical social policy in the United Kingdom. Firstly, young adult carers deemed ineligible to claim the £64.60 per week Carers Allowance in England, Scotland, and Northern Ireland if they are in full-time education, i.e., in a course that exceeds 21 hours per week. Known as the “21 hour rule”, this law appears to arise out of a belief that young adult carers do not have identities outside of caring. Some young adult carers argue that the current law overlooks that it can be advantageous for young adult carers to maintain full-time education whilst providing unpaid care for their families (Fixers, 2017). The discourse offered on young caring may be one that believes young adult carers do not have the resources, time, or ability to maintain full-time caring roles and full-time education. Such a belief may overlook the adeptness and resilience of young adult carers and their ability to juggle multiple roles. I do not suggest that young adult carers *should* be engaged in a caring role that equates to over 35 hours per week (this is a debate for another space and time), rather, I recognize that is the reality for many young people in full-

time education and currently, social policy dictates that they do so without formal financial support. Additionally, building upon our understanding of young people as active agents with competencies in managing their experience in home, school, and community, I recognize that some young adult carers will elect to juggle their various roles and a formal recognition by the state of their position would facilitate practical financial support for them.

Other prevailing discourses can affect social policy involving young adult carers. The notion of who is considered vulnerable is also proving to influence the exclusion of young adult carers from receiving the 16-19 bursary. The 16-19 bursary is intended to provide up to £1,200 a year to a “vulnerable” young person’s place of learning, whether it be at college or university, training course, or unpaid apprenticeship in England. Young people in Wales, Scotland, or Northern Ireland may apply for its equivalent, the Education Maintenance Allowance. The 16-19 bursary is paid directly to the young person’s place of learning, and is meant to pay for things like clothes, books, course-related equipment, transportation costs and meals on the day(s) of learning. Presently, the bursary classifies those in care, care leavers, people on income support, and disabled young people as “vulnerable” persons eligible for the financial award. Young adult carers, however, are not named as a “vulnerable group”, and consequently, they are excluded from receiving the bursary. It is unclear why the 16-19 bursary has excluded young adult carers in their consideration of vulnerable young people. It may be young adult carers do not fit the government’s perception of vulnerable young people, but it is perhaps more likely that the government simply has not considered young adult carers at all. Their identity in society has likely been rendered invisible due to the private nature of caring within families. Older adult carers continue to fight to have their rights centered in social policy; the advent of the Care Act of 2014 serves as evidence to their slow recognition in government and society. Young adult carers possess an identity that is further rendered invisible—even within the discourse on “carers” —due to their young age. Therefore, young adult carers find themselves in a second-class citizen status with their lived experience positioned outside of both the discourse of vulnerable young people and the discourse on carers. Organisations such as the Learning and Work Institute have taken up the issue and have pressed upon the government to include young adult carers in the law, recognizing the likelihood for young adult carers to not be engaged in education, employed, or training (NEET) with financial barriers as a strong factor (Ryan, 2018).

However, such a campaign will first need the prevailing discourses to expand to include young adult carers as full participants before they can win full rights.

A resolution to the debate of the inclusion or exclusion criteria in the definitions of young caring was not one this research was originally designed to undertake. However, as more insights are gained in understanding the identity development in young persons with caring responsibilities, including the creation of a “young carer/caregiver identity, this debate grows critically essential, particularly as we consider how social policy may be informed. It is also hoped that our understanding of the historical tensions of the disabled rights movement and the carers movement can challenge new thinking in forging a modern agenda for justice for both young carers and their families.

3.3.1. INTRODUCTION

We will now shift to deepen our exploration of the theoretical approaches to the social construction of identities in view of sociology and sociolinguistics. The concepts of labelling theory, performance, voice, stigma, embodiment, and code-switching will be examined in their relation to the lived experiences of young adult carers/caregivers. Throughout all, literature from poststructuralist and postmodernist perspectives, including Foucauldian approaches to discourse and power will be drawn upon.

3.3.2. LANGUAGE & LABELLING

Ting-Toomey and Dorjee (2014, p. 27) define language as an “arbitrary, symbolic system that labels and categorizes objects, events, groups, people, ideas, feelings, experiences, and many other phenomena”. Our daily use of language helps us convey our thoughts about our world and maintain social interactions with others. Ting-Toomey and Dorjee (2014, p. 27) also suggest that language allows us to “assert or negotiate our multiple identities”. Whilst ostensibly this research is being conducted within two English speaking nations, there are differences within and between both countries in the forms this takes (and whether English is a primary language in the home and wider day to day life). As participants will experience differences in the linguistic tools available to them in their social context (e.g. labels such as ‘carer’, ‘caregiver’), it is for this reason that I will present an exploration of language and its relation to identity and identification in the following sections. Taking an interdisciplinary approach, I will draw on both sociolinguistics and sociological contributions to the understanding of the implications of categorization and naming/labelling.

For the purposes of this research on identity, a working knowledge of sociolinguistic theory is valuable. Sociolinguistics is a study of the way people use different language(s) in different contexts with different individuals (Deckert & Vickers, 2011). Social context, in particular, positions itself as one factor amongst many, in determining which language we opt to use. The theories found in the field of sociolinguistics has profound usefulness for an examination of identity, as sociolinguistics can help us better understand our social construction of identity, or perhaps more accurately, *identities*. The concept of multiple identities has relevance in sociolinguistics as Deckert and Vickers (2011, p. 3) suggest that we “construct and co-construct all kinds of particular aspects of our identities throughout the day in all our interactions with others”.

Schultze (2014) also maintains that we socially construct our identities through our lived bodies, leading to the concept of *embodied identity*. Embodiment in the social sciences is derived from the work of poststructuralists like Foucault. The body, and especially the actions of one’s body, are seen as the central mechanism for emotions, thoughts, and experiences, both individual and collective (Vacchelli, 2018). Ellingson (2017, p. 60) suggested the connection between embodiment, language, and identity as “identities are constructed within the sticky web of culture by embodied people and embodied communication among them”.

It may be that young adult carers/caregivers embody the identity of “carer/caregiver”, in part because of the way they could be viewed as *able-bodied* who “care for” their *sick, ill, or disabled* family members. Their presentation to the world as the ones who are healthy and able to provide care sits juxtaposed to the presentation of their family members as ill or disabled. Such a view, of course, neglects to consider that young adult carers/caregivers may not necessarily be “able-bodied” themselves, and additionally, such a view leaves little room for a consideration of mutual, interdependence in caring relationships. Nevertheless, the perception of young people with caring responsibilities as *able* to care may constrain them into the identity of “carer/caregiver”. The *ability* to care is a notably different concept than whether young people *should* care. I use “ability” here to reflect that young people may be viewed as physically capable to provide care, for example, one may believe that some young people have the physical strength necessary to push a wheelchair, clean around the house, or cook meals. They may fit within our constructed meanings of what it means to be healthy and therefore, society categorizes them as the “carer”, instead of the “care recipient”. Young people with caring responsibilities may also

embody identity of “carer/caregiver” through the generation of a particular mode of behavior. The act of caring, i.e., the *doing* of literal care tasks, can make one a “carer”, alluding to Becker’s diagram of the differences between caring about and caring for. The act of *caring for* can cause one to embody the identity of a “carer/caregiver”. The words their mouth speaks serves as another form of behavior, and that language can further construct an identity.

Related to post-modernist and post-structuralist theories of performance, Schiffrin (1996, p 198) asserts that “social identity is locally situated; who we are is, at least partially, a product of where we are and who we are with”. This understanding social identity echoes the contributions of the theory of sociolinguistics discussed earlier. The sociological theory of labelling suggests that people can elect to identify and act according to the labels given to them by others. Historically, labelling theory addressed mental illness and crime, examining the manner in which society can distinguish the “mentally ill” and the “criminal” (Scheff, 1974). From this study, our understanding of stigma and stereotyped identities of sociologist Erving Goffman arose. Goffman’s (1963) work on stigma promoted the idea that stereotypes function to categorize individuals and are especially useful in classifying strangers. These stereotypes can create a “virtual identity” consisting of false assumptions, perceptions, and expectations. The way a person truly is, without the imposition of stereotypes, is their “actual social identity”. Goffman (1963) believed that there is a persistent tension between one’s virtual identity and one’s actual social identity, and therein lies the issue of stigma. Stigma has its relevance in light of the concept of labelling theory, as those who have a connection to a stigmatized group are “treated by society in such a way that their life chances and prospects of realizing their own potential are significantly reduced” (Bates & Stickley, p. 570). Those who experience stigma face a host of significant ill effects, such as discrimination, social isolation, and a higher risk of poverty and poor mental and physical health (Shrivastava, Johnston, & Bureau, 2012). As labelling theory purports that individuals who are labelled may perform in accordance to their assigned labels, it may be true that those who experience stigma may also feel disempowered as a result of the way society has mistreated them. Wisdom and Green (2004) in their research on mental illness with adolescents in the United States found that the diagnosis of depression felt like a label imposed upon them and negatively affected their feelings of self-worth. It was also reported that the label of depression had an adverse effect on their view of the future, as they believed they took on an “illness identity” that hindered their ability to recover (Wisdom &

Green, 2004). Similarly, Dolphin and Hennessy (2017) suggest that “illness labels” and stereotypes continue to have potentially negative and limiting impacts onto the identity of adolescents with mental illness. Thus, socio-linguistic and sociological contributions on labelling and stigma can be combined usefully to consider the language which might be used by and in relation to young adults with care responsibilities.

Research in the United States on the potential stigma caused by the label of “young caregiver” appears to be non-existent. This is likely because the terms “young caregiver” and “caregiving youth” are not widely known and used due to the lack of awareness of young caregiving generally. I suggest that it remains a strong likelihood that those terms could have a stigmatizing effect even in a low young caregiving awareness context like the United States, as the terms are both different and unfamiliar. Previous research has shown that young caregivers in the United States may face stigma and mistreatment such as bullying or workplace discrimination in association with the condition of the person for whom they provide care (Pakenham, Bursnall, Chiu, Cannon, & Okochi, 2006). Because of the risk of associated stigma, it follows that the labels of “young caregiver”, “caregiving youth” or “young adult caregiver” may carry inherent stigma. More research in this specific area is needed. In the United Kingdom, there is a supposed greater level of societal awareness of young caring according to the cross-country classification scale of Leu and Becker (2016), however, it certainly remains true that awareness of young caring differs widely across sectors and on a micro-level. Therefore, I surmise that it is also possible that young people with caring responsibilities in the United Kingdom face stigma with the label “young carer” because the socially constructed term may be different and unfamiliar to other people in their world, such as classmates, teachers, doctors, and even their own families who have not come across the term previously. There is more evidence in previous research that young people face mistreatment when using the term “young carer” because of stigma by association (Aldridge, Clay, Connors, Day, & Gkiza, (2016). Their work found that adolescent young carers in the United Kingdom were more likely to report more sensitivity regarding the use of the term because of their fear of being “singled out as being different and treated differently by pupils and staff alike” (Aldridge et al., 2016, p. 48). One young carer in Aldridge et al.’s (2016) research expressed that the term “young carer” was not a term they preferred to use because of the burden of its stigma:

“Because like most people are quite judgmental and most of the people that I go to school with if I told them they’d say that they understood, but then they’d talk about it behind my back and use it like as an insult”.

Young carer cited in Aldridge et al (2016, .p 48)

It may be true that the term “young carer” signifies a loss of social status. The concern over the stigma of the term “young carer” may not exist solely within the perspective of young people themselves: parents of young carers can also worry that the term would have a stigmatizing effect. In the research of Aldridge et al. (2016, p. 48), one such parent expressed her concern:

“I don’t want to label her as a young carer, as such. I don’t want her to carry that with her at this moment in time, because I think, you know, being 12 years old is stressful enough without putting a label on her. She probably wouldn’t like the idea of it”

Disabled mother cited in Aldridge et al. (2016, p. 48)

Aldridge et al (2016) noted that their concern was rooted in the belief that receiving formal support through a young carers project would “formally” label their child a young carer. Notably, this alludes to the belief that the receipt of a formal support service also symbolizes deeper meaning than simply the receipt of beneficial resources, but rather, that it communicates and pronounces *something* about the individual receiving the service. Without explicit statement, the sentiment expressed in this excerpt implies that the labelling a young person affects who they are, their sense of self, and their identity. In the excerpt given above, it appears that the term “young carer” may be one that feels potentially harmful and burdensome. This parent also alluded to her child’s young age in recognition that the term “young carer” could cause distress, perhaps indicating that her youth and maturity level should not be forced to navigate the imposition of the term onto her personhood. Finally, it seems evident that this parent does not want this label attributed to her child, nor does she believe her child would want this label placed upon her either.

On the subject of stigma and labelling, it may be that parents (or other family members receiving care) are also concerned with the image the term “young carer” conjures up in relation

to their parenting. In the following excerpt from Aldridge et al (2016, p. 49), the parents feel that the term “young carer” is a negative label because of their own self-perception:

“I was quite upset because with the name “young carer”, it isn’t something that you should be proud of as a mother....And it makes you feel like you’re not a good parent”.

Disabled mother cited in Aldridge et al (2016, p. 49)

The experience of disabled parents expressing negative feelings in relation to their children’s care roles has been documented in a host of previous research (Aldridge & Becker, 1996; Olsen, 2000; Newman, 2002, Olsen & Clarke, 2003; Prillienltensky, 2004). Indeed, in the rights movements of disabled parents and the advent of young caring research and advocacy in the United Kingdom, there has been a historical tension between the two movements (Aldridge & Becker, 1996; Olsen, 2000. The notion that parents with disabilities or health conditions are otherwise unfit and incapable to care for their child, coupled with the threat of social service involvement has undoubtedly fueled this tension (Morris, 2002). In the excerpt given by the research of Aldridge et al (2016), it is apparent that the stigma of “parenting whilst disabled” has also attached itself to the term “young carer”. The term then can further stigmatize parents. In consideration of this view, we can surmise the term “young carer” also may cause into question their self-perception of normative family practices. In the negotiation of family, young people may also be aware of the negative stigma attached to the term “young carer” and how it might affect their parents’ sense of self-worth. I suggest that it is possible young people understand the potential stigma that their disabled or ill parents experience, and this awareness may also cause them to decline to associate or use the term “young carer”. A desire to maintain or protect their family’s image as normal, healthy, or functioning could be at the root of their decision-making in relation to the term “young carer”. In essence, I feel that it is important that we consider young people may be negotiating the potential effects of the term “young carer” not just for themselves, but also their family members.

Recalling the work of Goffman, I suggest that young people with caring responsibilities exist in a tension between their actual social identity and their virtual identity. If we continue to think of “young caring” as a discourse created by academics and social care professionals, we could argue that young caring and the language generated as a part of the discourse, i.e, “young

carers”, “young caregivers” and so on, are young people’s virtual identity. Subsequently, their actual social identity would be their sense of self that feels like a normal child or young adult. This perspective may fit suitably in the views of young people with caring responsibilities who express that they want to be seen as normal children and young adults (Nagl-Cupal & Hauprich, 2018; Phelps, 2012). Therefore, the discourse of young caring and its associated language could serve to stigmatize some young people due to its negative or unfamiliar perceptions.

In this way, young people with caring responsibilities may perform the discourse of young caring. As I suggested earlier, academics and professionals (including policy makers and practitioners) have defined the current knowledge about the young caring experience: care-related language and definitions of what precisely is young caring, as well as controlling access to beneficial resources in relation to young caring (i.e., formal support services). In view of labelling theory, when young people with caring responsibilities chose to engage in the current discourse on young caring, they may be coming to act in the very way academics and professionals have labelled them. For example, when young people use care-related language, it is possible that they are acting in alignment with the notion that they exist in a social group, i.e., young carers/caregivers. Researchers with Carers New South Wales (St. James Ethics Centre, 2009, p. 65) in Australia noted the benefits of labelling in their focus groups with adult carers: “it allows the focus group members and us a language for communication”. They suggested that the labels of “carer” and “care recipient” facilitated a way for both the carers and the researchers to talk about caring. Labelling does not come without risk; the Carers New South Wales researchers found that adult carers believed that the label “carer” took away from their sense of self and identity as persons with familial roles, i.e., mother, father, daughter, or son (St. James Ethics Centre, 2009). It was also felt that the labels of “carer” diminished the sense of “individuality and normality of relationships e.g., “I am not a carer, I’m a son” (St. James Ethics Centre, 2009, p. 65). The views expressed by the adult carers in the work of Carers New South Wales is not unlike the findings in other research with both adult carers and young carers (Hughes, Locock, & Ziebland, 2013; Smyth, Blaxland, & Cass, 2011). A further danger of labelling alludes to the work of Goffman on stigma. The stigma facing carers/caregivers of all ages makes the labelling theory particularly relevant. It is increasingly understood that young carers/caregivers can experience associated stigma due to their proximity to the person for whom they provide care; however, the label of “carer” or “caregiver” itself can also carry stigma and the threat of negative

treatment (Phelps, 2017). One member of the Carers New South Wales' focus group expressed that stereotyping of both the ill family member and the carer "made them less than human and their potential is locked into this label forever and a day" (St. James Ethics Centre, 2009, p. 66). For this individual, their personhood was lost and they experienced othering. Furthermore, the label of carer or "care recipient" felt as if it was a permanent attachment to their identity (St. James Ethics Centre, 2009). Such a view feels reminiscent of Bates and Stickley' (2013) view of stigma, one that suggested mistreatment from society could affect an individuals' perception of themselves and their life chances. Therefore, it may be true that labelling within the discourse of young caring can provide some benefits (e.g., ease of communication and a common language), it can also influence the self-perception of young people with caring responsibilities, as well as the way others view them.

3.3.3. PERFORMANCE

Thus far we have considered socio-linguistic and sociological contributions to understanding categorization and labelling. As well as understanding the negotiation of meaning in relation to language, we also can usefully consider in more depth how language might influence how people perform their roles and relationships using the script of a particular form (or forms) of labelling. Performance is the idea that we are social actors, striving to execute roles, scripts, and styles of ourselves, fitting within a constructed understanding of who we are and how we are supposed to be. British philosopher J. L. Austin (1962) declared that every spoken word is an *act* of doing something, giving way to future scholars to attribute performance to countless facets of everyday life. Gender, for example, is thought of as performance, according to post-structuralist philosopher Judith Butler. In her view, gender is performed, "constituting the identity it is purported to be" (Butler, 1990, p. 24-25). Speech, therefore, can be a performative act, not only indicating who people already are, but speech can also produce identities through its performance (Cameron, 2011).

Deckert and Vickers (2011) also suggest that identity is a performance; reiterating their point that different aspects of ourselves are displayed in different situations. I will briefly mention here that the theory of multiple roles (further explored in Chapter 2, section 6) also sits appropriately within our understanding of socially constructed identities. The multiple roles individuals possess are created, manifested, and refined in the context of their diverse social

interactions with others. It follows then that people select certain words to use when performing certain identities or roles. Knowing which language to use when, where, and with whom is an ability called *language competence* (Deckert & Vickers, 2011). While this term is often used in reference to speakers of two or more national languages, i.e., bilingualism and multilingualism, it could additionally be used when addressing monolingual speakers in possession of varying cultural codes and vocabulary.

In our consideration specifically of sociolinguistics and young adults with caring responsibilities, it may be helpful to think of those in receipt of formal support services as “bilingual”. They exist in spaces in which they occupy two languages. Their native, or birth tongue, towards care, might be thought of as the language that they originally used to talk about their caring activities. For instance, the notion one may have of their identity as a daughter or son—familial role language—may be positioned as their native language. Alternatively, it is also true that young people may have carried out their care tasks without a language at all. Care may exist as something they *do* without descriptor words or labels. After contact with a formal service, their language competency grows, as they familiarize themselves with the language of the one who provides their support, i.e., the service provider. Under receipt of formal support services, they are introduced to vocabulary such as “young carer”, “care”, and “young adult carer” in reference to both the actions of their family role (“care” as a verb) and their identity (“young carer or young adult carer” as a noun). They may begin to adopt the language, using words like “carer” to describe their activities. They may choose to retain wholly or in part the language they used previously; some may still use language referring to their familial role. This process may show how young adults with caring responsibilities become “bilingual”.

Alternatively, young people with caring responsibilities may also adopt “care-related” language *without* the influence of formal support services. It is possible that they self-identify with the language of “carer” or “caregiver” through their personal understanding of the meaning of those words. Their contact with care-related language could have come about through a societal awareness of young caring—more likely for those living in the United Kingdom than United States, however, it could have come about for those in any milieu. In any case, young people with caring responsibilities who identify with care-related language *without* the receipt of formal support services could also exhibit “bilingualism” and “language competence” for the

purposes of our discussion. I will address this particular scenario in greater detail in the subsequent chapters during my presentation of this research's findings.

3.3.4. CODE-SWITCHING & POWER

As defined by Milroy & Muysken (1995), code-switching in bilingual or multilingual individuals refers to the use of “two or more languages in the same conversation”. Additionally, code-switching can be observed when speakers can also switch styles or dialects dependent upon the setting or audience. In this research, I take an expansive view of code-switching, as I recognize that code-switching may take place not merely within the same conversation, but also in different conversations with different people. Swann (2009) explains that code-switching is not without meaning, rather it functions as a part of the context of the social interaction. Likewise, Gumperz (1982) argues that language alternation should not be seen as a flaw on the part of the speaker, but rather a practice through which further meanings can be expressed. An individual's selection of language can maintain or negotiate different social identities and even help an individual gain *access* to another social identity (Swann, 2009). Why might an individual seek to acquire another identity? Heller (1995, p. 160) promotes a view that code-switching can function as a resource that can be “deployed” “in order to gain or deny access to other resources, symbolic or material”. In this view, language can be both political and hold varying positions of value. Speakers may exercise their knowledge of a situation to use a certain language or dialect to gain advantages for themselves or others. For example, speakers from the north of England may recognize the *perceived* value of their local dialect as existing as a lower status than the speech of those from the southern region of England (Mugglestone, 2007). In situations necessitating the use of language with more “value”, such as a business or educational setting, speakers from the “North” may switch their language to one practiced in the “South”. Code-switching in this type of situation can help attract benefits such as power and prestige, and it may also function to bolster notions of power and solidarity, particularly for the group perceived to exist higher on the barometer of social stratification (Heller, 1995). Her understanding of value in relation to code-switching is built upon the work of Bourdieu (1977; 1982) and Gumperz (1982). Bourdieu's work centered on the ideas of symbolic capital and symbolic marketplaces, whereas Gumperz explored the notion of speech economies and verbal repertoires. Their work mutually agrees that linguistic capital does in fact exist, and moreover, it is not equally displaced within communities. This sense of unequal distribution is felt most strongly when the members

of the dominant group set the language at play, thus, the language and behavior of lower status members of the community may then exist as “inappropriate” practice (Heller, 1995).

Furthermore, Heller (1995, p. 161) asserts that code-switching is political: “language practices are inherently political insofar as they are among the ways individuals have at their disposal of gaining access to the production, distribution and consumption of symbolic and material resources, that is, insofar as language forms part of processes of power”.

Brown and Gilman (1960, p. 255) define power as “a relationship between at least two persons, and it is non-reciprocal in the sense that both cannot have power in the same area of behaviour”. Mesthrie (2009) explains that power is of historical significance in linguistics, as the grammar construction of many Medieval European languages incorporated certain pronouns for those of a higher status and those who are deemed inferior. Whilst power can denote to institutional structures, like the state, church, and the family, it can also refer to factors such as age, gender, and race (Mesthrie, 2009). Definitions of power can additionally include access to resources (Mesthrie, 2009). When reflecting upon the position of young people with caring responsibilities, power has particular relevance. Such young people live in varying degrees of marginalization for a host of complex and nuanced reasons, for instance their status as carers and associated stigma through the person for whom they provide care. A formal support service like those offered through a young carers project may be perceived as an extension of the state, albeit an arguably altruistic one. Formal support can carry its own levels of bureaucracy; for example, a young carers assessment is conducted by a social worker to facilitate the receipt of services from a local authority. To access formal support, young people are asked to disclose information of a potentially sensitive and intimate nature regarding the family practices in their home. For migrant or refugee young carers, their own legal status in the country (or that of the person they care for) could add tension to their disclosure. Those caring for family members with substance misuse issues may also fear sharing details of their family life out of protection from criminal prosecution. In addition, young carers could possess a spirit of mistrust towards professionals, particularly within Black and Minority Ethnic or traveler communities. Social workers, project workers, or other professionals in a local authority could therefore be perceived as representatives of institutional structures, i.e., the state. It follows that those professionals can signal power and a superior status than those of the young people they are tasked to serve. The implications of this social stratification mean that young people must “play by the rules” of

institutional structures, so to speak, in order to solicit formal support. In the process of becoming “known” to professionals, young people with caring responsibilities are introduced to potentially new ways of thinking about their family practices. Beyond revealing potentially personal and intimate information to a professional, young people must contemplate whether to adopt the language of the professional— “caring”, “young carers”, or “young adult carers”— in the process of receiving the formal support service. Before their contact with a professional, young people may not have used care-related language to describe the activities performed for their families. Instead, they may not have labelled their activities at all, or their word choice was task-oriented such as “I need to cook, bathe, or clean for my mum”. Their language could have been generalized, for instance, “I help my family”. It is also understood that “caring” can be nested into their notion of familial roles, so a language strictly dedicated to describe their caring activities may seem foreign, as they understand “care” as simply a fulfillment of their duty as children, grandchildren, and more generally, membership in the family. Receipt of formal services, therefore, may feel contingent upon their acceptance of the language of the professional. At the very least, barring full acceptance, young people are faced with the prospect of needing to *negotiate* this potentially new language. This prospect highlights the power differentials at work in the relationship between young people and professionals. Power can be maintained not only through threats and displays of control, but by the “internalization of the norms and values implied by the prevailing discourses within the social order” (Mesthrie, 2009, p. 316). Language created and chosen by the professional can exist as the “norms” and “values” in the sphere of formal support services, and the language of the young person with caring responsibilities can be relegated to a position of lower status. Professionals are the conduit for accessing resources, i.e., a formal support service. Power, therefore, can be displayed in their ability to control a young person’s access to formal support. In a consideration of power and young people with caring responsibilities, I argue that a discussion of the power differentials at work in service provision can be held, without attributing Machiavellian characteristics to professionals nor the actual formal support service.

Michel Foucault suggests that power is *everywhere*, alluding to the idea that power exists in an endless array of contexts and relationships (Mesthrie, 2009). Foucault (1979, p. 93) presents an expansive view of power, one in which power is “not a thing, an institution, an aptitude or an object”. He proposes that theories of power should not be restricted to common

conceptualizations of structures and hierarchies (Foucault, 1979). For Foucault, power is socially relational (Barker, 1998). Thinking of power as relational fits nicely within our idea of social construction of identity, language, and meaning. This understanding by Foucault is helpful as it may help render a critique which is constructive whilst maintaining criticality in our current discussion of power. I maintain that a discussion of power is not meant to allude to ill intent or overly problematize the work of service providers. Rather, I believe we must closely examine the ways that young people may view the process of receiving formal support in the aim of centering their experiences. The issue of power could have significant relevance for the way young people with caring responsibilities negotiate identity and language in their pursuit of formal support. In the subsequent chapter, I will further explore the issue of language and power for young people in receipt of formal young carer support services in this research.

In Foucault's understanding of power as multi-directional and networked, non-hierarchical, young adults in receipt of formal support services who engage in code-switching may not necessarily be rendered *power-less*. Heaton's (1999, p. 771) writing on Foucault and the discourse of the term 'carer' reminds us that in Foucault's view, subjects are neither "empowered" or "disempowered", yet remain as "active mediators". Building upon this Foucauldian view, I suggest that young adults' ability to use language in a certain way—and furthermore, knowing in what exact context certain language is appropriate—is the practice of *communicative competence* (Deckert & Vickers, 2011). Their understanding that using care-related language gains them social capital and access to beneficial resources demonstrates a high level of communicative competence. Similarly, it shows that such young people have unique, individual linguistic repertoires with membership in multiple groups, each with their own speech communities (Deckert & Vickers, 2011). Deckert and Vickers (2011, p. 69) affirm that one's "unique linguistic repertoire" to the helps to refine one's "unique identity". This aids our understanding of the social construction of identity, as young people with caring responsibilities are highly competent in their development of unique codes of language, varied between their group membership.

3.3.5. DISCOURSE OF YOUNG CARING

Continuing our examination of sociolinguistic perspectives, it may be helpful to also consider a Foucauldian understanding of discourse in relation to young caring. Mooney et al. (2011) make clear that discourse can have multiple meanings, some believe it simply refers to

the words individuals say, whilst others believe discourse refers to the way a particular subject is thought and spoken about. Discourse theory alludes to the social meanings constructed by language, and discourse can inform *something* about the user. Macey (2000, p. 100) writes that “discourse is a social language created by particularly cultural conditions at a particular time and place, and it expresses a particular way of understanding human experience”. Indeed, from a Foucauldian perspective, the terms ‘carer’, ‘young carer’ or ‘young adult carer’ did not exist until the development of its discourse in policy and practice in the 1980s and 1990s in the United Kingdom (Heaton, 1999). Whisnant (2012, p. 4) asserts that discourse helps us distinguish one person from one another, and illuminates those “small differences in languages that allow us to tell the difference between a scientist and a lawyer, or a journalist and a pimp”. If we think of young caring existing as a discourse itself, we may better understand the ways young people may or may not choose to participate in the language of young caring offered by professionals and academics. Participation in the discourse of young caring may reveal something about the user. Perhaps such language use indicates that an individual somehow identifies with the meaning behind the labels of “care/caregiving”, “young carer/caregiver”, “carer/caregiver”, or “caregiving youth”. For instance, a young person using the language “caregiving youth” may reveal that they have had contact with the sole non-profit organization in the United States serving children with caring responsibilities, as that term is promulgated by that particular organization. Because of the deep lack of societal awareness of young caring in the United States, I argue that it is unlikely at this moment in time that any person using the term “caregiving youth” has not had some sort of contact with the organization. If a young person uses that term, we can likely surmise that they are a recipient of the services of the organization – or at least hold that as a hypothesis. Conversely, it may be true that an adult using the term “caregiving youth” also had contact with the organization in some function, perhaps as a social worker or an educator. Continuing with this example of the term of “caregiving youth”, its use indicates a common understanding about young people with caring responsibilities. It generates an attainable *knowledge* of the lives of these young people; through the discourse of young caring, knowledge is produced about the who, what, and how.

Foucault (1969) believed that discourse creates knowledge and truth about the world around us. Foucault often made sense of discourse through his perspectives on medicine and madness; he used the example of certain medical practices that were acceptable in the past, and

even conceptualizations such as madness, that have been generated as historical discourse that would be looked at differently in modern times. Those particular discourses were accepted as truth during their period of history, especially as its users—physicians, for example—were “socially embedded networks of power” (Whisnant, 2012, p. 7). It follows that the current discourse of young caring has been accepted as truth because of its primary promoters—health and social care professionals, academics and researchers, and politicians—are generally trusted members of society. What we have come to understand about young caring has largely been produced by those individuals, including the definitions of who young carers are and who they are not. The discourse offered, or arguably *imposed*, by professionals is that young people with caring responsibilities should be viewed as a social group with the labels of “carer” or “caregiver”. Furthermore, professionals allow that those labels would be advantageous for young people to accept as their own, as it provides them with benefits, such as the opportunity to access young carer/caregiver projects, societal recognition, and financial support (e.g., carers allowances and bursaries) if available.

In keeping with his other post-structuralist contemporaries, Chris Weedon (1997, p. 107) wrote about the subjectivity of discourses: “Where there is a space between the position of subject offered by a discourse and individual interest, a resistance to that subject position is produced”. If people do not accept a discourse as their own, we can consider that to be an act of resistance. Beauboeuf-Lafontant (2009) argues that we are not, in fact, determined by the discourses laid upon us. The subject of “voices” becomes relevant here as Beauboeuf-Lafontant (2009) suggests that language is a critical way to explore subjectivity. In her view, the state of being voice-centered, rather than discourse-centered widens the opportunity for both an embrace of subjectivity and resistance. We can extend this view towards young people with caring responsibilities, as we consider the way the discourse of young caring does not necessarily render them power-less. Their resistance may be demonstrated in their decision to reject the care-related language offered by the professional and academic sectors, create their own language, and code-switch in particular settings. Our earlier discussion of sociolinguistics and identities revealed that identity development does not occur in a vacuum, but rather is fluid, changeable, and constructed in part through our social interactions with others. Young people with caring responsibilities can perhaps maintain their voice through deciding to what degree they wish to

participate in the discourse of young caring, and how they negotiate (and develop) the care-related and other aspects of their identity, including through their use of language.

3.3.6. CONCLUSION

In this chapter, I sought to address the sociological and sociolinguistic theoretical understandings of care, ethics of care, and identity for young people with caring responsibilities. The multiple meanings of care and its relational nature was narrowed in focus to the context of the care rehearsed by young adults in families with the presence of illness and disability. The notion of Morgan's family practices as something that individuals do in their relationships guided our examination of the intersection of 'normative' family practices to the actual, lived experiences of young people. The family practices of young people with caring responsibilities are those marked by change, adaption, and possible acceptance of their regular, daily lives—what they and their families *do* is their 'normalcy'. The contested nature of care for young people was further explored, particularly through the historical debate between the carers movement and the disabled rights movement in the United Kingdom. The social construction of young caring and its implications for social policy was considered, with attention given to the ways the constructed term 'young carers' sought to center and politicize young caring. Finally, I addressed the usefulness of the ethics of care in rethinking how we conceptualize 'care', whilst also holding the complexities of the identities of "cared-for" and "carer". Ethics of care can help avoid harmful and exclusionary assumptions, such that those who 'care' cannot also be the 'cared-for'. Whilst the notions of mutual interdependent care are both acknowledged and valued, I also posit that for young people, the way 'care' is enacted in their family practices can feel distinctive, explicit, and significant.

In the following section on sociological and sociolinguistics approaches, the social construction of language in young caring was critically important. The social construction of young caring was thought to influence the embodiment of a 'carer' identity through the performance of 'doing' care. The theories of labelling show that it may be that the socially constructed labels of 'young carers' or 'young caregiver' may be adopted and practiced, or refused. Stigma, both direct to the label of 'young carer/caregiver' and associated stigma with the family member for whom they provide care, was considered as a strong influencer to the ways young people may negotiate the label imposed by professionals and academics. The Foucauldian understanding of power and discourse helped guide our reflection that young people are not

disempowered through the social construction of young caring, rather, it is surmised that just as young people are active agents in their own lives, they also enact agency in their navigation of socially constructed labels and identities.

I will now present the findings from this present research study, turning first to the experience of identity development of young adult carers in the United Kingdom.

CHAPTER FOUR: METHODOLOGY

4.1. INTRODUCTION

This research study is an exploration of the identity development of the young adult carer and young adult caregiver in the United Kingdom and United States. This is a comparative research project between the contexts of the United Kingdom and United States, concerned with a critical comparison of the different national contexts of public awareness, recognition, and formal support for young adults with caregiving responsibilities. The views, thoughts, and feelings of the young people themselves took a central focus in this qualitative work.

Semi-structured qualitative interviews were conducted with 27 young adult carers in the United Kingdom and 28 young adult caregivers in the United States. An inductive, interpretive approach was utilized to discover the meanings of identity and identification within the young adult caring experience in the United Kingdom and United States. The data collected was examined using a thematic analysis.

I use Cresswell's (2014) framework for research design to structure this chapter. In this chapter, I state the research questions and aims, the research paradigm, and the epistemological underpinnings guiding this research. I follow with a detailed explanation of the research methods, including the ethical issues, data collection process, and analysis.

4.2. RESEARCH AIM

The aim of this research study is to explore the identity formation of young adult carers and caregivers living in the United Kingdom and United States, respectively.

The research focus, and the specific research questions devised, required a qualitative methods approach in this investigation. Drawing on the literature review and an understanding of the knowledge gaps in young adult caring experiences with identity development, this research sought to address the following question:

- What factors have influenced the identities of young adult carers in the United Kingdom and young adult caregivers in the United States?

The following sub-sections will be addressed:

- Has the experience of providing care influenced the identity development of the young adult carer/caregiver?
 - 1.1. Has caring influenced the identification with the young carer/caregiver identity?
 - 1.2. Has caring influenced a young adult carer/caregiver's consideration of "who am I"?

2: What supports young adult carers/caregivers through their transition into adulthood?

- 2.1. If a young adult has received dedicated, formal young adult carers-specific support services, what role have those services played in the young adult's identity formation and overall sense of wellbeing in their transition to adulthood?
- 2.2. Conversely, if a young adult has not received dedicated, formal young adult carers-specific support services, what role has the absence of formal support services played in the young adult's identity formation and overall sense of wellbeing in their transition to adulthood?

In view of the aforementioned research questions, this research study has the following objectives:

- To provide theoretical underpinning for a more complete and accurate understanding of the lives of young adult carers/caregivers in the United Kingdom and United States
- To determine the relationship of caring and identity formation in young adult carers/caregivers in the United Kingdom and United States
- To consider how the receipt of formal support services may influence the identity of young adult carers/caregivers in the United Kingdom and United States

4.3. RESEARCH PARADIGM

The research focus concerns the influence of caring upon the development of identity for the young adult carer, with particular attention given to the ways in which the young adult carer explores and commits to various life domains. To explore these interests, the research invokes a qualitative methodology in a single study program of inquiry. Hesse-Biber (2010) suggests that a

qualitative methods approach provides the researcher with a more holistic understanding of the complexities and nuances of the experiences of the research subject. A qualitative methods approach also has the advantage of an “exploratory and theory-generating nature”, which will prove useful in creating a theoretical framework on the intersection of identity formation within the lives of young adult carers living in the United States and United Kingdom (Hesse-Biber, 2010, p. 64). Qualitative research places an emphasis on detailed description so that the meanings of the participants’ actions, views, and beliefs can be understood (Bryman & Becker, 2012b). Emergent theory arising from a close scrutiny of the collected data is a defining feature of qualitative research (Bryman & Becker, 2012b). As this research study sought to explore participants’ experience to garner new theoretical understandings about identity development, a qualitative approach was undertaken in this research study.

Brewer (2012) recommends the use of qualitative methods when conducting research on sensitive topics. Brewer (2012, p. 71) defines sensitive research as research that “has potential implications for society or key social groups, and is potentially threatening to the researcher or subject in bringing economic, social, political, or physical costs.” Because this research study involves young people who are typically seen as vulnerable members of society in both country contexts, I consider this work to be a sensitive research study. Qualitative methods in sensitive research can provide participants with the opportunity to expound on their responses, and open-ended questions can facilitate nuanced answers (Brewer, 2012). Brewer (2012) also asserts that the nature of qualitative research is one that requires time and a slower pace to conduct thoroughly, and such a pace may help build rapport with participants.

4.4. EPISTEMOLOGICAL POSITIONS

Epistemology refers to the assumptions that I as the researcher may make, “whether these are implicit or explicit, concerning the nature of the knowledge” which I deem necessary to answer the research questions (Oliver, 2004, p. 122). An awareness of my epistemological position allows one to understand why I think about the research data in the way that I do. This research was guided by the premise of Joseph et al. (2006) that qualitative methods also require a qualitative *approach*. Sprung out of a concern that while qualitative research in the mental health field has become enmeshed in positivism, Joseph et al. (2006) argued that practitioners have simultaneously lost their awareness of the influence of the medical model. Practitioners may

engage in a method without a full awareness of the contextual basis from which their methodology is derived (Joseph et al., 2006). Thus, there are “implicit and unspoken values inherent in the research” of which people may not be cognizant (Joseph et al., 2006, p. 39). For this research study, it was increasingly apparent that I should ensure that my chosen methods accurately and appropriately reflect the same approach. As I sought to engage in qualitative research, I remained vigilant that my approach reflected the true hallmarks of qualitative research: a concern for the social world in which my research participants live, holistic analysis, and an ever-present awareness of reflexivity (Mason, 2002).

With regards to theory construction, this research takes an inductivist and interpretive approach. Inductivism refers to the generation of new theory from a critical analysis of the cases presented in the research (Pinker, 2012). An interpretive approach means that the understanding that human lives are context-driven and subjective undergirds the research (Flick, 2014). Social construction of meanings is a crucial element of the interpretive model (Flick, 2014). I chose to follow an inductivist and interpretive approach in this research study because I desired to generate new theories about young adult caring within the contexts of the United States and United Kingdom, led by the felt-experiences of the participants themselves. I sought to explore their construction of social reality, particularly as it relates to identification and identity as young adult carers and caregivers. Through exploration of the participants’ perspectives, I hoped to generate new theories and understandings, rather than testing a researcher-driven hypothesis. It follows that qualitative research, rather than, a quantitative research was appropriate.

4.5. RATIONALE FOR INTERNATIONAL COMPARATIVE RESEARCH

This research study features international comparative social research on the identity development of young adult carers and caregivers in the United Kingdom and United States. Hantrais (2009, p. 2-9) defines international comparative social research as “the explanation of similarities and differences between socioeconomic and political phenomena in two or more countries”. May (2016) notes that there are two major types of comparative research. The first, *domain-specific* comparative analysis, focuses on particular sectors and micro-level problems, such as policy proposals, and the scale of problems (May, 2016). The second, *whole system* comparative analysis, can deal with welfare outputs and productions on a macro level (May, 2016). This research study takes a micro-level approach, as I was particularly interested in

drawing individual comparisons on identity for young adult carers and caregivers (Carmel, 2012). I am also interested in exploring the experience of identification with the young carer/caregiver identity between the United Kingdom and United States. The “problem” that this research seeks to answer is the differences (or conversely, similarities) in the identity development of young adult caregivers living in a country in which formal support is essentially non-existent—the United States— in comparison to a country in which public recognition and formal support has had a longer period of expansion and remains embedded in policy and practice.

As detailed in the literature review, there are stark differences in the historical positioning of young adult carers and caregivers in their respective countries. As acknowledged by the research of Leu and Becker (2016), the United Kingdom is traditionally considered to lead the world in respect to its research, policy initiatives, and supportive organizations for children and young adults with caregiving responsibilities. In contrast, the United States, with its “emerging” ranking on Leu and Becker’s (2016) cross-national country classification scale, is around 20-25 years behind the United Kingdom in its development of recognition and supportive interventions for young caregivers and young adult caregivers. As a former young adult caregiver in the United States, I possessed a deep personal understanding of the ways a country’s level of awareness of young caring can significantly influence the experience of a young caregiver. Indeed, I was never identified as a young caregiver and like most of the young adult caregivers in the United States sample of this research study, no one ever spoke to me about my experience as a young caregiver. I remained hidden from the view of educators and health and social care professionals. Through research, I gained an understanding of the discrepancies in the positionality of young carers and young adult carers across various Western nations. A desire to work under the expertise and thought leadership of my primary supervisor, Professor Saul Becker, coupled with a desire to understand more fully the experience of young caring in a country context with increased recognition and formal support, led me to move to England from the United States to begin my PhD studies. While it was of critical importance for my development as a young caring advocate and researcher to be physically present in the United Kingdom, I was also committed to my desire to gain a better understanding of the potential differences and similarities of young caring in such vastly different country contexts. I surmised that the public representation of young caring and the opportunity to receive formal supportive

interventions might play a significant role in the ways young adult carers shape their understanding of their identity; conversely, I surmised that a lack of public representation and formal support might also affect the identity development of young adult caregivers in the United States. These suppositions guided my rationale for a comparative research study between the United Kingdom and United States.

4.6. ETHICAL ISSUES

This section will address the ethical issues found in this research study. While a serious reflection of ethical issues is critical for any research project, ethical issues are of principal consideration in sensitive research. Brewer (2012, p. 71) defines sensitive research as research that “has potential implications for society or key social groups, and is potentially threatening to the researcher or subject in bringing economic, social, political, or physical costs.” Because this research study involved young people who are typically seen as vulnerable members of society in both country contexts, I considered this work to be a sensitive research study.

4.7. PARTICIPANT VULNERABILITY

Nyamathi (1998, p. 65) defines vulnerable persons as those who are “impoverished, disenfranchised, and/or subject to discrimination, intolerance, subordination, and stigma”. In fitting with previous research with young carers and young adult carers, I felt it was critically important to consider the young adult carers and caregivers participating in this research study as potentially “vulnerable adults” (Becker, 2008). Before recruitment for this research study began, I was aware that this research study may involve participants providing care for those with conditions that are historically stigmatized: visible physical disabilities, HIV/AIDS, mental illness, substance abuse issues, and other conditions. Previous research has established that young carers and young adult carers are at risk for experiencing courtesy stigma (also known as associative stigma) as a result of their proximity to their ill or disabled family members (Barry, 2011; Smyth, Blaxland, & Cass, 2011). It may also be true that the carer or caregiver identity itself may possess stigma.

Liamputtong (2012) asserts that respect and reciprocity for vulnerable participants is of utmost importance, particularly taking steps to reduce the power differential between the researcher and the participant. One suggestion to show respect to vulnerable participants is the

use of monetary compensation (Liamputtong, 2012). Often seen as controversial, compensation (either through monetary means or vouchers/gift certificates) has been supported as a way to equalize the researcher-participant relationship (Hollway & Jefferson, 2000). Conversely, compensation may be viewed a form of coercion to participants who may be in desperate financial need (Liamputtong, 2012). I declined to offer compensation to the participants in my research study solely because of the financial constraints in the data collection stage of the study. The financial budget of this research study necessitated a conservative approach because of the high costs of Trans-Atlantic and domestic travel, the need for numerous hotel stays, and various transportation costs, including rental cars, petrol, train and subway passes, and toll charges. In theory, I agree with the argument for compensating research participants for their time, as I feel that financial assistance is the one of the primary needs for the participants in this research study. However, because I was bound by my own financial limitations, I sought to compensate their time in other ways. In the United Kingdom, most of the interviews took place within their young carers project. I brought various sweets, chocolates, and snacks with me for the participants to enjoy if they desired. I was also made aware by their project staff that the project provided the participants with financial assistance for transport to the project if needed. To lessen the financial burden on the young carers projects, I attempted to schedule the research interviews during the times when the participants would already be present at the project whenever possible. In the United States, I sought to schedule the interviews in the participants' closest public library or quiet coffeeshop. I would also bring sweets and chocolates for the participants, and if our interview took place in a coffeeshop, I would offer to purchase food and drink for them. Such gestures may not have completely remedied the issues of reciprocity and power imbalances, but it was my goal that participants understood that I valued their time and contributions.

4.8. ANONYMITY AND CONFIDENTIALITY

To preserve participant confidentiality, participants were given the option to provide a pseudonym at the start of the interview or I stated that I could provide a pseudonym on their behalf. Many participants expressed that they did not care if their real names were used, and some indicated that they believed sharing about their caring experience was a way for them to exercise agency. Banks (2012, p. 59) asserted that “some participants may wish to be named, and an overly protectionist approach may actually be disrespectful”. To respect their autonomy, I

allowed the participants to make a final decision on whether they wanted their real name to be used, and all decided to either choose a pseudonym or allow me to choose one for them.

This thesis has included information on the participants' occupation, age, location, and the condition of the person for whom they provide care but such information has been stated only in association with a pseudonym. In the release of the findings to the public, only pseudonyms will be used to protect their identity and the identity of the person for whom they provide care. In the consent form, the participants were asked to give their consent to allow third parties to review the data and/or research findings. They were also asked to give their consent for me to analyse the data in the future for further research.

While not a part of the inherent research design, it was possible that illegal activities or criminal behavior could be discovered incidentally through information revealed by participants. I understood that my responsibility as a researcher in such cases was to consult the University of Birmingham's Legal Advisor, however this need did not arise. I also understood that participants may during the research interview reveal that they are distressed (either as a result of the research or incidentally), that they require support or assistance with health, mental or child protection issues, or that they are vulnerable or at risk of harm. This did not occur in the research interviews. If I had felt it was necessary to break confidentiality, I would have discussed this with the participant first and explained their concerns, unless doing so would have been likely to increase the risk to the participant or risk to the myself. The boundaries of confidentiality were explained when first seeking informed consent. To avoid the need to breach confidentiality, I was equipped with information for appropriate support or counseling, and I would have been able to encourage the participant to talk to a third party regarding the issue.

Participants were assured that their information would be kept confidential and that any reference made to them within the thesis or subsequent publications would have been anonymised. To this end, each participant interviewed was given a pseudonym. Any identifying information such as contact information (name, telephone number, and email address) of the participants are kept only for the duration of the project. The interviews were recorded by a recorder, and the digital recordings are stored in an encrypted file. Electronic copies of the signed participant information sheets and consent forms are held on a password protected computer in an encrypted file.

4.9. POTENTIAL FOR HARM OR DISTRESS

I did not anticipate any risks to the participant other than those encountered in everyday life. The research study was not designed to trigger sensitive or distressing situations. However, I understood that asking young people for deeply intimate details of their lives could be very distressing. Furthermore, I was aware that I may have participants who have experienced catastrophic events in their lives (or are currently experiencing) such as deaths and near end of life, sudden accidents and injuries, food scarcity, homelessness, poverty, and other traumatic events. They may also have mental health problems or substance abuse issues of their own. As a part of ongoing informed consent, I explicitly stated that if at any time during the interview the participant wanted to stop the interview, the participant could do so. This did not occur in any of the research interviews. I also had relevant contact details on hand for support agencies (counselling agencies, confidential chat hotline telephone numbers, and carers organizations). In the United States, I am qualified as a nationally certified mental health counselor. This also means that I am a legally mandated reporter if the participant provides any reason to cause concern of abuse, harm, and neglect (to themselves or others). Neither set of interviews in the United Kingdom or United States elicited the need to contact social services or legal authorities. As some questions in the study questionnaire were designed to ask participants if caring had impacted their mental health, most of the participants in both samples described severe mental health impacts, including depression, anxiety, and self-harming thoughts and behaviors. As a part of assessing their risk to themselves, I utilized my training as a mental health counselor to determine their current risk for harm. With thorough questioning, I felt confident that the risk of harm was quite low, as the participants could usually confirm that they were already in receipt of a counseling service, or, their emotional distress was experienced in the past.

Craig (2012) notes that there is an increasing concern in social science research for the potential risks to the researcher. This research study was not designed to have any inherent risk to the researcher, however, as Craig (2012) asserts, research conducted by lone female researchers such as myself may present issues of safety and vulnerability. Care was taken that the interviews were conducted in well-lit, neutral, public areas, e.g., quiet study rooms in libraries, in coffee shops, or in young carers projects. Interviews were never conducted in the home of the participant or at night. Whilst conducting interviews, I would call and inform a trusted friend or family member of the scheduled interview start time and expected end time and location, and I

also called when the scheduled interview was complete. I continued to have monthly supervision meetings by telephone whenever I was located away from the University of Birmingham or conducting interviews in the United States. For the data collection in the United Kingdom, I remained based at University of Birmingham in Birmingham, England and traveled throughout the country to conduct the research interviews. For the data collection in the United States, I made my base in my family home of Nashville, Tennessee, and I would travel as necessary across the country to hold the research interviews. My primary supervisor, Professor Saul Becker, also had a copy of my itinerary for interviews, as well as a list of my emergency contact details. Whenever travelling outside of the city of Birmingham or the city of Nashville, I sent confirmation emails to Professor Becker and his personal assistant of my arrival and departure. Finally, I was aware that my previous experience with young caring could unintentionally elicit complex feelings and emotions during the research process. I understood that the University of Birmingham offered free counselling sessions to students if needed and desired. While I did not feel the need to seek out formal support during this research study, I made an intentional effort to debrief with my supervisors Professor Becker and Dr. Harriet Clarke after any interviews that felt particularly distressing. I also surrounded myself with a support system of trusted friends and family members who would check in to monitor my mental well-being.

4.10. INFORMED CONSENT

Peel (2012) asserts that researchers have an ethical responsibility to provide clear explanations of the research study process, the risks and benefits from participation, and an understanding that participants are free to withdraw without negative consequence at any time. I consider informed consent to be an ongoing process, in which it is my responsibility to obtain consent before and *during* the research study. A participant information sheet was given to the participants before the study began. The participant information sheet contained details about the subject of the research study, why the research was taking place, why their involvement was sought, and information about the research study's affiliations, i.e., the University of Birmingham. They were given the opportunity to review and to ask questions. A copy of the participant information sheet and informed consent form can be found in the Appendix. As a part of the ongoing consent process, it must be ensured that participants have the opportunity to freely consent to take part. In this research study, most participants, particularly those living in the

United Kingdom, were recruited through their local carers project. Therefore, as it was essential that young adult carers did not feel pressured or that their participation was made mandatory by their project service providers; thus, I sought to communicate clearly the freedom to participate (or decline participation at any time) to both the young adult carers and their gatekeepers.

4.11. MULTICULTURALISM AND DIVERSITY

The issue of multiculturalism and the diversity of the research participants requires significant consideration. As identity is undoubtedly influenced by nationality, ethnicity, gender, class, sexual orientation, religion, and language, I was prepared to engage with such subjects throughout the research process. To aid in addressing the nuances of young adult caring, it was important that the pool of participants come from a diverse background and geographical location. However, it was not always feasible or possible to locate participants across various sectors. Future research will need to address the issue of diversity.

4.12. REFLEXIVITY

In the research process, I must attend to the issue of reflexivity. As my research engaged a subject of which I have a personal connection, both because of my own experience of involvement in caring and because of witnessing my brother's involvement in caring, it is imperative that I reflect upon my position as researcher. Mason (2002) asserts that reflexivity in the qualitative research process involves thinking critically about every step: the who, what, and why of every decision that will affect the research. It also means recognizing the extent to which my "own thoughts, actions, and decisions shape how you research and what you see" (Mason, p. 5, 2002). *What I see* is an important point to highlight. As my research questions and hypothesis were born out of witnessing my brother's own restrictions in educational, career, and interpersonal relationships as a result of his caring responsibilities, I recognize that it will behoove me to remember that not every young adult carer will share in his experience. Furthermore, how shall I consider the young adult carer who has made the commitment to care, but doesn't feel that caring has shaped his/her identity? I cannot force my own preconceived notions of identity development upon my research participants, and I must be mindful of even the slightest hint of imposing my own theories in the questions I ask during the unstructured interview process. Finlay (2002) warns of the potential for the researcher's voice to overpower

the voice of the research participant, or the potential for the researcher to express implicit biases onto the participant. This is based upon the assumption that the researcher can never truly be neutral or objective from the context of their research (Mason, 2002; Joseph et al., 2006). This stance helps to undergird my positionality towards the assumption of Joseph et al. (2006): a qualitative method requires a true qualitative approach.

It is nevertheless important to note that Finlay (2002) asserts that the issue of reflexivity does not necessitate a negative assumption on the part of the researcher. The involvement of the researcher can be viewed as an opportunity for the researcher to provide context for the situation of the participant (Finlay, 2002). By self-introspection, the researcher can facilitate a deeper understanding of the research participant (Finlay, 2002). Researchers who have remained cognizant of their own thought processes and motivations in the research process can empower the participant's own sense of consciousness (Finlay, 2002). It was therefore hoped that I could use my experience of caring (and in connection, the knowledge of my brother's caring experience) to facilitate a space of mutual understanding and respect for the research participants, thereby encouraging the participants to use their voice freely.

4.13. THE RESEARCHER-PARTICIPANT RELATIONSHIP

In this research study, I took a strong *emic perspective* by which I held the thoughts, feelings, and views of the participants in utmost regards. An emic perspective, according to Harris (1976), seeks to take an insiders' view in research, attempting to view the world through the eyes of the participants. Such a perspective was particularly important in this research as I desired to understand the world in which the young adult carers and caregivers lived in. Their views about how they saw themselves and their place within their family were of primary focus for my understanding of their identity development. An emic perspective allowed me to value their subjective reality.

As discussed in the Introduction Chapter, the motivation and idea for this research project was birthed out of my personal family experience with young caring in the United States. I have a close investment in the subject, because of my personal history with young caring, but also as an advocate seeking to use this research to create real societal change for children and young adults with caregiving responsibilities on a country-wide scale. My position as a former young caregiver and young adult caregiver afforded me an insider-status in this research study. Corbin

Dwyer and Buckle (2009) defined insider-outside status as the membership researchers may have in the group or population that they seek to study. They believed that insider-status is not an inherently advantaged or disadvantaged position, rather, it is shaped by the approach of the researcher to the participant (Corbin Dwyer & Buckle, 2009).

Throughout the entire research process, I have been reflective of my experience as a young adult caregiver and the caring experience of my older brother. At the start, this meant holding an appreciation for the idea of the research topic from my brother's experience with identity in young caring, whilst also releasing his experience as simply one example of young caring in the United States—rather than uplifting his experience as a hypothesis to test in my research. At the time of the research interview, I felt it was critically important that I center the participants' experience. To achieve this goal, I explicitly stated to the participants that I was primarily interested in hearing their honest views, stories, and life details; I often said that this research interview was their “space and time to share” and that the interview was “all about you”. As a part of the informed consent process, I introduced myself and my institutional affiliation, yet I did not verbally disclose that I was a former young caregiver and young adult caregiver. I understood that as a part of recruitment, the video I used to publicize the study featured my discussion of my experience as a young caregiver. It is possible then that some of the participants were already aware of my insider-status. However, most of the participants did not express that they were aware of my history as a young caregiver, likely because in the United Kingdom, most were told about the research study through their young carers project worker (who may or may not have disclosed that I was also a former young caregiver). In the United States, most participants were recruited by word of mouth and therefore likely did not have access to the recruitment video. Because most of the participants in the United States expressed curiosity about my reasons for studying in England and how I came to choose my research topic, at the *end* of the formal interview, I chose to disclose that I was a former young caregiver and young adult caregiver. This disclosure and the information shared will be covered in greater detail in Chapter Five.

While I was aware that an earlier disclosure of my insider status might have helped build rapport, as suggested by Corbin Dwyer and Buckle (2009), I did not find it difficult to build rapport with the participants so therefore my personal disclosure felt unnecessary. Instead, I found that participants were quite excited and enthusiastic to share their experiences with me,

truly viewing the research interview as an opportunity to voice their views and help create change on a larger scale. This was particularly true for the participants in the United States, as for most, this was the first time that they had openly discussed their caregiving experience. In addition, the participants in the United States were eager to participate as they expressed that they hoped this research study would help improve the lives of other hidden young caregivers in the United States. During the research interview, I was acutely aware of the weight they placed in this research study and in myself as the researcher to use their interviews for greater societal good. I was also aware that as a hidden former young caregiver, these research interviews were also the first time that *I* openly discussed the experience of caregiving with another younger aged caregiver outside of my own immediate family. I considered their willingness to share so openly and entrust their stories with me as a true honor.

4.13.1. METHODS: INTRODUCTION

In this section, I will now outline the process by which this research study took place. I will discuss the study settings, the method of identifying participants, the pilot study, and the main study recruitment process. I will conclude with an explanation of the chosen data analysis methods.

4.13.2. ETHICAL APPROVAL

This research study was granted ethical approval by the University of Birmingham Ethics Committee. In addition, the participant information sheet, informed consent form, sample interview protocol, and the recruitment flyer received ethical approval by the ethical committee. It was not necessary to obtain ethical approval within the United States. I carried the official notice of ethical approval with me on site visits, and was able to present evidence of ethical approval when asked by potential gatekeepers.

4.13.3. SAMPLING STRATEGY & RATIONALE

A discussion of the methods of this research study would not be complete without a close and critical examination of the chosen sampling strategy. Morse (2004, p. 994) defines sampling as the “deliberate selection of the most appropriate participants to be included in the study, according to the way that the theoretical needs of the study may be met by the characteristics of

the participants”. In qualitative research, sampling is a necessary step to ensure that the data produced from the selected participants will indeed answer the designated research questions (Ritchie et al., 2014). This study sought to answer the following research questions:

- Has the experience of providing care influenced the identity development of the young adult carer/caregiver?
 - 1.1. Has caring influenced the identification with the young carer/caregiver identity?
 - 1.2. Has caring influenced a young adult carer/caregiver’s consideration of “who am I?”?

2: What supports young adult carers/caregivers through their transition into adulthood?

- 2.1. If a young adult has received dedicated, formal young adult carers-specific support services, what role have those services played in the young adult’s identity formation and overall sense of wellbeing?
- 2.2. Conversely, if a young adult has not received dedicated, formal young adult carers-specific support services, what role has the absence of formal support services played in the young adult’s identity formation and overall sense of wellbeing?

Thus, this study sought to answer its research questions through the use of purposive sampling. Purposive sampling is the intentional selection of individuals or groups that are “information-rich” in order to most efficiently resolve a study’s objectives (Palinkas et al., 2015). To answer this study’s research questions, it was essential that young adults with caring responsibilities currently living in the United Kingdom and the United States were purposefully sought for participation. This research used Becker and Becker’s (2000) definition of young adult carers (see chapter 1, section 2.4) to inform and determine the selection of this research’s sample. Becker and Becker’s (2000) definition differs only through its range of 18-24 year olds; this research study includes the perspectives of young people age 18 to 25. This minor age range extension was simply to incorporate the theoretical understanding of emerging adulthood (Arnett, 2000; Konstam, 2007), which considers young adulthood as ages 18-25. Furthermore, as this research study was also concerned with the influence of the receipt of formal young adult carers-specific services, young adult carers who had received such services must also be included

in the sample, as well as those young adult carers who had not received a formal support service. Using a purposive sampling approach, it was thought that those young adults who had received a formal dedicated young carers service, i.e., those who were engaged in a young carers project, would be best suited to share perspectives on the potential influence of formal support services on identity development.

In addition, this research study used a combination of convenience sampling and snowball sampling, particularly through a strong reliance on the study's gatekeepers. Convenience sampling refers to the selection of "sample units that are readily accessible to the researcher" (VoonChin, 2004, p. 197-198). It is typically used in qualitative research because of its accessibility, low financial cost, and efficiency, particularly with those populations that others have deemed "hard to reach" (VoonChin, 2004). Atkinson and Flint (2004, p. 1044) define snowball sampling as a "technique for gathering research subjects through the identification of an initial subject who is used to provide the names of other actors". Whilst not without its criticism as a potentially less rigorous method, snowball sampling is thought to possess advantages for gaining entry into groups such as "the deprived, the socially stigmatized, and the elite", and otherwise known as hard to reach (Atkinson & Flint, 2004, p. 1044).

This research study utilized convenience sampling by recruiting participants from young carers projects and through my personal contacts with stakeholders in both the United Kingdom and United States. Participants connected to a young carers project or a stakeholder were utilized because they were easily accessible, particularly due to the time restraints and funding restraints of this doctoral research project. Convenience sampling allowed for me to reach a suitable amount of participants who identified as young adult carers/caregivers in the most time and resource efficient manner. I sought to use snowball sampling with the research participants, particularly in the United States, however, the majority did not know of any other young adult caregivers. The technique of snowball sampling rarely proved fruitful; it was most useful when interviewing sibling carers as they would suggest that I interview their other sibling with whom they shared caregiving responsibilities. Instead, I utilized a purposive strategy with the gatekeepers, requesting that they share information regarding the study within their networks. This strategy was successful in helping to locate potential participants.

The choice to use multiple strategies—purposive, convenience, and snowballing sampling—and specifically, to recruit participants from young carers projects and carer support services, follows previous research in this field. Both quantitative and qualitative research involving young carers in the United Kingdom to date has typically recruited in young carers projects (Aldridge, Clay, Connors, Day, & Gkiza, 2016; Earley, Cushway, & Cassidy, 2007; James, 2017). Moreover, Dearden and Becker (2003) found that the emergence of young carers projects in the mid 1990s allowed for the first larger scale study involving young carers to be conducted. Other research in the United Kingdom has identified young carers within schools; Lloyd (2013) actively sought to recruit from school systems in Northern Ireland to identify young carers, as other research in the United Kingdom had primarily relied on young carers projects. It is understood that the United Kingdom has a substantial number of young carers projects in comparison to other countries who have identified young carers as a group of children/young people requiring formal support (Leu & Becker, 2016). In those countries with only limited formal dedicated support services for young carers, research involving young carers primarily recruited from the existing young carers projects and schools. In Europe, research studies have also indicated that reaching young carers for research study involvement can face significant barriers. In Germany, one qualitative research study on children and teenagers utilizing semi-structured interviews reported that access was “extremely difficult and required multiple strategies” (Metzing-Blau & Schnepp, 2008). In Switzerland, one of the first Swiss research studies to indicate the prevalence of young carers used convenience sampling to recognize relevant stakeholders and targeted schools to use a survey to identify young carers (Leu et al., 2018).

Research in the last decade in Australia has also featured the perspectives of young people recruited from young carers projects or carers respite services (Moore, McArthur, & Morrow, 2009). One such qualitative study with young carers in New South Wales, Australia utilized the setting of a young carers respite camp to conduct focus groups (Smyth & Michail, 2010). The authors indicated that the study setting provided them with the most efficient means of reaching their sample, especially allowing them to reach young carers living in rural areas, as those young carers were present at the camp.

In the United States, the studies on young caregivers are notably few. However, a literature review of research involving young caregivers in the United States revealed that older

research (in the 1990s and early 2000s) followed purposive sampling, similar to this research study's selected research methods (Beach, 1994; Beach, 1997; Lackey & Gates, 1997). In Gates and Lackey (1998)'s research with child and adolescent caregivers of adults with cancer, they asked nurses and social workers in oncology clinics to identify potential participants. More recent research conducted in the United States utilized convenience sampling in connection with the only national supportive organization for young caregivers (Cohen, Greene, Toyinbo, & Siskowski, 2012; Siskowski, 2006).

For research involving young adult carers, the sampling strategy has also focused primarily on those in contact with young carers and young adult carers projects. In their qualitative research with sixty young adult carers across England, Dearden and Becker (2000) recruited from carers and young carers projects. The work of Becker and Becker (2008) on the experiences of young adult carers across the United Kingdom surveyed 25 young carers projects and 13 adult carers services. As adults of legal age, researchers may encounter young adult carers in an infinite number of places: on the street, in a university lecture hall, in the workplace, or even in a club. This can prove useful to researchers as it widens the possibility that they may be able to locate a young adult carer and solicit their participation in research. However, because of the significant likelihood for young adult carers to be NEET, i.e., Not in Education, Employment, or Training, young adult carers may not necessarily be present in the places that researchers "traditionally" seek to find them (Dearden & Becker, 2002; Sempik & Becker, 2014; Smyth & Michail, 2010; Yeandle, S. & Buckner, 2007). In addition, in the specific context of the United Kingdom, there are fewer dedicated young adult carers projects available in comparison to young carers projects, as both a recognition of the specific needs of young adult carers and the development of specific services is relatively recent. Furthermore, it is imperative to note that in the United Kingdom, the majority of young people with caring responsibilities—as high as 80% of young carers in England—are not currently engaged in a formal dedicated service such as a young carer project, nor have they been in contact with a service in the past (Burns, 2016). Therefore, recruitment from educational settings or carers projects alone may not serve to wholly reach young adult carers. This means that a truly representative sample of young caring in the United Kingdom is extremely challenging to collect.

In the United States, with the absence of both young caregiver projects and young adult caregiver projects, it remains true that researchers do not have the "easily accessible route" of

recruiting from a formal, dedicated young caregiver service. Rather, research studies may utilize caregiver services dedicated to adults. Blanton's (2013) qualitative in-depth interviews with ten young adults providing care for grandparents recruited participants from contacts within eldercare services. Other small-scale, survey-based research may seek to identify young adult caregivers through convenience sampling in a university-setting or a combination of both eldercare services and university-settings (Dellman-Jenkins, Blankemeyer, & Pinkard, 2004; Greene, Cohen, Siskowski, & Toyinbo, 2017). Thus, this research study's selection of multiple sampling strategies has both complemented and expanded upon previous research in the United States with young adult caregivers.

Notwithstanding this research study's chosen approach using purposive sampling, it was still hoped that participants would self-refer themselves to participate. As referenced in the recruitment strategy in section 3.13.9, this research recognized that self-referrals to this research study would present distinct advantages. First, it was thought that a self-selected sample would be less likely to carry the risk of coercion from a gatekeeper, particularly if that gatekeeper happened to be a young carers project worker from whom there may be an existing power imbalance. Second, if young people came forward to participate in this research, thereby recognizing themselves in the recruitment material's language of "young adult carer" and "providing unpaid care or support to a family member with a health condition", this also tells us something about the way young people identify—or conversely, do not identify—with the oft-used language surrounding care. Indeed, participants would sometimes share their reaction to the recruitment material as it related to their identification as a young adult carer during the research interview (see Chapter 4, section 4.4.2). Finally, as Masson (2004) asserted, research must seek to include children are not readily accessible. It may be true that those young people with the most needs are the "most important" to involve in research, as an understanding of their experience can help guide the creation of inclusive policy and supportive interventions (Kennan, Fives, & Canavan, 2012, p. 276). For these reasons, I approached this research's sampling strategy seeking to privilege self-referred participation, and therefore introduced a recruitment strategy to mirror these efforts. This explains why I publicized the study in spaces in which I thought young people inhabit on the course of their daily lives, e.g., universities, social media (Twitter, Facebook, and Instagram), places of worship, clubs and social organizations. This is also why I advertised the study broadly by placing announcements in newspapers, email list-

serves, and writing articles and taking part in interviews and podcasts for national media organizations such as The Huffington Post and New York Times. As noted in this chapter in section 3.13.10, only a small number of participants in both the United Kingdom and United States came forward as self-referrals. Most participants were recruited to participate in this research through a gatekeeper, either a young carers project worker, a person acquainted with me and familiar with my research, or even through my own approach to an “eligible” young person. This follows other previous qualitative research with young carers in low-awareness contexts; Kennan, Fives, and Canavan (2012) in their small-scale exploratory qualitative research with young carers in Ireland also originally sought to prioritize self-referred participants, but low response rates meant that they therefore had to rely heavily on the use of service providers as gatekeepers. Kennan, Fives, and Canavan (2012, p. 277) illustrated the difficulty they encountered in garnering self-referrals: “Despite sending posters and flyers to over a thousand venues populated by children and young people nationwide, the information campaign generated only one referral.” Turning to gatekeepers, the researchers found that in the absence of dedicated young carers projects in Ireland, child and youth-oriented service providers “seemed to have no direct contact with or awareness of young carers” (Kennan, Fives, & Canavan, 2012, p. 278).

Their revelation parallels what I also found in my research in the United States: in conversations with seemingly relevant stakeholders, i.e., social workers, mental health counselors, educators, and disability and health advocates, there was a persistent myth that young caregivers did not exist, or they did not know of any personally. Similar to Kennan, Fives, and Canavan (2012), it was necessary that I devoted much time to explaining the concept of young caring to potential gatekeepers, in addition to communicating the value of the research for young adults with caregiving responsibilities and the implications to service providers. Kennan, Fives and Canavan (2012, p. 278) found that their time spent “building relationships and raising awareness” was the “single most influential factor” in obtaining gatekeepers who could introduce the study to families with young carers. In the United Kingdom, I found that relevant stakeholders were aware of the concept of young caring but rarely knew of someone personally. I assert that this speaks to the growing societal awareness of the existence of young carers and young adult carers in the United Kingdom, but on a micro-level, there remains a lack of personal contact with young people with caring responsibilities. A lack of personal contact could be because there is an actual absence of young carers in their personal contacts, but more likely,

young caring continues to exist as a hidden, private, and normalized facet of family life (Banks et al., 2002; Kennan, Fives, & Canavan, 2012).

Previous literature has identified young carers as a group that may be “hard to reach” for participation in research studies and service delivery (Banks et al., 2002; Kennan, Fives, & Canavan, 2012; Smyth & Michail, 2010; Thomas et al., 2003). I am at times cautious of such language. It has been my experience that occasionally key stakeholders, e.g., educators and social care professionals, who arguably *should* hold an interest in developing awareness and support for young people with caring responsibilities can use the term “hard to reach” as a rationale to cease making an effort to contact this group of young people. In essence, such language can feel as if it problematizes young people and particularly young people that society has marginalized, such as Black and Minority Ethnic carers, carers for those with substance misuse problems, HIV/AIDS, mental illness, LGBT carers, and those in migrant, traveller, or refugee communities, for being *too* difficult to locate. Other research on “hard to reach” populations have addressed the problematic nature of the language (Barrett, 2008; Doherty, Hall, & Kinder, 2003; Katz, La Place, & Hunter, S., 2007). Freimuth and Mettger (1990, p. 232) assert that the label of “hard to reach” can be used pejoratively, and is often applied to groups based on their “socioeconomic status (SES), their ethnicity, or their level of literacy”. In actuality, the label may reflect “communicators’ frustration in trying to reach people unlike themselves” (Freimuth & Mettger, 1990, p. 232). Boag-Munroe and Evangelou (2012, p. 210) referred to “hard to reach” language as “convenient labels” yet they can function to “disguise the complexities of these families and the factors which lead to their disengagement”. Furthermore, Crozier and Davies (2007) found that it was the service itself that was disengaged and hard to reach, rather than the individual or families. In the pursuit of addressing marginalization, groups labelled “hard to reach” may be *othered* by researchers and practitioners, with an over-emphasis on their *deficits* rather than *differences* (Freimuth & Mettger, 1990, p. 235).

Reflecting on young carers specifically, Aldridge et al. (2016, p. 15) alluded to the difficulties of researching young people with caring responsibilities: “Historically, researchers have experienced challenges in engaging with children and families where ‘hidden’ young caring is taking place.” Aldridge et al. (2016) uses the term “hidden” to describe young people who have not had contact with a formal support service; they are not “known” to social services. In the United Kingdom, this section has already noted that for ease of access, researchers often

recruit participants from young carers projects or another carer-related service. Those young people not in contact with a formal dedicated service are then labelled “hidden” or “hard to reach”. In seeking to recruit young adult carers who do not have contact with a social service, there are number of factors that make it difficult to “find” such young people. The confusion over the term “carer” still exists within the United Kingdom with some believing that the term refers to a paid care worker, rather than an informal unpaid family carer (Barton, 2008). The cultural expectations of interdependence and intergenerational care may mean that the term “carer” lacks meaning within an individual’s culture (Aldridge et al., 2016). The act of caring can also be enveloped into the performance of the familial role, particularly for girls (Abebe & Kjørholt, 2009; Evans & Skovdal, 2015). Some young people may feel stigmatized due to their status as a carer, or they may experience associated stigma related to the health condition of their family member—in such cases, young people may not want to identify themselves for either research participation or service delivery (Phelps, 2017). Some young people with caring responsibilities may not want to be identified for fear of social service involvement (Kaiser & Schulze, 2015).

Thus, I assert that the onus is on researchers and any other relevant stakeholders to recognize the nuanced factors affecting young people with caring responsibilities, for example, social isolation, time-intensive caring activities, and an embedded culture of care in family practices, that can make it difficult to connect with those young people and think creatively on how to reach them. It is critical to avoid using pejorative language when discussing the difficulties encountered in both research participation and service delivery with families in which young people have caring roles. I maintain that the focus should remain on an adaption of research design or recruitment strategies in respect to the dignity of young carers and their families. In the following section, I will provide an overview of the ways I sought to adapt my selected sampling strategy to better connect with young adult carers/caregivers.

4.13.4. STUDY SETTINGS

I was deeply aware of the implications the hidden nature of young caring in both the United Kingdom and United States would have on the recruitment process for this research study. From the start of my PhD studies, I often travelled to attend young carers and young adult carers advocacy meetings and events throughout England, such as those hosted by the non-profit

organization Carers Trust. I also reached out through social media and email to young carers project managers to make visits to their projects. In these visits, I typically did not meet with young carers and young adult carers directly, rather, I engaged with organizational leaders and project staff. I built contacts with those involved with young carers and young adult carers because I wanted to foster rapport with potential gatekeepers for this research study (in addition to taking advantage of the learning opportunity to talk to front-line workers). I did not engage in formal recruitment for this research study, but I hoped my initial contacts would prove fruitful later in the research process. Indeed, my preliminary efforts at building friendly relationships with project staff were advantageous at the start of formal recruitment in the United Kingdom. In the United States, I proceeded with the same approach, however my contacts with social care professionals were created in the stage of formal recruitment. This will be discussed in greater detail in Section 3.13.9.

The original intention was to recruit participants from both city and rural settings with the United Kingdom and United States. I had this intention because I wanted to facilitate data collection from young adult carers and caregivers who might be particularly hidden in rural areas. To address this issue, I intentionally reached out to young carers project workers in the Devon and Cornwall area of England to recruit participants living in rural, isolated areas. Unfortunately, I did not receive a response. Admittedly, because of the sheer lack of organized potential gatekeepers for this research study in the United States, the recruitment of participants from rural settings was less of a priority, because I was mainly concerned with finding participants *at all*. However, every effort was made to reach out to those who might have contact with young adult caregivers living on farms, in the countryside, and other rural areas in the United States. Conversely, I also sought to recruit participants from large, global cities, such as London and New York City, as well as smaller cities, towns, and villages, such as Birmingham, England, Newry, Northern Ireland, and Nashville, Tennessee, United States. I was successful in this regard.

I was also strongly motivated from the outset of this research study to include young adult carers living in Northern Ireland, as I recognized the dearth of academic literature on young carers and young adult carers in Northern Ireland. Scholarship on young caring in the United Kingdom is markedly focused on children and young adults in England, and to a lesser degree, in Scotland and Wales. I was able to include participants from Northern Ireland because of an

earlier connection with a young carers project manager in Belfast who served as the gatekeeper for the Northern Irish research sample.

Generally, the study sample was derived from purposive sampling through gatekeepers I developed a relationship with as the primary source of respondents. This had an effect on the study settings, as I could only interview participants in the locations in which I could make confirmed contacts with young adult carers and caregivers. To preserve financial costs, I did not travel to any city in the United States or United Kingdom unless I could confirm that I would be able to interview at least three young people in the particular location. Because of this self-imposed rule, this meant that in the United States, contacts were made in locations such as Texas, California, and Indiana, but I did not travel to conduct a formal interview because only one potential participant was confirmed in those areas. In the United Kingdom, financial costs were less of a barrier to finding study settings, however, I primarily travelled to cities in which there was more than one participant willing to be interviewed.

4.13.5. IDENTIFYING PARTICIPANTS

As this research study was aimed at exploring the identity development of young adult carers and caregivers in the United Kingdom and United States, participant criteria were as follows:

Inclusion criteria:

- 18-25 years old
- Currently living in either the United Kingdom or the United States
- Fluent in both written and speaking English (American or British)
- Providing unpaid care, assistance, and support to a family member who has a health condition requiring care. Conditions may include physical and learning disabilities, mental illness, chronic health issue, and substance misuse.
 - Individuals who began to provide care during the ages of 18-25 are welcomed to participate, as well as those who began caring under the age of 18
 - Provide care for any number of hours per week, but on a regular basis

- Types of care can include: physical, emotional, intimate, household management and financial support
- May reside in the home with the family member or “care at a distance”
- Those in receipt of a formal, dedicated young adult carer service, those in receipt of other support services (such as counseling services), and those who do not receive any formal support services.
- The person requiring care may (or may not) be receiving formal support services.

Exclusion criteria:

- Minors, i.e., under the age of 18 years old
- Non-English speakers
- Those who **only** provide parenting tasks to dependent child(ren)
- Paid, professional carers and caregivers

Participants could have affiliations with the University of Birmingham, e.g., they may be currently enrolled students attending the university, but such an affiliation was not a focus of the research study. The research did not intend to include people without the capacity to consent to participation and the consent form and participant information sheet clearly indicated that the study was not approved under the Mental Capacity Act (England and Wales) and the Adults with Incapacity Act (Scotland) and that no one should participate on another’s behalf. Participants were assumed to have the capacity to make the decision to participate by the act of consenting.

I made the decision to have some flexibility regarding age and living status of the care recipient. Primarily, this research study was interested in hearing the perspectives of young adults aged 18-25 years old. However, I was contacted by a small number of potential participants who were 26-28 years old living in the United States. I declined to involve the potential participants aged 27 and 28 years old. For those who contacted me of the age 26, I decided that if their birthday was within one month (i.e., recently turned 26 years old) of the scheduled research interview, they were welcome to participate in the research study. My rationale was driven both by the difficulty in finding participants for the United States sample, and by taking a subjective, qualitative approach in this research process. I believed that there was

likely little impact the involvement of a recently turned 26 year old participant would have on the major themes in the research study. Secondly, I practiced some flexibility in recruiting participants whose care recipient was no longer living. If the care recipient had died within the same year as the research interview, I welcomed their participation in the research study. Again, my rationale was driven by the need to find research participants in the United States, as well as an assumption that the major themes of identity development may not be significantly impacted by the recent death of the care recipient. However, I was also aware that the death of the care recipient may have an effect on the identification process of a young adult carer/caregiver. I hoped that through the inclusion of participants with a recently deceased care recipient, I might pick up nuances in the identity and identification development of young adult carers/caregivers.

4.13.6. SEMI-STRUCTURED INTERVIEWS

The use of semi-structured face to face interviews were employed to help resolve the research questions surrounding the influence of caring upon identity development. In the beginning of the interview, I engaged the research participant with the following statement: “Tell me about a typical day in your life.” Galletta (2013) suggests that the opening segment of the semi-structured interview is the most unstructured and participant-led portion of the interview, during which, it is also important for the researcher to build the participant’s trust. It was hoped through my use of reflective listening skills, open-ended questions, and unconditional positive regard that the participant felt comfortable and free to self-report on his/her ability to make life decisions in the midst of caring, thereby decreasing the risk that I imposed a directional bias (either positive or negative assumption) onto their caring experience. Miller and Glassner (2011, p. 138) maintain that when the interviewee “talks back”, he/she provides “insight into the narratives they use to describe the meanings of their social worlds and into their experience of the worlds of which they are a part”. The interview made use of an interview protocol that will serve as a guide for exploring the research questions. Jacob and Furgerson (2012) advocate for the use of an interview protocol to help the researcher stay on topic and to ensure that the necessary topics are covered in the interview. However, I used the interview protocol as a guide only and was not discouraged from asking off-script questions as deemed relevant. Indeed, Mason (2002) asserts that a “rigid or structured” approach in qualitative research is not

traditionally appropriate; hence this provides a rationale for my insistence that my interviews with the young adult carers remain semi-structured and amendable (p. 7). Mason (2002) also argues for flexibility in the qualitative research process such that decisions made by the researcher should remain sensitive to the changing context of the research situation.

The interviews typically lasted an hour to an hour and a half. Bryman and Becker (2012a) suggest that it is helpful to record and transcribe semi-structured interviews. I followed this advice and used a digital recorder for the interviews, and transcribed the interviews using Express Scribe Transcription software.

4.13.8. RESEARCH QUESTIONNAIRE DESIGN

Carmel (2012) warns that one risk of international comparative social research is that the language of the research study may not smoothly translate between countries. Conversely, one advantage of varying conceptualizations of the same subject could reveal deeper complexities and meanings across countries (Carmel, 2012). I sought to take the “middle ground approach” with this research study. I understood that the diverse language differences between British English and American English could unnecessarily confuse the research participants when using the semi-structured interview questionnaire. I was also aware of the existence of regional and local language differences, particularly within locations in the United Kingdom. However, I was also interested in protecting what I viewed as the “beauty” of conducting qualitative research within diverse settings. I further believed that diversity in care-related language, e.g., “care”, “carer”, “caregiver” might provide revelatory knowledge on how young people consider those terms in relation to their identity. The principal reason for the pilot study was to test the semi-structured questionnaire for any language differences that might serve as a barrier to effective communication. In the final design of the semi-structured interview questionnaire, I chose to use care-related language that one might typically encounter in the United States (e.g., “caregiving” and “caregiver”) and United Kingdom (e.g., “care” and “carer”). Beyond that, I asked specific questions regarding which language or terminology the participants preferred or identified with during the formal research interview.

4.13.8. PILOT STUDY

Jarirath, Hogerney, and Parsons (2000, p. 92) defines a pilot study as a “typically smaller scale version of the parent study with similar methods and procedures”. Kim (2010) asserted that there are numerous benefits for conducting a pilot study in qualitative research: it can allow researchers to make adjustments for the final research study, it can test feasibility, and it can train researchers to be competent interviewers. I was primarily interested in conducting a pilot study to test the language of the semi-structured questionnaire, as I wanted to use the same questionnaire in the United States and United Kingdom. For the pilot study, I recruited three individuals from the United Kingdom and three individuals from the United States. The composition of the pilot study participants in the United Kingdom is presented below:

Table 1

	A	B	C
Age	20	22	25
Sex	Male	Female	Female
Location	Liverpool, England	London, England	Birmingham, England
Previous Caring Experience	Yes [Mother; Breast cancer; now deceased]	Yes [Father; Alcoholism; now deceased]	Yes [Sister; Down syndrome]

I recruited the pilot study sample through word of mouth to my friends. I loosened the study criteria in regards to the living status of the care recipient, as I was primarily interested in ensuring the language of the study questionnaire was suitable. I conducted the interview with Participant B by telephone to conserve costs for the data collection process in final study. The pilot study interviews with the United Kingdom did not necessitate any changes to the study questionnaire in terms of language. However, it was revealed that the length of the study questionnaire as originally designed was too long, as it took Participant A and C nearly two hours to complete the interview. I revised the interview questionnaire to decrease the number of questions for the pilot study with participants living in the United States.

The composition of the pilot study participants in the United States is presented below:

Table 2

	D	E	F
Age	24	19	23
Sex	Male	Female	Male
Location	Detroit, Michigan	Austin, Texas	Boston, Massachusetts
Previous Caring Experience	Yes [Grandfather; Heart disease]	Yes [Mother; mobility issues]	Yes [Mother; Diabetes]

As I was living in Birmingham, England at the time of the pilot study, I conducted the interviews with participants in the United States over video through Skype. Conducting interviews through online methods allowed me to conserve costs for the final research interviews set to take place face to face. The participants in the United States pilot study were recruited through word of mouth to my friends and family, except for participant E. Participant E was known to me through my caregiving advocacy work in the United States. Understanding that I would likely not have the financial means to travel to Texas to conduct interviews for the final research study, I reached out to Participant E to ask her consent to participate in the pilot study. I did not encounter any feasibility issues regarding language with the pilot study in the United States. Therefore, there was no need to alter the study questionnaire. The final study questionnaire can be found in the Appendix.

4.13.9. MAIN RESEARCH STUDY RECRUITMENT: DETERMINING DATA SATURATION

The research study originally sought to involve 30-40 participants in total. The total number of participants surpassed this number largely due to overwhelming response from young carers projects throughout the United Kingdom. Once data saturation was reached in the United Kingdom at Participant 27, I used that number to guide the participant recruitment in the United States, i.e., I sought to recruit as close to the numbers of the United Kingdom sample as possible. As noted by Fusch and Ness (2015), the point of data saturation may seem mysterious to qualitative researchers. They suggested that data saturation occurs when the study can be replicated, when further coding seems no longer feasible, and when there is not an abundance of new information (Fusch & Ness, 2015). I decided that data saturation occurred when I felt comfortable with the emerging themes from the interviews to the extent that I could begin to draft initial theories, and secondly, when I felt that the time restraints of the PhD would limit the time available for transcription and analysis, and finally, when I felt that it would not be feasible to “match” the numbers of the United Kingdom sample in the United States. Because of the hidden nature of young caring in the United States, I was cognizant of avoiding an overwhelmingly large United Kingdom sample, as I knew I may not be able to find a “matching” sample in the United States. To be clear, with the cooperation of various young carers project staff, it would have been quite possible for the United Kingdom sample to reach an N size of 40-50 participants, if not more. Indeed, I declined potential participants in the United Kingdom for this research study even through the data analysis phase.

4.13.10. RECRUITMENT STRATEGY

In beginning of the formal recruitment process, I understood that the major barrier to finding participants for this study is the hidden nature of young caring. Most of the children and young adults in the United Kingdom and United States would not be formally identified as carers/caregivers, nor would they be in receipt of a formal support service. The public representation of young adult carers is much more widespread and informed in the United Kingdom in comparison to the United States, and there is a large network of supportive organizations for young adult carers across the United Kingdom. Thus, while young adult carers continue to be hidden from the view of social care professionals in the United Kingdom, it was

clear that for the purposes of this research study, recruitment would likely be far easier in the United Kingdom. Indeed, formal recruitment in the United Kingdom took three months in total. It was critically important to me to reach participants in the United Kingdom who had not been in receipt of a formal support service, as I surmised that engagement in such services may bias the views of the sample, particularly towards identification as young adult carers. To reach that goal, I created a YouTube video about this research study. In the video, I discussed my own caregiving experience in the United States and I explained the aims and rationale of this research study. In every email and social media post, I included a link to my YouTube video. I also created a recruitment flyer (see Appendix). I created a Twitter account so that I could publicize my research study on Twitter. My PhD supervisors also made announcements of my research study on Twitter. I used my already created Facebook and Instagram account to post photos of the recruitment flyer and to connect with young carers project workers. I sent over 200 hundred emails to young carers and young adult carers project staff. I also acquired university approval to hang the recruitment flyer in multiple places across the University of Birmingham. I also advertised this research study through university Facebook groups, including a student carers society. This research study was listed on the University of Birmingham research database homepage, so that every student enrolled at the university might see the recruitment call whilst logging into their university email account. Making a personal connection with gatekeepers remained a focus of my recruitment, and I travelled to various projects and universities to meet with relevant staff. At those sites, I was allowed to post the recruitment flyer. Finally, I sent out a notice of the open recruitment for this study through my affiliated organizations and memberships, including my local church in Birmingham, England. It was hoped that some participants for this research study would come through self-referrals, i.e., that they saw the recruitment materials in a public space, self-identified as a young adult carer, and would contact me to participate. A small number of participants disclosed that they found out about my research study through the various public recruitment outreaches, such as seeing a Facebook post or a flyer on their university campus. For most of the United Kingdom participants, they were recruited through my contact with their young carers project workers.

In the United States, my recruitment strategy was much more intensive. I originally planned to spend three to four months in the United States for recruitment of the sample. I seriously underestimated the difficulty I would encounter in recruiting participants in the United

States. In total, I took nine months for participant recruitment in the United States. From my arrival in the United States from Birmingham, England, I began my recruitment in South Florida through the American Association of Caregiving Youth (AACY). As the organization is mainly involved with children under the age of 18, I sought to interview participants who “graduated” from the organization. Their founder and director, Dr. Connie Siskowski, served as the primary gatekeeper. As the AACY is the only organization in the United States specifically dedicated to serving young caregivers, recruitment grew far more difficult as I sought to reach out to participants in the rest of the country. Over the next nine months, I followed my United Kingdom strategy by utilizing my YouTube video and social media accounts to publicize the research study online. I sent over a thousand emails to various social care professionals, educators, health care workers, government agencies (local, state, and federal), and disease-related organizations. I scheduled meetings with Congressional representatives in Washington D.C. and with State Senators in my hometown of Nashville, Tennessee to speak on the hidden nature of young caring and to publicize my research study through their governmental contacts. I sought to reach out to colleges and universities, but I was typically declined as most universities require external research projects to undergo ethical approval through their institutional research board. I encountered the same access difficulties when seeking to recruit in high schools; I was required to undergo their own ethical review process. The time constraints of my PhD studies would not allow for me to submit my research project to other universities or schools’ ethics committees. Some colleges and universities welcomed the advertisement of my research study, and with approval, I was allowed to post flyers on campus and internal university emails were sent on my behalf. I also took out advertisements in my local newspapers. It was an important aspect of recruitment that I intentionally seek out participants who provide care for family members with conditions that are traditionally stigmatized, i.e., substance abuse, mental illnesses, and HIV/AIDS. To that end, I made personal visits (with group leader approval) to my local HIV/AIDS advocacy support group, multiple Alcoholics Anonymous and Narcotics Anonymous support group meetings, Huntingdon’s disease support group meetings, and National Alliance on Mental Illness advocacy meetings. I publicized the research study with my personal affiliations and memberships with local, regional, and national networks, including my church, Greek sorority, and alumni associations of my undergraduate and graduate institutions. Finally, at the advice of a fellow caregiving advocate, I began to publish online articles about my research with

The Huffington Post and other caregiving related publications. I also participated in numerous online podcasts about my personal caregiving story and research study, including an interview with the New York Times.

Despite these efforts, it was tremendously difficult to find participants in the United States. I viewed every person I came into contact with as a potential gatekeeper. I found myself even asking strangers if they knew of anyone who might fit the criteria for my research study whilst at dinner and at social events. On a personal level, the nine months in the United States required a great deal of tenacity and discipline, and I am grateful for the personal development the process of this PhD has cultivated within me.

Throughout the recruitment process, my contacts with friends, colleagues, and family proved most useful in garnering participants for this research study. For example, most of the participants from the states of Tennessee and Virginia arose because of a few gatekeepers who took an interest in the research subject, saw its value, and committed to helping me find participants through their networks. The YouTube video, flyer, online articles, and social media announcements were most helpful in acquiring the samples in Washington D.C., Maryland, Massachusetts, and Michigan. I should also note that I was contacted by a number of individuals across the country who wanted to take part in the research study, but I excluded them because they were older than my selection criteria by two to three years. In those instances, I sometimes continued communication with those contacts because of the general knowledge gained in speaking to *older* young adult caregivers. I was also contacted by a small number of participants in locations that I was unable to travel to conduct the interview because of financial constraints.

In the following tables, I present the ways recruitment was achieved in each country:

Table 3

<i>UK Recruitment Method</i>	<i>Gatekeepers in Young Carers Projects</i>	<i>'Reach out' activity, e.g., flyer, social media, blogging, YouTube video, email list-serve</i>	<i>Known personally</i>	<i>Snowball via other participant</i>
<i>England</i>	8	2	2	
<i>Northern Ireland</i>	5			

<i>Scotland</i>	5			
<i>Wales</i>	5			

Table 4

<i>USA Recruitment Method</i>	<i>Gatekeepers in Young Caregiver Project</i>	<i>'Reach out' activity, e.g., flyer, social media, blogging, YouTube video, email list-serve</i>	<i>Other gatekeepers, e.g., social care professionals</i>	<i>Known personally</i>	<i>Snowball via other participant</i>
<i>Florida</i>	6				
<i>Kentucky</i>		1	1		1
<i>Massachusetts</i>		1			2
<i>Maryland</i>		1			
<i>Michigan</i>			1		
<i>Minnesota</i>					1
<i>New York</i>			1		
<i>Tennessee</i>			6	2	
<i>Virginia</i>			3		
<i>Washington D. C.</i>		1			

The tables indicate the strong reliance on gatekeeping to achieve the study's sample, either through young carers/caregivers projects or through other gatekeepers with whom I built personal relationships. After the aid of gatekeepers, the activities undertaken to reach out to participants proved most useful, e.g., social media announcements, posted flyers, emails through

list-serves, blogging, and my YouTube video. Finally, the tables demonstrate that snowball sampling was the least successful, perhaps drawing attention to the potential issues of social isolation and ‘hiddenness’ of young caring in both countries.

4.13.11. MAIN RESEARCH STUDY PARTICIPANTS

The main research study, hereafter called “the research study”, has a total number of 55 participants. There were 27 participants from the United Kingdom, and the majority came from England. There was an equal spread across Northern Ireland, Scotland, and Wales.

Table 5

<i>United Kingdom Study Sites</i>	<i>N</i>
England	12
Northern Ireland	5
Scotland	5
Wales	5
Total N	27

In the United States, there were 28 participants in total. The majority of the participants came from the southeast region (Florida, Kentucky, and Tennessee) of the country, five participants from with mid-Atlantic region (Maryland, Virginia, and Washington D.C.), two participants from the mid-West (Michigan and Minnesota), and four participants from the Northeast regions (New Jersey/New York and Massachusetts).

Table 6

<i>United States Study Sites</i>	<i>N</i>
Florida	6
Kentucky	3
Massachusetts	3
Maryland	1
Michigan	1
Minnesota	1
New Jersey/New York	1
Tennessee	8
Virginia	3
Washington D.C.	1
Total N	28

4.13.11.1 AGE

The age range for the United Kingdom participants was between 18-23 years old. The average age of the United Kingdom participants was 19.88 years old. The age range for the United States participants was 18-26. The average age of the United States participants was 21.8.

4.13.11.2. GENDER

In both countries, there were overwhelmingly more female participants than male. The following table provides the gender breakdown between the United Kingdom and the United States:

Table 7

<i>Gender</i>	<i>United Kingdom</i>	<i>United States</i>
<i>Male</i>	9	8
<i>Female</i>	18	20

4.13.11.3. SAMPLE COMPOSITION

As the following sample composition table demonstrates, most of the sample in the United Kingdom provided care for parents, and often both mother and father. The United States sample primarily featured those providing care for siblings and grandparents, and also parents. It was also evidently clear that United Kingdom sample tended to begin providing care earlier in life. For both samples, the condition of the care recipient tended to be classified as a chronic physical condition or a developmental disorder. Finally, it was also clear that the United Kingdom sample had some involvement in formal support services in a greater percentage than those in the United States.

Table 8

	<i>United Kingdom</i>	<i>United States</i>
<i>Caring for multiple family members</i>	44.44%	39.28%
<i>Caring for parents only</i>	62.96%	25%
<i>Caring for siblings</i>	11.11%	28.57%
<i>Caring for grandparents</i>	3.7%	21.42%
<i>Started caring before age 16</i>	88.88%	57.14%
<i>Started caring after age 16+</i>	11.11%	39.28%
<i>Care recipient with substance abuse issues</i>	11.11%	3.57%
<i>Care recipient with mental illness</i>	22.22%	14.28%

<i>Currently in/had been involved in formal support services</i>	85.18%	25%
<i>Never involved in formal support services</i>	14.81%	75%

4.13.12. DATA ANALYSIS

To analysis the data collected, I chose to use a thematic analysis. Thematic analysis is a process for analyzing qualitative data that involves the recognition of themes found in the data (Boyatzis, 1998). A theme is an overarching pattern related to the research phenomenon that is *seen* by the researcher in the data; the patterns in the data may either be directly observed by the researcher (manifest level) or “seen” as an underlying assumption by the researcher (latent level) (Boyatzis, 1998). The statements collected from the research interview were used to identify themes on a latent level, as I was concerned with both the explicit wording of the responses and any hidden, implicit meanings (Braun & Clarke, 2008). Recognizing a moment worth coding is dependent upon the openness and flexibility of the researcher, and whether the researcher takes an inductive or deductive approach to the data. Thematic analysis occurs in four distinct stages:

1. The recognition of the codable moment, i.e., the actual “seeing” of possible patterns in the qualitative information
2. The recognition of the codable moment is done in a consistent fashion
3. The development of code
4. The interpretation of the data and themes, in the context of either existing theories or the data itself, that generates new knowledge (Boyatzis, 1998)

A thematic analysis seemed most appropriate to use to direct my research methods, as I was interested in interpreting themes that are largely driven by the data. As the researcher, it was necessary that I maintain a sense of openness when reading the data so that I do not project my own assumptions and try to force the data to fit into my mind’s “pre-existing” codes and categories. It is hoped that using a thematic analysis approach will enable me to produce new theories for understanding the experiences of young adult carers and caregivers as it relates to their development of identity during the young adulthood stage.

In the first stage of coding, I created a total of 58 codes from the data collected in the United Kingdom and United States. The codes ranged from the participants' university aspirations to their experience of self-harm. The codes were wide and varied. With a focus to the major aim of this research study—the exploration of identity development—the emerging themes from the codes included:

- The official identification moment as a young carer/caregiver
- The experience of identifying as a carer or caregiver
- The questioning of identity
- The role of young carer/caregiver services in identification
- The development of an overall sense of identity
- Uncertainty over transitions to adulthood
- The negotiation of life paths and care/caregiving
- Absence of formal support
- Contextual differences in young caring awareness in the United States and United Kingdom

These interconnected themes were used to provide the basis for the emergent theories in this research study. Due to the limited space available in this thesis, I chose to exclude a detailed examination of the themes of the participants' overall sense of identity and their negotiation of life paths. I will re-visit these themes in the Conclusion Chapter. During the research interviews, it became clear that the themes of the official identification moment as a young carer/caregiver and the identification with the young carer/caregiver identity were a significant focus of the participants. Their understanding of themselves as carers and caregivers emerged as the major theme relating to their identity development. As this research sought to be driven by an inductive, interpretive approach, I focused my attention on the patterns of identification to generate new theories.

4.13.13. SELECTION OF QUOTATIONS

In a final note on my research methodology, I have included a discussion on my selection of quotations in my presentation of the research findings. Corden and Sainsbury (2012) argue that there are infinite reasons why a researcher chooses to select a particular quotation for inclusion into the presentation of the research findings. Similarly, they argue that there are not any definitive

rules on which quotations to include and how to present the quotations (Corden & Sainsbury, 2012). Some researchers may choose to present quotations verbatim, whilst others may edit words significantly to correct grammar and style. I selected quotations that I felt were representative of the emerging themes from the data. At times, I selected quotations for inclusion because they demonstrated uniquely held views and stories, seeking to show that there is subjective reality in all ways. I also made every attempt to present at least one quotation from every participant in this thesis. It may be observed that several participants are quoted more than once in this thesis; I made this choice because I felt their views succinctly articulated the issue being discussed and served as an adequate representation of the sample as a whole. In the presentation of the quotations, I edited the participants' words for brevity; this may be indicated by an ellipsis. I also removed any identifying names of persons, institutions, or places of employment to preserve confidentiality and anonymity of the participants and their families. At times, I added explanatory terms in parenthesis to add context for the reader. Finally, I removed excessive uses of "umms", "you knows", and other filler words.

4.13.14. CONCLUSION

In this chapter, I have laid out my research methodology and methods. I stated the research questions and aims, and provided a rationale for my epistemological approach. I reviewed the methods taken to undertake this research study, with considerable attention on the recruitment process within the two countries. The final section detailed my data analysis and reasons for a thematic analysis. In the following chapters, I will present the findings on identification with the young carer identity in the United Kingdom and identification with the young caregiver identity in the United States.

CHAPTER FIVE: IDENTIFICATION WITH THE YOUNG CARER IDENTITY IN THE UNITED KINGDOM

5.1. INTRODUCTION

This chapter explores how young adult carers in the United Kingdom may come to understand their contributions to their family through the young carer identity. As previous research has established, young people with caregiving responsibilities often do not ascribe the label of *carer* to their activities within their family (Metzing-Blau & Schnepf, 2008). Rather, young people think and talk about their support of their families as a fulfillment of their duty as a family member. The recognition of their contribution as ‘care’ does not usually occur until their first encounter with another individual who tells them that they are ‘young carers’. In this chapter and in subsequent chapters in this thesis, I will refer to the instance of their first recognition as young carers as their *official identification*. As previously discussed in Chapter 3, the language to describe young caring continues to be contested in both the United Kingdom and United States. In the United Kingdom, however, discourse has advanced to the extent that a socially constructed and politicized understanding of what constitutes young caring has emerged. The post-modernist and post-structuralist perspectives on labelling theory, performance, and embodiment can help us understand how the label ‘young carer’ could become an identity for young people. To be clear, a label is not necessarily interchangeable with identity. Rather, a label, through mechanisms like performance or embodiment can become a facet of one’s identity. This research will show that the enactment of the label imposed upon young people can become how some come to understand who they are. The embodiment of the conceptualization of young caring and its defining characteristics can then be understood as the young carer identity. In the broadest sense, the young carer identity refers to a young person providing unpaid care and support to an ill or disabled family member, although as discussed in Chapter 3, an understanding of what constitutes young caring can be quite complex, diverse, and situational.

During the research interviews with young adult carers in the United Kingdom, it became clear that the process of identification with the young carer identity was a significant part of their young caring experience. The majority of the research participants in the United Kingdom spoke in some way about the time that they were officially identified as a young carer during

childhood, or conversely, for the very few who were not identified, what it was like for them to remain unidentified through young adulthood. The subsequent chapter will discuss the experience of identification with young adult caregivers in the United States, a context in which there is a lack of national discourse on young caregiving. The subsequent chapter will also make comparisons to the perspectives found in this chapter featuring young adult carers in the United Kingdom. Immediately clear from both interview samples in the United Kingdom and United States is the strong significance of the young carer identity as they regarded their contributions to their family and their overall sense of identity. The act of providing care was a central aspect of their lives, and for many, the term ‘young carer’ provided them with a label to ascribe to their acts of care.

This chapter will discuss the moment of official identification with the young carer label and the decision-making process for young people in accepting or declining to identify as young carers or young adult carers. A point to note: young people were asked in the research interview if they identified with the label of young adult carer. Their responses typically used the term young carer interchangeably with the term young adult carer, and my language throughout the following sections reflects their responses. Thus, when I refer to the ‘young carer label’, I am also referring to the ‘young adult carer label’. It appeared that many of the interviewees did not make a distinction between the terms young carer and young adult carer, although some found the distinction useful in theory. For example, some found the term young adult carer advantageous when considering the need for specialized services targeted for their age and maturity level as young people entering young adulthood. I suggest that this is because the majority of the young people interviewed in this research study in the United Kingdom were identified in regards to their caring role as young carers during their childhood and have been referred to as young carers for some time. In addition, many of the services they received used the label of young carers, even after they entered their young adulthood years. Thus, it will be helpful for the reader to understand that at times, “young carer” may be used in place of “young adult carer”, however, distinctions will be made clear when necessary. Section 4.3.2 will discuss in greater detail the rationale of those choosing to use the terms young adult carer and young carer interchangeably.

The following section in this chapter will introduce the meaning of an official identification moment for young adult carers. A framework for the identification process for

young adult carers will follow in the subsequent section, and the final major section will examine the way young adults providing care for siblings may come to understand their identification as young adult carers. I will begin by presenting the experiences of young adult carers as they engage with the young carer label for the first time in life.

5.2.1. THE MOMENT OF DISCOVERY: YOU ARE A YOUNG CARER

This section will provide contextual understanding of the young adult carers interviewed in the United Kingdom's first encounter with the young carer label, or alternatively, young adult carer label. In reflection on their caregiving history, the majority of the young people interviewed in this research study expressed a moment in time in which they were officially recognized as a young carer. Official recognition denotes that an external individual took notice of their caring activities within their family and made the assertion that those activities fit the typically accepted definition of young caring (see Becker, 2000). For most of the young people in this research study, official recognition was usually made through the initial contact made with a social worker in the parents' home, and more rarely, through contact from a school teacher, nurse or GP, or through the parent's direct request to a young carers project. Very few young people interviewed in this research underwent a young carer identification process exclusively through their own cognitive discovery, i.e., no one told them that they were young carers, and they realized that they fit the accepted definition of young caring through their own cognitive reasoning. One such young person realized during late adolescence that they were a young carer through their own awareness of the public representation of young carers and experience with social services. Another young person self-identified as a young adult carer through the advertisement flyer for this research study. The experience of both these young people will be discussed in detail in subsequent sections. In the research study interview, young people were asked to provide details of the start of their caregiving experience. For many of these young people, their responses included a reflection on their identification process with the young carer label. For other young people, they did not forthrightly provide details of their identification process and thus, I explicitly asked them questions about how they begin to receive services with a young carers project or how they were identified as a young carer. In both instances, the quotations in the following sections are selected from the discussion that flowed as part of their

interview responses.

Firstly, it is critical to understand that before the official identification “moment in time”, these young people had various notions and understandings of their role in the family. Broadly speaking, they have an awareness that they contribute to their family’s life in some way and possess varying degrees of responsibility towards the wellbeing of their family. For many, this understanding arises at an early age, as their caregiving tasks begin as early as they can remember, and may or may not intensify as they age into young adulthood. These young people typically care for parents with long-term health conditions diagnosed in their childhood, parents with mental illness or substance misuse problems, or siblings with developmental disorders such as autism. For others, their caregiving tasks begin in late adolescence (16-18 years old), and far fewer in early young adulthood (18-20 years old). This is usually due to a sudden health crisis, e.g., heart attack or stroke, a worsening progression of a long-term health condition, or because an aging grandparent requires care and moves into the family home. Indeed, the reasons why each particular young person provided care and the care activities themselves were varied, however, they each possessed an understanding that they were contributing *something* to their family. Their sense of contribution corresponds with the notion that young carers are active agents in their own lives and family practices. Until the young carer identification “moment”, this role in their family went largely unnamed, or it was simply categorized under a general notion of “helping”. From our understanding of ‘normalcy’ in the ‘doing’ of family (i.e., family practices), it may be that their role was unnamed because it was what they ‘do’. The following statement from young adult carer Elizabeth illustrates how the experience of being told “you are a young carer” can feel like a new revelation about their identity:

“I’ve always been a young carer, it’s who I am. I didn’t know at the age of 4. But I was told at the age of 8. And I was like, ‘What?!’. It’s like a new thing.”

Elizabeth, 20, Solihull, England, United Kingdom. Cares for father with physical and mental illnesses [unspecified and undisclosed].

This statement from Elizabeth demonstrates the complexity inherent in the identification moment for young carers. She not only perceives herself as a young carer, but she states that she has *always* been a young carer. Elizabeth reported that she began caring at the age of 4 years old, although she noted that she has been providing care for as long as she can remember, and she

indicated that 4 years old is the earliest she can remember. It is implied that she was likely caring before the age of 4, which explains why she feels that she has always been a young carer. By noting that being a young carer is “who I am”, Elizabeth expressed that young caring has always been a part of her identity, following from the belief that she has been a young carer her entire life. Her moment of discovery, like so many other young people interviewed in this research study, occurred once a young carer project worker gave her an assessment and identified her as a young carer. This provides the reasoning for her statement that she didn’t know she was a young carer at the time of her earliest memory of caring, age 4. Until she was introduced to the label of young carer at age 8 by a project worker, she did not understand her care provision as the actions of a young carer. That identity was one that was unfamiliar to her, like many other young people. Notably, the label of young carer was a “new thing” to her; while she did not perceive the activities of caring as new. Caregiving was something she was used to, yet she did not have a name for her contributions to her family.

Every young person stated that they were not familiar with the label of young carer until it was “given” to them by someone else, or until they had encountered it through the interactions with the public, the latter referring to the two individuals who identified as young carers through general awareness of young carers in society and through the advertisement of this research study. For the majority of the young people in this research study, someone verbally told them that they were young carers. As the following excerpt from Elise demonstrates, the young carer label was unfamiliar to them until their first encounter with the term, typically through a social service provider:

“I’m not quite sure who notified young carers. The first time I remember it was one of the workers coming round to assess. So kind of like an interview where they’d ask you questions and assess what kind of care you have to do and things like that. And that was the first time it was just somebody came round and had a chat with me kind of thing.... Obviously I was recognised when I was nine [or] ten years old. Before that, when I was caring for my brother, I didn’t even know about the service.”

Elise, age 20, Salford, England, United Kingdom. Cares for father with a physical disability requiring the use of a wheelchair, depression and paranoia; and cares for brother who is profoundly

deaf and has learning difficulties.

Elise, like many young carers and young adult carers, had the experience of being told that she was a young carer by a service provider. Notably, no one else has spoken to her about her activities in her family as a carer until the age of nine or ten years old, despite that she had been caring for her father and brother for as long as she could remember into her early childhood years, although her care provision increased as her father's condition worsened over time. What is also particularly interesting about Elise's statement of her moment of discovery is her use of the word "recognise". The use of this word indicates that someone else considered her experience and reasoned that her family contributions constituted care. There is a sense of both external confirmation and validation of what she contributes to her family as a carer. In addition, Elise reported that during the time when her care provision was directed primarily towards her brother, she was not in receipt of services. When her father's condition worsened, social services entered her home and she was then identified as a young carer. The case of Elise suggests that young people providing care for siblings may be overlooked as carers by social service professionals; previous research in England has also found that sibling carers are less likely to be engaged in formal support services compared to carers of other family members (Roth, Lindley, & Ashley, 2011). I suggest that young adults providing care for siblings may find it difficult to identify as carers unless another individual has formally identified them. Formal identification may prompt and help to reinforce notions that their family contributions constitute care. The issues of self-identification for sibling young carers will be discussed in greater detail in Section 4.4.

Young people may find that their understanding of themselves as young carers can be enveloped into their conceptualization of normal family life. For young people who have been providing care for their families from very early ages, this may be particularly true. In the following statement from Suzanne, she describes her experience of not knowing that she was a young carer because she was unaware that she was different from other young people her age:

"I didn't really know any different. Because they didn't realise I was a young carer until I was sixteen. So I thought it was just that everyone did it, but it was just part of me growing up. I didn't know any different like I didn't know how it is like being like my friends, well they didn't have the same responsibilities as me [...] I became identified because my brother when he started secondary school, because he was dyslexic they were like "oh he's a young carer", because they saw my

mum when my mum went in to his interview things for school and then when they came to assess my brother, they realised he had two sisters and that's how they discovered that I was a young carer just because of my brother.

Suzanne, age 19. Chatteris, England, United Kingdom. Cares for mother with multiple sclerosis; brother with dyslexia, and sister with anorexia.

Suzanne's statement expressed the sentiment of the normality of young caring felt by many young people with caregiving responsibilities. Her contributions to her family were central to who she was, as indicated by her statement that caring "was just part of me growing up". Caregiving was a part of her identity and who she was, even if she did not yet have a label to her activities and role in her family. She was not aware of her status as a young carer throughout her childhood years, and while she understood that she had responsibilities towards her family, she believed that those were the type of responsibilities that her friends also performed in their homes. Continuous acts of care provision were normal to her as a child and she didn't realize that other children did not possess that same level of responsibility nor performed activities as she did. She later discovered that other children did not have the same experience of providing care in the family home, and therefore she was "different" to them. She presents an interesting aspect of identifying as a carer: until presented with otherwise, her sense of a normal childhood is everyone's normal. Her social construction of childhood is filtered through her perception of what is normal to do in a family home because of *her* activities within her home. As a child, she was likely not afforded the intimate understanding to witness the inner working of another's home. Therefore, in her experience with family life at home, she could only infer that other children had the same experience. Not only does Suzanne have the experience of being told she is young carer when previously she did not have that named identity, but also, she must grapple with the notion that she is not the same as her peers. Her identity as a daughter and sister is not a shared, common identity with that of her peers. While in the research interview, Suzanne did not explicitly state the exact age that she realized that she was different than her friends, it is surmisable that her realization would have come during late childhood or early adolescence—up until that time, she had a "normal" identity. Upon her realization that her home life is different than her peers, she ceases to be "normal" in comparison to her friends. Furthermore, not only is her identity as "normal" in flux during this time, but also her family identity has shifted. Her *family life* is not the same as her peers, and her sense of family

identity is also in contention.

Suzanne echoes the sentiment of Elise; she had the experience of being told that she was a young carer by someone else, in her case, a social services worker who entered her home to assess her brother's care needs. Suzanne supposes that she has provided care for her family throughout her entire life, however she can indicate her earliest memory of caring is at 7 years old. Her brother was identified a young carer because their mother had an interview at the start of his secondary schooling regarding his dyslexia. Despite caring for many years as a child, she was not officially recognized as a young carer until age 16 when social services, through the contact made at her brother's school, came to assess her brother's needs and they became aware that she was the sibling to her brother. During the research study interview, Suzanne expressed a belief that without the initial contact made by social services at her brother's school because of his dyslexia, there was a strong likelihood that neither he nor she would have been officially identified as young carers. Both research and the public representation of young carers perpetuates an image that young carers are hidden from society and from social services. Previous research with young carers in the United Kingdom revealed that social care professionals may have contact with young carers without realizing that they are young carers: "Some social workers who go into families where a child is caring just don't see it" (Aldridge & Becker, 1993, p. 71). This image of a hidden young carer is epitomized through the experience of Suzanne, as her caring role was not brought to the attention of social services except through happenstance. She would not have encountered social services (leading to her engagement with a young carers project) without the event of her brother entering secondary school with a diagnosis of dyslexia. In Suzanne's case and with many young carers, she likely would have continued with her caring role without any opportunity to receive a formal supportive service.

This differs substantially from Joe, whose statement below helps to illustrate the experience of a young person who comes into contact with a formal support service through *intentional* means:

"I had to be told I was a young carer, I didn't realise I was a young carer until I came home from school one day to find this woman sitting in the kitchen table talking to mum and sort of you know saying 'oh yeah James, you know she's here about the young carers project, 'you're a young carer' and so you know we spoke about it and I guess I am."

Joe, age 20. Alton/London, England, United Kingdom. Cared for mother who died of cancer, and currently cares for brother with a rare chromosomal disorder

Joe reported that his mother contacted their local young carers project to enroll him into their services. This was an intentional move towards accessing support, which stands in contrast to the coincidental initiation to support services of Suzanne's experience. In Joe's case, someone recognized his caring role and intentionally reached out to a service to offer Joe help. For Suzanne, there was no one who recognized her role as young caring, or even acknowledged her mere presence in the home until the completion of an in-home assessment that required the naming of the family members in the home. Suzanne's discovery as a young carer was rather coincidental and had the strong likelihood of never happening at all. This differs starkly from Joe, in that his mother was aware of young caring (how she knew remains a mystery) and thus, recognized her son as a young carer and sought help for him. In the interview, Joe could not state how his mother came to identify him as a young carer, nor could he distinguish if his mother initiated a young carers support service because of the overall perception of his family caring responsibilities or if she felt he needed support specifically because of his caring role to her or to his brother. Nonetheless, Joe communicated clearly that his mother understood that not only was he entitled to support, but that Joe also *needed* support. This is a critical juncture as their two differing points of access to formal supportive services may indicate a better way to getting young carers support: by targeting those individuals who have intimate knowledge of the activities a child is performing in the home—the family members themselves. The implications for future service delivery will be discussed further in the Conclusions Chapter.

The manner in which Joe was identified as a young carer also holds critical importance. While his mother identified him as a young carer to the extent that she contacted a young carers project worker to come into their home, her realization of her son as a young carer was not a conversation that took place with Joe before the project worker appeared. While it is impossible to know why Joe's mother did not discuss his identification as a young carer before she invited a young carers project worker into the home, it remains a noteworthy moment in Joe's identification process. His first contact with the young carer label came not from his mother, i.e., the person for whom he provided care, but rather his initial contact came in a surprise moment.

Many young people may have experiences such as Joe's, in which they were first introduced to the young carer label by a social worker, a young carers project worker, or another practitioner. These individuals may be strangers to the young people, and arguably, they are people in various positions of authority and power. In Joe's situation, this was also his first time to meet with the person who identified him as a young carer, implying that there could be a lack of rapport between him and the social care professional. Other young people who are identified formally as young carers may encounter the same experience, in which they lack rapport and relationship with the person pronouncing a new identity onto them. Some young people may not have a preference for the way in which they are identified as a young carer, as long as formal identification leads to the opportunity to receive support. For others, how they are told may be just as important as that they are told. Because this research study was not explicitly designed to ask young people to reflect on their preference for the manner in which they are identified as young carers, future research must consider the delivery of the "young carer identification moment" and the best setting to do so. We will revisit the implications for how young people are identified in the Conclusions Chapter.

The case of Joe presents the experience of a young adult carer who was not familiar with the young carer label until it was bestowed upon him. The following story from Louise presents the perspective of a young adult who was familiar with the label of young carer, but had not ascribed that label to their contributions within their family:

"I just thought, 'I have to do this stuff now.' I had a 'You gotta do what you gotta do' attitude towards getting things done. I didn't imagine this [becoming a young carer] would be a problem for me in life before it happened to me. You hear about it on occasion on TV, but I never pictured myself—you see Children in Care on TV, but I didn't see myself as that person. Because I was 16, a bit older, I didn't see myself like that."

Louise, 21, Shirley, England, United Kingdom, Cares for mum
with a spinal fracture

Louise presents another alternative perspective to the discovery of the young carer identity. She also had a moment of discovery similar to Elizabeth and other young adult carers, she was identified as a young carer by a project worker. Before that time, she did not identify as a young carer. She began caring at 16 years old, unexpectedly, when her mother had an accident

and received a spinal fracture. As stated above, Louise did not foresee herself as needing to take up a caregiving role for her mother until the accident necessitated it. She was not a young carer until the role was thrust upon her at the age of 16. Her approach to the sudden occurrence of her caregiving role was to immerse herself into her caring duties and take up the tasks that needed to be done in her home. Louise expressed that she was familiar with the term young carer from television programs, but she did not perceive herself as a young carer. Her rationale alludes to her age; she believed that young carers were very young children in desperate need of support. She did not believe she fit her perception of a young carer because she was nearing young adulthood. Thus, her sentiment implies that she views caregiving (or perhaps at the very least, *some* aspects of caregiving) to be acceptable for her age. That implication fits well with her earlier sentiment of “you gotta do what you gotta do”, a notion that feels even more significant because of her age. She appears to possess the view that individuals of her age—late adolescence—are more capable of taking on the tasks of caregiving, and perhaps therefore, not in as much need of attention and support as younger carers, all because of their higher perceived maturity level. It is not unusual for both young carers themselves and society at large to possess a perception that young carers, and particularly those in need of support, are young children. This perception can serve as a barrier to both official recognition as a young carer and the access to formal support services. Section 4.3.4 will address the age of young people as an obstacle to official identification and access to support in greater detail.

This section provided an overview of the experience of young people who were formally identified as young carers. For all of the young people interviewed in the United Kingdom sample of this research study, the young carer label was a new conceptualization of their family contribution. Before the moment of official identification, they thought of their caregiving as a fulfillment of their membership in their family and furthermore, an enactment of *their* normal family practice. The following section will provide greater understanding of the ways young people traditionally viewed their caring responsibilities through their role as a family member.

5.2.2. CARE AS A FAMILY ROLE

When thinking of their caregiving responsibilities, their reflection was filtered through their primary, relational identity: their relationship with their family. Young people saw their

care activities as a performance of their familial role as a child, sibling, or grandchild. When asked if they saw themselves as a young carer during childhood (before the time of the official identification), overwhelmingly, they did not. Instead, these young people reflected upon their identification as a child, sibling, or grandchild:

“I wasn’t aware that I was a young carer until Salford Young Carers reassessed what I do and told me, that I was a young carer....I didn’t see myself as a carer. Just taking care of my mum and dad....Being a young carer for my parents is most important [to his identity], they cared for me when I was young, so I feel like I should care for them now.”

Matt, 18, Salford [Manchester], England, United Kingdom. Cares for mum with a bad back and chronic pain; and dad with a brain condition similar to Parkinson’s disease

For Matt and many other young people, their caring activities were viewed as a part of their familial role and obligation to their families. Smyth et al. (2011) reported a similar finding with their research with young carers in Australia, noting that the “normative framework” of familial obligation and responsibility” served to “obscure the nature of those responsibilities” (p. 149). Because young people viewed their activities as a normal part of family membership, it was difficult for them to think of their activities as distinctive acts that warrant a different label, i.e., “caring” or “caregiving”. As Matt noted, caring was a normal act within his responsibilities as a son to his parents. Matt revealed that providing care to his parents was the most important thing to his identity, following Smyth et al. (2011, p. 150) that “identifying as a young carer is not about embracing a label, but rather an acknowledgement that the normative relationships of familial care-giving sit at the heart of their sense of identity”. Subsequent sections of this thesis will further discuss the ways young people express the influence of caregiving upon their identity; however, Matt’s statement demonstrates how the act of caregiving is central to a young person’s identity, irrespective if they understand their actions through the label of carer.

The importance of family to young adult carers remains clear: the central role of family may also be expressed through an understanding of the type of actions that are predicated upon membership in a family. Thus, young people engaged in caregiving activities may also view their role as carer through a sense of familial duty:

“I was doing my duties as a granddaughter, I was looking after my grannie.”

Ann, age: 22, Glasgow, Scotland, United Kingdom, cares for maternal and paternal grandmothers and grandfather with vascular dementia.

Ann’s statement notes her perception of her caring role through her relationship with her grandmother. Providing care for her grandmother was a function of her duty that was implicit in her familial connection to her grandmother. In Ann’s interview, she expressed frustration that her grandmother’s daughters (her aunts) did not provide care for her grandmother and that she served as the sole carer. She emphasized that she felt that her aunts were shirking their responsibility to their mother, and in contrast she was fulfilling her duty.

Not only did these young people express that they viewed their caregiving activities through the lens of their family role, but it was also clear that there was a notion of obligation and *owed* reciprocity. For Matt and others like him, the act of providing care was undertaken out of a sense of a reciprocal exchange: his parents took care of him when he was a child, and now that his parents require care, it seems only fitting that he “return” the favor. For Ann and others like her, it is apparent that care provision is significantly motivated by a consciousness of duty and responsibility. They have an internalized awareness of their role as children, grandchildren, and siblings and its implication of duty to their families, an awareness that is also layered in reciprocal notions of care. This is a strongly felt awareness, although it is one that is cultivated on a more individualistic level than may occur in other cultures. Western culture does not traditionally recognize filial piety, the virtue practiced within some Asian cultures that children must honor, obey, and respect their parents, preserve their family’s reputation, and provide physical care and materially support their parents as they age (Yee, 2006). Filial piety has its roots in Chinese Confucianism and its numerous principles play an important role in undergirding Chinese cultural traditions. One of the most important principles maintains that the needs of the parents always come before the child as a way of preserving a generational hierarchy within society. Filial piety, as previous research has indicated, is a strong motivator for the act of family caregiving in Chinese, Singaporean, and Indian cultures (H.Y., Griva, Lim, Tan, & Mahendran, 2016; Diwan, Lee, & Sen, 2011; Funk, Chappell, & Liu, 2011). There exists a cultural understanding that there is a debt owed to one’s parents and grandparents because of their sacrifices made during child rearing. Under the practice of filial piety, the various forms of

caregiving, e.g., physical and financial care provision, can serve as an absolution of that debt. While it remains clear that the young people in this research study were not reared under a sense of filial duty as defined within Asian cultures, they did indeed possess a strong consciousness of obligation to their family, and for some, an understanding of *owed* reciprocity. This extends beyond the traditionally understood notions of mutuality of care in which it is believed that care is exchanged between mutually interdependent individuals, rather than the repayment of a “debt” in care provision acquired long before (Lundgren & Berg, 2011; Noddings, 1984). The belief that “they cared for me when I was young, so I feel like I should care for them now” is one that conveys a striking similarity to the virtue of filial piety than the traditional understanding of interdependent care. The sense that providing care to one’s family members is an action that one *should do* can carry significant weight for young people. Arguably, there is a nuanced difference between the perspective of interdependent care: “I care for you, and you care for me” and the sentiment of owed reciprocity: “You *cared* for me, so now I will care for you”. The former can indicate a present time interaction of receiving and giving care, or it can also indicate periods of time throughout life in which various types of care is given and received. The latter approach, “You cared for me, so now I will care for you”, implies an earlier time period of giving and receiving care that necessitates a future exchange of care. Notably, the young people overwhelmingly expressed that this is an internalized sense of warranted care; the parents or grandparents of the young people in this research study did not explicitly state that they desired or needed care because they provided care to the young people during their earlier childhood years. This is a critical deviation from the tradition of filial piety. Within the cultural practice of filial piety, the family elders would likely verbally express that they expect their children and grandchildren to provide care for them whenever needed. In the more individualistic and youth-centric culture of the West, parents and grandparents may not necessarily carry the same expectations of future care from their offspring, although it is certainly a possibility. Thus, the perception of owed reciprocal caregiving is one that differs within the individual, personal experiences of young people.

In their United Kingdom-based work on the negotiations of family responsibilities over the life course, Finch and Mason (1993, p. 4-5) asked in what sense do families help each other “*because they are relatives?*”. “A history of mutual aid” could give adults sufficient reason to continue helping each other (Finch & Mason, 1993, p. 25). A sense of “built up commitments”

(Finch & Mason, 1993, p. 35) help serve as the “driving force” for one’s familial connection to one another. Reciprocity amongst family members doesn’t appear to be governed by hard-and-fast rules, according to Finch and Mason (1993). They agree that the notions of “generalised reciprocity” seem to be important within kinship networks (Finch and Mason used “kinship” to pay respect to some individuals’ broad definition of family) but it is difficult to predict (Finch & Mason, 1993, p. 51). When Finch and Mason (1993) used vignettes to ask their respondents if an adult granddaughter should quit her job to move into her grandmother’s home because of her ill health, only 29 percent answered affirmatively, that the granddaughter should quit her job to provide full-time care. Finch and Mason (1993) were not able to assert why the majority of their respondents did not believe that the granddaughter should quit her job to become her grandmother’s caregiver, but they surmised it likely has to do with our notions of the prioritization of young women and their work. Evidently, the concept of reciprocity did not dictate the respondents’ views. Similarly, reciprocity did not seem to dictate Ann’s choice to take care of her grandmother, rather her sense of obligation served as her motivator.

In their research, Finch and Mason (1993) concluded that there was little evidence to support the notion of duty as inherent within family relationships, rather than expectations within family units were much more fluid than one might presume. What makes young carers different in the way that they express duty as a part of their family role? Finch and Mason (1993)’s work might help to explain why “likely” members of the family did not “step up” to provide care, i.e., those family members who are older, have stable incomes, or are in closer relational proximity to the family member in need. Perhaps one reason why these young carers stay to care is that they were not left with a choice: if older siblings left the home, the care fell to them. If other relatives lived far away, as was the case for Ann, the care also fell to them. These young people serve as safety nets in their families, and thus their duty to care gets wrapped up in a complex set of reasons, including guilt, the reality of being the only family member in close proximity, and moral reputation, i.e., caregiving is what good, decent individuals do for their family members in need. With the complexity of all those reasons, it may be verbally easier for young carers to articulate that they have a *duty* to care, yet under the surface, it is much more complex than that. Finch and Mason (1993) do stress that duty to family relationships is developed over time, i.e., many years of relational investment. This can help explain why Matt expressed that his parents cared for him all these years, so he felt that he *should* care for his parents.

The most striking influence to determine how young people may perceive owed reciprocal caregiving is dependent upon the time when young people began caring. It is indicated that young people may not perceive a notion of owed reciprocity in care if they have been caring since early childhood. These are the young people who report that they have been caring for “as long as they remember”, or at the very least, since before the start of adolescence. These young people may feel as if they have not “stored up” years of care from their parents from which they should repay or reciprocate. There is no *felt* surplus or stored up bank of care provision. Instead, these young people communicate their motivations and experience of care provision around the sense of duty because of their relationship to their family member. This is a noteworthy finding as it demonstrates that young people may hold a particular view of the care their parents gave them during their childhood years. Indeed, they may distinguish between the care that they give their parents as a result of their health conditions and the care that their parents gave them as children. The varying practice of care may *feel* differently to them. Under the social construction of childhood in the West, childhood and youth is a protected phase in life, at least in theory, and that caregiving duties are not expected to be performed by young people on a continual basis (Becker, 2007; Dearden & Becker, 2000; Frank, Tatum, & Tucker, 1999; O’Dell, Crafter, de Abreu, & Cline, 2010). The societal belief that children are not expected to perform ‘care’ may undergird why young people may feel parent-to-child caregiving is “normative” and child-to-parent caregiving on a continual, long-term basis during childhood feels *less* “normative”.

Like Matt, those most likely to resonate with the sentiment of caring out of a repayment of a debt are those who do not feel that they have been providing care for all of their lives. These young people are most likely providing care because of a relatively new health condition diagnosis or the worsening of an already present health condition. Notably, the sentiment of owed reciprocity in care is not one that was expressed by those caring for grandparents or siblings. It is possible that the young people may feel that they do not *owe* care provision to their grandparents, siblings, or other relatives because those relatives may not have provided “direct” care to them during their youth. Similarly, the notion that parents would (or should) provide direct care to children follows societal norms; there is an expectation that care is given parent-to-child. Smyth et al. (2011) asserted that some young carers may possess a sense that caring is a parental responsibility and this may serve as an explanation for why young people are not described as carers. For the young people providing care for grandparents, siblings, and other

relatives, the sentiment expressed is one that communicates duty out of a sense of family relationship or the notion that caregiving is the good, decent action to do.

In addition, the young people did not explicitly communicate any belief that parents *owe* them care in response to their care provision. Rather, overwhelmingly, young people expressed that they felt they missed out of having a normal life in which they did not have to worry about providing care for their parents at such early ages, or particularly for those young people who cared for parents with early onset Alzheimer's Disease, severe mental illnesses, or substance abuse problems, they wished that their parents were cognitively present to bear witness to major life events. Those two strongly felt sentiments, however, are not entirely equivalent to the idea of desiring one's parents to return the "favor" of care provision. Instead, their desires indicate a longing for their perception of "normality" and the opportunity to experience the journey of life with their parents. Undergirding such sentiments is the desire for stronger or more actively present parental guidance in life, particularly as they began to navigate young adulthood. This provides the rationale to explain why some young people reported that they wished they felt they needed more adult guidance in making life decisions and problem-solving various scenarios. The question remains if such parental guidance can be considered as "care". While this research study did not explicitly ask young people if they experienced or felt care from their parents, future research should consider the ways young carers and young adult carers understand "care" directed to them from their parents, particularly those young people who have been caring since early childhood. Indeed, if young people feel that parental guidance and the cognitive presence of their parents counts as a facet of caregiving and specifically, those types of care are the kind of care that parents are expected to do, then arguably, they are likely to feel that they have not adequately received parental caregiving. Their reflection on the constitution of care helps provide a better understanding of the ways they view their own caring activities, and furthermore, their formulation of a "young carer identity".

For many of the young people interviewed in this research study, they communicated that the act of caregiving is synonymous with familial role fulfillment. This does not differ significantly from older adult carers: Hughes, Locock, and Ziebland (2013) found that adults providing care for family members and friends with multiple sclerosis had varying views about being called a "carer", and some abstained from the use of "carer" in lieu of their named relationship with their family member. Many of the adults interviewed in the research of Hughes

et al. (2013) viewed their caregiving tasks as an extension of their family role, performed in fulfillment of their obligation to family. The care required by their relatives was undertaken with the notion of *caring for* as a state of action, rather than the noun of carer (Hughes et al., 2013). Young people's understanding of their contribution to their families as "caring for" their family was observed throughout this research study. As discussed in this section, young people's contributions are also expressed through a sense of familial role fulfillment, morality, obligation, duty, and reciprocity, in varying degrees unique to the individual. Their relationship with their family members acts as foundational thread whether they articulate their caring role through duty, obligation, or reciprocity. A closer examination of their perspectives on duty and obligation, including notions of choice and autonomy, is warranted as it may reveal a better understanding of how young people consider whether the young carer label fits their identity. Future research must continue to ask such questions as, if young people do not feel they have a choice to take up the act of caregiving, does it then follow that they do not have a choice in the label that is attributed to their actions? If caring is not optional, does it therefore mean that the young carer identity is "forced" upon them? The following sections will discuss in greater depth how young people navigate the complexity of the "young carer label" and how they conceptualize their identity as young people who provide care and also their overall sense of self when they do not consciously choose to identify with the young carer label.

For every young person, this was an experience I chose to describe as an "awakening" or a "discovery" to their personal consideration of themselves as "young carers". For many, this was the first time in their life that attention had been paid to their role in the family and the contributions they made on a daily basis, particularly from individuals external to the family. This distinction allowed for focus to be expanded or shifted from solely concerning the family member(s) requiring care, but to begin to include the young people into a frame of mind. The young carer label provided recognition of the ways in which the family member(s)' disability, illness, or health condition affected the life of the young person. This recognition gave credence to the understanding that family life, and in particular, *childhood*, with a parent, sibling, or grandparent with a condition requiring the provision of care was different, special, and unique. Not only did the label provide recognition from others, e.g., family members, school staff, and health and social care professionals, but the young people now had the opportunity to *self-recognize* their family contributions. Their awareness of their caregiving activities could be

broadened from a performance of their family role to a specific, distinctive one: the role of young carer. The notion that their contributions were “just what they did” as their normal family practices were commonly expressed amongst the young people. A self-recognition of what they did within their individual families became interlaced with an understanding of what *young carers* did. The young carer label itself possessed an identity; it had a conceptual meaning.

A final note: who makes the decision of “what a young carer is” is also as important as the definition itself. This research study was not explicitly designed to examine the potential issues of agency and participation in a “top-down” approach to creating a young carer definition. However, it is worth noting that young people have not traditionally participated as active agents in the creation process of the definition of a “young carer”; rather this has been constructed by scholarly researchers, social care professionals, and politicized by social policies and community care practices. Whereas academics and social care professionals likely do not go as far to hold the belief that the language young people use to describe their caring role is inferior to any definition they might create, it is critical to acknowledge the power of language and discourse, particularly for those who do not control the prevailing narrative, i.e., young carers. Young people with caregiving responsibilities did not create the language that is used to define them and their caring role. Recalling that under a Foucauldian understanding of power, young adult carers are not innately “disempowered”. The adoption of this label and its connection to social capital, i.e., formal support services, can function as a conduit of exercised power. Working from this foundational understanding will guide the rest of our examination of the process of identification for young adult carers.

5.2.3. CONCLUSION

This section addressed the moment of discovery of the young carer label which jumpstarts the identification process for young carers. This section first discussed what it was like for young people to be told that they were young carers, as that was a new label to their lives. Not only were children presented with a label that they could use to describe their contribution in their families, but that label also provided them with a new identity of themselves. They are now a *young carer*, whereas before the moment of official identification, they were understood solely through their familiar role, i.e., child, grandchild, or sibling. Presented with this label, young people have the opportunity to fully accept, partly accept, or reject completely this label of

young carer. The following section will explore the moment of choice facing young people after they are introduced to the label of young carer and how they choose to navigate their decision process.

5.3.1 INTRODUCTION

As discussed in the previous section, the majority of the young adult carers in the United Kingdom sample of this research were told by another individual that they were young carers, typically in their childhood years. I have chosen to refer to this experience as a moment of discovery of their status as young carers. It is also helpful to think of this moment in time as the juncture that they were officially identified or recognized as young carers. Recalling the discussion in Section 4.2.2, young carers possess an understanding of their family contributions, but they are not aware of carer-related language to use to describe their experience. They typically would not use the words carer, young carer or young adult carer to refer to themselves and to their caring role in their family. Instead, young people filter their experiences through their role in the family, and their caring role is encompassed into their familial role as child, grandchild, or sibling. The presentation of the young carer label provides them with a new label to refer to their experience. I assert that the young carer label is not simply a word to describe their caring activities, but can become an identity itself if young people embody and perform through the label. The label of young carer (or interchangeably, young adult carer) possesses meaning, and when presented with the new label of young carer, young people are then forced to contemplate whether that label fits their idea of themselves and the actions they perform for their families.

Therefore, when young people are first officially called a young carer or young adult carer, they are also presented with a new identity in which to affiliate. Immediately following the moment of discovery comes the moment of choice: do young people accept the label of young carer when presented to them?

Our understanding that young people typically have not conceived of the young carer label themselves, rather it was a label bestowed upon them, adds a particular nuance to our understanding of the ways young people with caregiving responsibilities accept, reject, and

potentially come to identify with the label young carer. What does it mean that these young people did not arrive at the young carer label on their own? To be explicitly told that they possess a new identity, when for much of their childhood, they did not identify with this identity, may present an opportunity, or conversely, a crisis, for children and young adults with caregiving responsibilities. The opportunity of choice: *choosing* to accept that label means that young people who provide care can now see themselves reflected in the experiences of other young carers; they are a part of a group. Additionally, Smyth et al. (2011, p. 150) noted several other benefits young people may experience because of their identification with the young carer label: “recognition and validation, acknowledgement of responsibilities, peer support, an explanatory label, and accessing support”. Because the acceptance of this label may lead to an assessment for formal support services, young people may then have access to a “whole new world” of support through the participation in a young carers project, the caveat being only if formal support services are available in their local area. Young carers projects often serve as the gateway to support: they can meet other people their age who also possess caregiving responsibilities, receive counselling, address interventions to help their families, engage in carer-related political activism, and much more. While official identification can serve as a conduit to the access of supportive services, conversely, this newfound label could create a moment of crisis in identification for young people. The crisis exists as follows: young people may be assigned a label that may not feel accurate to their experience, and the label may be a stigmatized identity, thus inflicting negative responses from others. However, to receive formal support services, young people may feel that they must accept the label of young carer despite its potential shortcomings. The following section therefore will present the perspectives of the young adult carers interviewing in the United Kingdom sample of this research as they contemplate the acceptance or rejection of the young carer label. I will first present the experience of young adult carers who felt that they could fully accept the label of young carer, second, I will address the perspectives of young adult carers who felt that they could accept the label only partly or in certain contexts, and finally, I will examine the rationale of young adult carers who completely reject the young carer label.

5.3.2. THE ACCEPTANCE OF THE YOUNG CARER IDENTITY

Once assigned the label of young carer by an external individual, young people faced the opportunity to accept or reject that label. Most choose to accept that label and began to identify as a young carer. In the following excerpt, Ann describes that she did not view herself as a young carer until she was officially identified by someone else. Once identified, she chose to accept that label as an expression of her continuous role as her family's carer:

"I didn't realize I was a young carer until someone told me. Like we even learned that in our groups, that no one identifies as a young carer until someone tells them. That's family, that's just what I gotta do....I'm a young adult carer because that [caring] role never left me."

Ann, age: 22, Glasgow, Scotland, United Kingdom. Cares for maternal and paternal grandmothers and grandfather with vascular dementia.

Like many young carers, Ann did not recognize herself as a young carer until she was told by another individual. Also like many young carers, prior to her official identification, her caring role was viewed through the framing of her responsibility to her family. She now views herself as a young adult carer because she has been providing care through her childhood into present time as a young adult. The young adult carer label is one that feels congruent with her understanding of herself and her contributions within her family.

All of the young people interviewed for this research study in the United Kingdom began caring for their families during childhood or late adolescence (ages 16-18 years old). The majority were officially identified as a young carer during their childhood by a young carers project worker, their parents, or school staff member. As noted by Ann in the previous excerpt, many of the young people in the United Kingdom sample of this research study reported that they continued to describe themselves as young carers, even as they entered young adulthood. These young people may feel that because both their caring role and their identification as a young carer began in their childhood, the label of young carer remains accurate, even as they age. Their official identification as young carers was solidified and embodied early in their youth, and thus the label becomes a familiar term to use to describe themselves through early adulthood. It was also observed throughout the course of the research interviews that young people typically use the labels young carer, young adult carer, and carer interchangeably. Their rationale can be summarized in the following statement by Sinead:

“We are young carers and young adult carers. They mean the same in a way”

Sinead, age: 19, Newry, Northern Ireland, United Kingdom, cares for mother who uses a wheelchair.

Thus, most young people chose to accept both the labels of young carer and young adult carer and preferred to use them interchangeably. Nevertheless, it is important to note that the specific label of young adult carer possessed a certain usefulness in their perspective. The term young adult carer served as an additional descriptor, by highlighting their age and stage in life as young adults:

“I really like the word ‘young adult carer’ and I know talking to young carers who will be young adult carers that word kind of means a lot, because they’re so used to the word ‘young carers’. They think ‘I’m young, look after me’, but as soon as you put the word ‘adult’ in, you’re still young but you are an adult and it just kind of mixes in nicely and I feel like a lot of other carers are comfortable with that word. You’re still young and we’ll still look after you, but you are an adult so we’re going to help you be more independent. That’s the way I see it.”

Jane, aged 19. Cambridge/London, England, United Kingdom.
Cares for mother with fibromyalgia

Jane’s statement alludes to the reasoning championed by social care professionals on the use of the term young adult carer: the term serves to acknowledge that young adults with caring roles are legal adults capable of handling greater responsibility and autonomy, while also recognizing that they are transitioning from childhood and continue to need targeted support for their life stage. Formal support designed with older adult carers in mind may not feel relevant to them, as some may navigate their entrance into higher education and paid employment while balancing their caring role—life events that often feel uniquely characteristic of young adulthood. Yet, young adult carers possess legal status as adults, and their increasing sense of maturity may mean that programs designed for younger carers are no longer suitable. The term young adult carer as Jane demonstrates can serve to bridge the gap in life stage transitions.

While most young people accepted the label of young adult carer, some expressed a tension in the “young adult” part of the label, largely due to their perception of their age and maturity level:

“I am a young adult carer, because I am a young adult and I care. But I don’t feel like a young adult. I feel 40, if I’m honest. I’m only just nearly turning 20, but I feel like the categories are wrong. Because we’ve grown up that fast, we’ve had no choice....I feel confused. I don’t know what I’m supposed to be. I’m supposed to be young and wanna go out clubbing but I’m not that. I’ve never done that. I’ve never gone clubbing, I don’t go out drinking, I don’t go out. So I’m not sure.”

Charlotte, 19, Smithwood, England, United Kingdom. Cares for
father with epilepsy.

Charlotte did not cease to identify as a young adult carer, as she felt that it succinctly summarized her position in life: she is a young adult and she provides care for her family. Her tension with the label young adult carer arose out of her incongruence with the felt experience of young adulthood. Her responsibilities as a youth caused her to feel that she was much older than a young adult, and she could not identify with the perceived markers of young adulthood, e.g., drinking and clubbing. Feeling significantly older than their peers as a result of their young caring experience was commonly reported by the young adult carers interviewed in this research study. This sentiment did not necessarily mean that they ceased to accept or identify with the young adult carer label, but rather that young caring made them feel like *mature* young adults.

5.3.3. IS THE YOUNG CARER IDENTITY BENEFICIAL?

Of all of the young people interviewed in the United Kingdom sample of this research study, the assignment of the young carer label was the gateway to accessing formal supportive services, namely the start of their participation in young carers projects. Participation in a young carers project was contingent upon their willing association with the label of young carer. Their acceptance of the young carer label typically meant that they would need to use the young carer label to describe themselves in formal assessments (both written and verbal forms), within the setting of the formal support service, and that others within the formal support service may refer to them as young carers. It did not mean, of course, that the young people were demanded to use the young carer label to describe themselves in a negative show of force by social care professionals. Rather, the mere receipt of services necessitated a minimal level of acceptance and association with the young carer label.

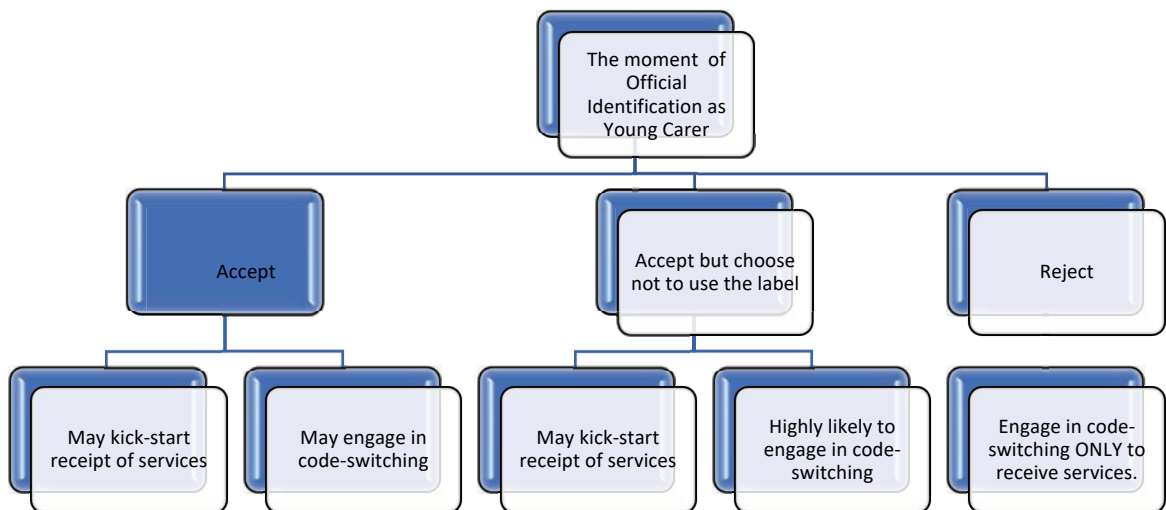
Previous research in Canada and the United Kingdom has indicated that one of the principal benefits to accepting the carer label is the subsequent receipt of formal support services; this has been established for both young carers and adult carers (Smyth et al., 2011; O'Connor, 2007). The following statement from Louise echoes this sentiment: once given the label of young adult carer, she is pleased to accept it, as she feels that the label has led to her ability to receive assistance as a young adult carer. In fact, she acknowledges that she would not receive support if she did not have the label of young adult carer assigned to her. Her statement alludes to the significance of this label for young people, particularly in regards to receiving support.

“I like the label [young adult carer] because it acknowledges that there is help for people my age, because I sort of thought things happen in life and you have to deal with it. I didn’t think I’d get help if I wasn’t a young adult carer.”

Louise, 21, Shirley, England, United Kingdom, Cares for mother with a spinal fracture

Louise’s statement also provides evidence of a pathway for young people to receive support as young carers or young adult carers, dependent upon whether formal support services are available in one’s local area. First, there must exist a societal awareness and mutual understanding of what it means to be a young carer or young adult carer; this is what is understood through the traditional young carer or young adult carer definition that is promulgated through researchers, workers in the health and social care sector, and policy-makers. Next, someone with an awareness of the label must come into contact with a young person and seek to bestow that label onto them; this is typically occurs when a family member or health or social care professional engages with the young person and recognizes them as a young carer. The young person must then accept that label and be willing to associate with that label to receive services. Without the combination of a societal awareness of the young carer label, coupled with an external individual who recognizes the young person’s caring role, followed by the young person’s identification with the label, there is a possibility that support would not be available. The process of identification and the pathway to support have been encapsulated in the diagram below.

Figure 4



The flowchart above can be used to demonstrate the pathway a young person may take once they are officially recognized as a young carer or young adult carer by another individual. If a young person fully accepts the young carer label, they may kick-start the receipt of formal support services, dependent upon if such services are available in their local area and if they meet the eligibility criteria. The young person may choose to code-switch their language when appropriate: in this discussion of identification, I use the socio-linguistic term *code-switching* to illustrate the instance of young people choosing to use carer-related terminology with other carers or during the times they find it useful to be categorized by the carer label, e.g., in school,

at the workplace, doctor's office, or in their young carers project. In sum, young people may choose to *switch* their language when they deem appropriate or advantageous. Section 4.3.6 will describe the phenomena of code-switching in greater detail; for the purpose of the discussion thus far, it is sufficient to understand that young people may choose various words to describe themselves and their caring role when they decide it is necessary to do so. The second bubble on the flowchart (*Accept but choose not to use the label*) indicates the young people who may partly accept the young carer label, typically preferring to think and communicate their caring role through their familial relationship, e.g., son, daughter, rather than as "carer". It is also possible that some young adult carers in this category identify with the young carer label, but choose not to use it openly because of stigma and fear of negative treatment. Many young adult carers will fall under this category. These young people likely engage heavily in code-switching when appropriate, aiding them in the receipt of formal support services (only if they meet the eligibility requirements and there is help available in their local area). Finally, the third bubble (*Reject*) indicates young people who completely reject the young carer label when they encounter it. These young people are likely those who feel that they do not fit the traditionally accepted definition of young caring, for instance, those who provide care infrequently or do not live in the home with their family member requiring care, those who care for siblings or spouses, or those who share caregiving activities with other family members. Those who reject the young carer label entirely may be those who *only* identify through their familial role as child, sibling, or grandchild. Because these young people face the possibility of society overlooking them as carers in conjunction with their lack of self-identification as carers, there is a high likelihood that they will not receive any formal support services in connection with their caregiving role. Alternatively, young people who reject the young carer label may engage in code-switching only to elicit the receipt of a formal support service. These young people do not internally identify with the young carer label, but they may choose to perform or embody the label of young carer to receive formal support services.

It will be helpful to think of this framework as we continue our discussion on identification, firstly in understanding the importance of official identification in launching the potential receipt of formal support services, and secondly, in understanding the process young adult carers navigate as they consider whether to accept or reject the young carer label. In this section, I addressed the experience of young adult carers accepting the young carer label, with the

understanding that it may lead to the receipt of formal support services. The *potential* to receive services must be emphasized as simply identifying as a young carer does not automatically secure the receipt of formal support. As we consider that young adult carers possess an awareness of their family contribution from a young age but may not identify as carers, it is also true that young adult carers may identify as carers yet this identification does not prompt the receipt of formal support. The following section will consider the experience of young people who identify as young carers in varying degrees, yet their receipt of formal support is either significantly delayed or never occurs.

5.3.4. WHEN THE EXPERIENCE OF YOUNG CARING DOES NOT LEAD TO RECEIPT OF SERVICES

The reality for most young people with caregiving responsibilities across the United Kingdom is that they will not be officially recognized as young carers or young adult carers and therefore, they will not have the opportunity to engage in a formal support service. There may not be a formal support service for young carers or young adult carers in their local area, or they may not be able to access the formal support services that are available, due to their lack of transportation or their need to be at home with the family member to which they provide care. Finally, they nor their family members may be aware of the formal support service that they may be entitled to receive as a result of their caring role. The following discussion is particularly concerned with the experience of those young people who are not officially identified as young carers/young adult carers despite their contact with potential gatekeepers, such as social workers and teachers. This section will first address the issues of age and false perceptions that can be perpetuated by potential gatekeepers and how it may hinder young people for receiving formal support. Next, this section will discuss how potential gatekeepers may be marginally aware of young caring but their lack of education and understanding about the realities of young caring may prevent them for fully supporting the young carers/young adult carers with whom they interact. Finally, this section will conclude by examining the possibility that for even those working in young carers projects, the socially accepted definition of young caring, their understanding of the definition, or the pressures they may face externally, may lead them to turn away young carers in need of support.

The distinction of age is critical for young adult carers and their access to support. While young people may not always perceive themselves as young adult carers (and thereby necessitating the need of service intervention), once someone officially recognizes them as carers despite their status as legal adults, this label can provide them with access to support services. Young adult carers may not believe that they are eligible to access formal support services because of their age. Because they are not young children, they often do not believe that their needs necessitate formal service intervention. This does not mean that they do not want interventions or support, but rather that they didn't realize they *could* access support at their age as late-stage adolescents and young adults. Similarly, the lingering perception that teenagers and young adults do not require support in comparison to young children also serves to prevent others from viewing them in need of support. One cannot be identified as a young adult carer, and thereby began receiving services, if gatekeepers, such as teachers, administrators, health and social care professionals, do not see them as needing support. When gatekeepers view young adult carers as mature adults who can “carry on by themselves”, they risk losing out on the discovery moment of identification, and unfortunately for some, they miss out on the support services they desperately need and are legally entitled to. For the few young people in this study who did not access dedicated support services in relation to their caring role, some reported that potential gatekeepers, i.e., teachers, school staff, and formal service providers, did not view them as in need of support because of their age. Nicola was one such young adult carer:

“My brother had a social worker, my mum had a social worker. My brother had got his social worker because he was getting in trouble at school and then they were like ‘oh there’s things going on’. I didn’t get any help, because when I was thirteen, fourteen, it wasn’t as bad and I think when it got worse, I was approaching sixteen. And then sixteen, that’s obviously the age when you sort of stop being a child and adult social services and adult support is quite different and I just sort of fell in that weird gap and everyone seemed to think that I was coping on my own fine. So they just sort of left me to it.”

Nicola, age: 23, London and Bristol, England, United Kingdom,
cared for mother who has Parkinson’s disease and her mother’s
partner who had throat cancer [now deceased]

Nicola reported that her brother and mother received formal support from social workers, yet she did not. She believed this was because she was viewed as capable of handling the challenges she faced at home, in addition to falling within the gap of child and adult social services because of her age. In reality, Nicola was in great need of formal support but the false perception of the potential gatekeepers in her life hindered her from receiving support. On an implicit level, Nicola also seems to talk about issues of adaptation to her family practices; what her family did and what she did in her family became normal. Her adeptness in handling her family's daily routine life was perceived as a function of her competency. It also appeared that social care professionals were unaware of services that she would be entitled to as an older adolescent. While not available in every local authority in the United Kingdom, young adult carer project services have been specifically designed to address the gap in transition from child to adult social care services and to prevent young people from experiencing an inability to access formal support services as they age. Nicola's statement gives credence to the need for social care professionals to be made aware of the various services available for older children in need.

It is also possible that potential gatekeepers may understand that a young person possess a caring role in their family, and yet that knowledge does not elicit access to an assessment for formal support services. In the following excerpts, young adult carers Rachel, Nicola, and Suzanne demonstrate their experience of witnessing their teachers overlook or decline to acknowledge visible signs that they were carers:

“There was one teacher in high school who briefly knew, but then after a while she thought I was talking bullshit. For the first few months, she was like ‘Oh yeah, I understand you’re a carer, you might be late to turn things in’. After a few months she was like ‘No, you’re just using being a carer as an excuse, you’re talking shit now.’ She stopped believing me after a while. Like so after a few months, you expected my mother to be perfectly fine? Okay, then keep telling yourself that.”

Rachel, 19, Edinburgh, Scotland, United Kingdom. Cares for mother with multiple sclerosis, depression, sarcoidosis, kidney failure, and chronic headaches

Rachel's statement indicates the possibility that school staff may be aware that a young person is a young carer, yet this awareness does not prompt the pursuit of an assessment for formal support

services or even flexibility within the structures of school life. Rachel's teacher initially understood that she was a young carer but ceased to understand that Rachel would need long-term, ongoing allowances at school in connection to her caring role at home. While it is impossible to fully know the perspective of Rachel's teacher, a fair claim can be made that Rachel's teacher possessed an inaccurate perception of young caring. Her teacher's insensitivity could also demonstrate a level of stigma associated with the young caring experience. The challenges presented by young caring may necessitate a need for relaxed guidelines at school or in the workplace, and such a need may extend for many years.

Conversely, the following statement from Nicola presents a situation in which flexible environments may not fully suffice in supporting a young carer, particularly if flexibility is not granted in conjunction with the pursuit of formal support:

“School sort of knew, I don't know like how much they knew, but they knew enough to sort of give me a few little allowances, like I could go and check my phone. I wasn't in [school] very much and I missed class a lot. They knew I had all this stuff going on, but there was never that thing where I could go and actually talk to them about it. They sort of let me get on with it and be a bit messy and not always there and not wearing the right uniform. They didn't really question it but at the same time, they didn't say “this is happening, you probably need some help”. So actually looking back, it wasn't necessarily the best thing, because I just had this free reign to keep not going to class[...]. I didn't know about young carers groups, I didn't know about young carers festivals, I didn't have anything like that.”

Nicola, age: 23, London and Bristol, England, United Kingdom,
cared for mother who has Parkinson's Disease and her mother's
partner who had throat cancer [now deceased]

Nicola's school allowed her some flexibility regarding the balance of her school life with her home life: she could check her mobile phone, she wasn't reprimanded for wearing the incorrect school uniform, and she could be absent from her classes. In hindsight, Nicola believed that their flexibility was not enough to effectively support her as a young carer, as her school staff was not available for emotional support nor did they bring her to the attention of a formal support service. She also never received an official recognition as a young carer; the terminology of

young carer was never applied to her. Thus, Nicola remained unaware of the formal services available to her as a young carer, such as young carer support groups or young carer respite events. In advocating for flexible responses from educators and employers, official recognition as a young carer continues to be vital to receiving formal support.

Finally, the following statement from young adult carer Suzanne illustrates what may occur when young carers present visible signs of young caring within the view of school staff yet the signs do not lead to official identification of their status as young carers:

“Even when we had parents evenings and I’d be pushing my mum about [in her wheelchair] to see my teachers, no one ever realised and I never was referred. It was only because when my brother started secondary school.

Suzanne, age 19. Chatteris, England, United Kingdom. Cares for
mother with multiple sclerosis; brother with dyslexia, and sister
with anorexia

Suzanne believed that school staff should have known that she was a young carer because she would provide mobility aid to her mother whilst her mother had meetings with her teachers. Unfortunately, even apparent, visible signs that would suggest the presence of young caring in the home did not get the attention of her teachers and thus, Suzanne went without official identification as young carer and lacked the opportunity to receive formal support.

The experiences of Nicola, Suzanne, and Rachel regarding the delay or non-receipt of referrals for formal support assessments despite contact with potential gatekeepers is reflected in previous research in the United Kingdom with young carers (Underdown, 2002). To be clear, teachers and other school administrators do not possess the same education and training as social care professionals trained to assess young people for instances of young caring. However, teachers and school staff are ideally placed as the first point of contact for young people in need of an assessment for formal support services. Under the Children and Families Act 2014 and the Care Act 2014 in England, the Carers (Scotland) Act 2016 in Scotland, the Children Order 1995 and Carers and Direct Payments Act (Northern Ireland) 2002 in Northern Ireland, and the Social Services and Well-being (Wales) Act in Wales, young carers and young adult carers have a right to an assessment for formal support, and schools and colleges could refer young people to their local

authority for an assessment. Therefore, there is great opportunity for those in the educational setting to serve as gatekeepers for young people to access formal support. I assert that more education and awareness building for school staff is essential in supporting the identification of young carers in schools.

Awareness building and thorough training on the subject of young caring is also needed by those who are working directly with young carers and young adult carers in formal supportive services. In the following excerpt, young adult carer Joe provides details of his experience as a young carer in receipt of support through a young carers project and his support was taken away:

A couple of people have been forced to leave or either they've not gotten on with the person who's taken over who's quite an unpopular figure with the young carers. A couple of people lost their parents or the person they're caring for. So [his previous young carer project worker] turned round to me and said 'well look you're grieving you're still welcome here'. That changed, the replacement turned round and said 'you're not a young carer anymore. So you don't need to come to the project.'

Joe, age 20. Alton/London, England, United Kingdom. Cared for mother who died of cancer, and currently cares for brother with a rare chromosomal disorder

Joe was accurately identified as a young carer and began attending project services. However, he was considered ineligible for services when the project came under new management. This young adult carer expressed that he believed that with pressures from the period of austerity, that local councils and the project managers may erroneously begin to tighten the socially accepted definition of young carers. Joe's statement illustrates that there is a possibility that those individuals commissioned to serve young carers may determine that certain young people do not fit the accepted definition of young caring. Because Joe's mother died, his new young carer project worker deemed him ineligible to continue receiving support services through the project. Even more striking, his new project worker claimed that he was no longer a young carer because of the death of his mother, and therefore claimed that he did not necessitate coming to the project. Joe ceased to feel welcomed at the project and stopped attending the project group meetings. Notably, Joe reported that he continued to believe that he was a young carer despite his negative experience with the new project worker. He firmly held that the new project worker falsely assessed his status as a young carer, and he did not allow her actions to influence his self-perception of his caring

role. In Section 5.2.2, I discussed the power dynamics that are situated within the creation of a young carer terminology and definition. As previously noted, there remains the possibility that children and young adults may not be perceived as active social agents of their own lives nor capable of self-selecting language that accurately defines them. The danger of “experts” not only choosing defining language to categorize young people with caring roles but also using that language to identify persons with the intention of leading to the receipt of supportive services is most clearly evident in situations such as Joe’s experience with the new project worker. In the social construction of young carers, and the way the social construction has become embedded in policy and practice, can work to exclude those who do not fit the discourse of young caring. While Joe maintained his belief that he was a young carer, it remains probable that other young people in similar situations may cease to self-identify as a young carer if they were told by an “expert” that they are not. In the research from Smyth et al. (2011), they found that one young carer who was found ineligible for income support as a carer then found it difficult to self-identify as a young carer as a result. The refutation of official recognition of her caring role proved damaging to her sense of identity. When young people who provide care receive messages that assert that they are not young carers from those in “expert” and authoritative positions, such as health and social care professionals, government agencies, and educators, this creates another potential crisis moment for young people. They are then forced to grapple with the notion that while they understand that the activities they perform for their families are extraordinary in comparison to their non-caregiving peers, those in the position to “recognize” their actions as “caregiving” or determine their eligibility for services, do not. It is even more troubling for those who were once deemed a young carer but now are deemed not to be, either because of the death of the person they cared for, or because the eligibility criteria to receive supportive services has been changed or made more restrictive. Some young people like Joe, may be able to separate and filter those external messages regarding their caring role and lessen the impact onto their identification as young carers and their overall self-concept. Others may find the external messages received during the identification process damaging both to their sense of identity as young carers and to their understanding of their contributions to their families.

This research study and previous research (Smyth et al., 2011) have found that the young carer label can be empowering for young people as an official recognition of the contributions they make to their families, conversely, when young people are denied the official recognition

that leads to services, they may disqualify themselves as carers. The receipt of services can solidify their identification as young carers, bonding them to the label of young carer as they function in young carer project group meetings, complete paperwork under the guise of their young carer “status”, and perhaps even receive a carer’s allowance. The performance of the “identity of young carer” can both consciously and subconsciously reinforce their identification with the young carer label, even as they may continue to code-switch their language amongst other groups of people. Nicola and Suzanne were cognitively aware that they are providing care for their families, and even reported that visible indicators of their caring role were evident to school staff and social workers, yet this visibility did not lead to identification as a young carer nor to the receipt of supportive services. Joe was identified as a young carer during his childhood yet he encountered a project worker who asserted that he was no longer a young carer due to the death of his mother, and therefore ineligible to continue to receive services. In each of these instances, through either the overlooking of their circumstances or the outright rejection of their status as carers, these young people were denied the opportunity to receive supportive services in connection with their caring role. With the understanding that the receipt of formal supportive services can reinforce one’s young carer identification, it follows that the denial of services could very well have an impact upon a young person’s ability to identify as a young carer.

5.3.5. WHEN THE YOUNG CARER IDENTITY HAS NEGATIVE CONSEQUENCES

Some young people may internally identify with the young carer label but will decline to use the label publicly. When speaking to others, they may use language that reflects their familial role, e.g., child or sibling, and they may describe their caring activities with other words that exclude “care”, such as *helping*, *assisting*, or *looking after*. Some young people make use of such language to help address the lack of conversational script in talking about young caring. In their consideration of their identification as young carers, several young people reported that they were hesitant to outwardly use the young carer label out of concern that they may encounter negative responses from others. This section will address the rationale of young adult carers who identified as carers yet felt that it was in their best interest to not use the label openly. To avoid negative treatment, some young people chose to abstain from using the young carer label altogether, while others decided to use the label only in certain contexts, i.e., expressing their

identity through code-switching. First, we will examine the reasons why young adult carers may choose not to outwardly use the young carer label.

The reality of associated stigma served as a major factor in preventing young people who identified as carers to openly refer to themselves using the young carer label. Associated stigma, or courtesy stigma, as defined by sociologist Erving Goffman refers to the negative treatment individuals may encounter as a result of their proximity or connection to a person who is a member of a marginalized or devalued group in society (Goffman, 1963; Ali, Hassiotis, Strydom, & King, 2012). An individual with a health condition may be stigmatized through stereotyping, discrimination, and prejudice (Ali, Hassiotis, Strydom, & King, 2012). Health conditions with particular risk for stigmatization are those with visible physical disabilities or impairments, those with a diagnosis of HIV/AIDS or mental illness, or those with substance abuse issues. Previous research in the United Kingdom (Bolas, Van Wersch, & Flynn, 2007; Gray, Robinson, & Seddon, 2008) has discussed the ways young carers experience stigma as a result of their connection to their family member. If the family member requiring care possesses a stigmatized identity, they may be risk for negative treatment from others because of their close proximity to their family member. Young carers may find themselves at risk for bullying, social isolation, discrimination in the workplace because of associated stigma (Barry, 2011). They may also experience greater levels of adverse effects on their mental health in relation to the negative treatment they have encountered. In their research with Australian young carers, Smyth et al. (2011, p. 154) found that associated stigma may lead young carers to be reluctant to reveal the “carer aspect of their identities” For the young adult carers in this research study, they found that their acceptance and association with the young carer label put them at risk for experiencing associated stigma:

“Some people might say they don’t want to talk about being a young carer because they don’t want people to start asking questions but it depends on what you’re caring for. If it’s caring for someone with a drug abuse problem, I can see why people have some stigma towards cause I experienced some stigma when I told people that I looked after my mum: ‘oh what’s your mum? Oh, she’s a functioning alcoholic.”

Ann, age: 22, Glasgow, Scotland, United Kingdom. Cares for

maternal and paternal grandmothers and grandfather with vascular dementia.

Ann's statement indicates that she experienced negative treatment from others when she disclosed that her mother was a "functioning alcoholic". She believed that certain conditions, such as substance abuse issues, might possess stigma and would lead young carers to decline to tell others about the condition of their care recipient. Ann's experience demonstrates that often young carers undergo a risk by sharing openly that they are young carers, and particularly, the condition of the person for which they are providing care. It is also true that young carers may be reluctant to reveal the condition of the care recipient to protect their career from harm, or to protect the family from social service involvement, especially when the condition is related to substance abuse, mental illness, or HIV/AIDS (Aldridge & Becker, 1993). Notably, none of the young adult carers in this research study reported that they declined to discuss their experience of young caring out of fear to their career or concern that they may be removed from their family home. Nonetheless, young adult carers did report that concern for mistreatment from others in connection to their caring role significantly affected their ability to openly discuss young caring. In the following statement from Suzanne, we see that the risk of bullying may hinder young carers from telling others about their caring role:

"I didn't tell anyone because I was bullied already and I think I was scared that it would increase the bullying. I didn't really want to talk to anyone about it."

Suzanne, age 19. Chatteris, England, United Kingdom. Cares for
mother with multiple sclerosis; brother with dyslexia, and sister
with anorexia

Suzanne was not alone in her experience of bullying in connection to her caring role. The majority of the young adult carers interviewed in the United Kingdom sample of this research study reported that they were bullied as a direct result of their caring role, and many reported that the bullying included severe verbal and physical abuse. Previous research in the United Kingdom has highlighted the prevalence of bullying for young carers in schools; in the Sempik and Becker

(2014) survey of young carers aged 14-25 years old, 26% reported that they were bullied in school in direct connection to their caring role.

The preservation of privacy and the unwillingness to disclose the condition of the care recipient may encourage young carers to stay quiet about their status as young carers. In the statement below, Aneira expressed that some young people are hesitant to announce that they are young carers because others may inquire too deeply into their family situation:

“People can be so reluctant to say I am a young carer because then people have loads of questions and stuff and want to know what’s going on and stuff. I think in society in general needs more awareness of young carers. And then young carers won’t have to make everyone aware of themselves.”

Aneira, age: 23, Newtown, Wales, United Kingdom. Cares for
mother with lupus and father with severe depression and
alcoholism

Aneira advocated for a greater awareness of the experience of young caring, so that young carers are not forced to make themselves known. The de-stigmatization of disability, illness, and young caring would likely be a great benefit to reducing the negative reaction young people may face when associating with a young carer identity. As society has not yet progressed to a point of whole inclusiveness and acceptance, some young adult carers have found another way to deal with the issues of stigma.

5.3.6. USING THE YOUNG CARER LABEL IN CERTAIN CONTEXTS

Some young people decide to use the young carer label in certain contexts, dependent upon the people that they are around. Many young adult carers reported that they did not feel comfortable outwardly identifying as a young carer because of stigma and the fear of being bullying. They expressed that they would feel more comfortable to sharing about their identity as a young carer or young adult carer with those who are their close friends or other young adult carers.

It is important to note that some young adult carers may use different words to describe

themselves and their caring activities at different times around different people. Context is key. The audience and surrounding environment influences the language that young adult carers elect to use to describe their caring role. As noted earlier, often the choice to use a particular word or descriptor may be due to stigma and the fear of negative reactions from their peers or those in positions of authority. In other instances, young people may decline to use the young carer label around individuals who do not possess a caregiving role because they want to ensure that those individuals understand the nature of their responsibilities for their families. The terms young carer or young adult carer may not be familiar to some people, and indeed, there remains widespread confusion regarding unpaid family caregiving, i.e., some mistake the word *carer* for a paid care worker for individuals outside of the home. Phrases like *looking after* or *helping* are simpler and less formal than the labels of young carer or young adult carer, and are likely easier for young people to use to describe their caring role and tasks to those unacquainted with caregiving. Allison is one such young person:

“It’s the context. With everybody here [at the young carers project] I have no problem, but if I’m out with friends or whatever, I don’t say ‘I’m a young adult carer’, I’d probably say ‘I’m looking after’ whoever I am looking after that day”

Allison, 23, Newry, Northern Ireland, United Kingdom. Cares for mother who is registered blind and father who uses a wheelchair

Allison preferred to use the young adult carer label with her peers at the young carers project. With her non-caregiving friends, she declined to use the young adult carer label, and instead chose to describe her caring role by the phrase *I’m looking after* to refer to the care for her mother and her father. The carer-related language of young carer, young adult carer, and carer could feel rather formal, cold, and professional, and may allude to paid care workers; previous research has also established adult carers often express the same disconnection with the *carer* label (Braine & Wray, 2016; Hughes, Locock, & Ziebland, 2013). Allison also indicates that the descriptor *I’m a young adult carer* is a title conveying a role. Young people may feel that titles are used to describe someone’s job or position, rather than a personal connection. For a young person attempting to communicate their family caregiving activities to their peer group, a title such as “young adult carer” may not accurately convey the messages they wish to send

about their contributions to their family. The phrases *looking after* and *helping* convey a greater sense of intimacy, and allows for young people to express their personal connection to their family member.

The distinction Allison makes between the language she uses with friends in contrast to the language she uses at the young carers project serves an important purpose: it shows that the label has a common understanding with other young people with caregiving responsibilities. Young adult carers can relate to each other because of their unique experiences at young ages, and additionally, this research study reveals that they understand the language they use to describe their activities. Their selective choice demonstrates that there is a difference between stating that one is a *young adult carer* and one is *looking after* a family member. The generally accepted definition of carer would suggest that the phrases *young adult carer* and *looking after* possess a close meaning, i.e., the latter offers a definition of the former. Yet, the selective distinction made by Allison and other young adult carers in this research study demonstrate that there is nuance and contextual meaning placed upon those phrases. Materially, it shows that Allison and other young adult carers may feel comfortable talking about their caring role with other non-caregiving individuals, but they may not feel comfortable using the word carer. Again, it suggests that the usage of the term young adult carer serves another purpose for young adult carers that is bound by the contexts of person, place, and time. While the label may be thought to give young people a unifying name to call themselves, increasing their public representation and notions of group membership, as we draw from the research interviews with the young adult carers, the label may only function adequately in particular circumstances. The public representation of carers and the belief that young people with caregiving responsibilities can belong to a group is valuable, yet arguably, the benefits may function only in certain contexts. As previously indicated, the use of the term carer may fuel incidents of bullying in school, as young adult carers can be marked as negatively different from their peers. Therefore, school, colleges, and universities may be one context in which young people may not wish to associate themselves with the label of young carer. In addition, those who identify as carers in the workplace may also face negative consequences such as discrimination and poorer relationships with their colleagues and supervisors.

Allison and other young adult carers present another broader context in which they may choose to decline to identify as a young adult carer: with anyone who is not a carer themselves.

Furthermore, they may feel comfort in expressing the label of carer, only in the contexts in which the individuals present would *understand* their identity as carers. Despite the efforts made to increase the public representation of carers, those who have had the experience of providing unpaid care for a family member may not yet understand the language used to describe young people with caregiving responsibilities. Therefore, young adult carers engage in a form of code-switching as they move between various contexts. As briefly discussed in Section 4.3.6, code-switching occurs when individuals use a particular language, dialect, and tone as they engage with certain individuals, then switch to another set of language “codes” with other people. Code-switching requires one to “assess the needs of the setting (the time, place, and audience, and communicative purpose) and intentionally choose the appropriate language style for that setting” (Wheeler, 2008, p. 57). Wheeler (2008) argues that code-switching builds cognitive flexibility because individuals are forced to comprehend their language in both formal and informal terms. Young people who provide care also demonstrate a form of cognitive flexibility when they make the conscious choice to use the label young carer or young adult carer in the presence of social care professionals but elect to use another terminology when in the company of family and friends. Such young people understand the language of both settings and understand the usefulness of each. In illustrating the performance of code-switching, Wheeler (2008) used the experience of African-American students using African-American Vernacular English (AAVE) rather than formal American English, showing that African-American students will opt to use the language of their community, i.e., AAVE, whilst with their African-American friends and family. When those students entered the classroom or a place of employment, they understood that they were expected to use formal English (Wheeler, 2008). This mirrors the experience of young people who provide care and their acute awareness that certain language is appropriate to use around other carers and social care professionals, but may not be appropriate to use around friends and family.

Young adults with caregiving responsibilities may code-switch to avoid any complications or confusion from using the formal word of carer. Being able to navigate quickly between one language to another is part of the competency within code-switching, and young adult carers appear to engage in a variation of code-switching when they use the terms young carer, young adult carer, or carer in particular settings. Young adult carers become adept at understanding around which individuals it is best to use the carer label and in what situations

using alternate phrases or descriptors is most advantageous. Amongst various motivations, code-switching can be performed as way of strengthening kinship bonds within social settings, particularly for minority or marginalized groups. Young adults may not explicitly use the carer identity to cultivate social bonds within their caregiving peer group, e.g., amongst fellow young carer project members, but deeper social bonds may exist as an unintended consequence.

One phenomenon of code-switching is the ability to engage in multiple variations of language without the fluctuation of their identity. When African-Americans engage in code-switching, they change the language they use with various groups of people, i.e., individuals of other racial groups or those in positions of authority such as teachers or work supervisors. They continue to identify as African-American even in the midst of their various language adaptations. Similarly, the work of Dovidio et al. (2006, p. 79) establishes that the development of a new social group identity “does not necessarily require groups to forsake their original identities”. This means that social categories can function fluidly, without detracting from one another. An identity can become more salient in a particular scenario and retreat from prominence in another. Thus, young people who provide care do not cease to identify as carers or with the act of caring, simply because they chose to use different language amongst different groups of people. As Iwan demonstrates below, these young people continue to identify (perform and enact the discourse of young caring) as carers, rather, it is the descriptive words that may fluctuate in any given social situation.

“If it’s sort of in the context of like an organisation I’ll say I was a young carer myself, because obviously that’s how people understand what that sort of thing is. But I wouldn’t just introduce myself to any old person on the street by being like ‘I used to be a young carer’. I just wouldn’t so it’s only in those certain things that I would say it which is why I think like it’s just a really weird thing to put a label on –“

Iwan, age: 19, Newtown, Wales, United Kingdom. Cares for mother with fibromyalgia and cared for father with pancreatic cancer [deceased]

Iwan clearly expressed that the label young carer was chiefly reserved for use in carer-related situations, such as when he is with a carers formal support organization. In those situations, the label of young carer is used to conceptualize the experience of caregiving during

youth; that label functions to categorize and thereby make sense of the activities of young people with caregiving responsibilities. He understood that the label serves a purpose in certain contexts and is not suitable in other instances, for example, when talking to strangers. By mentioning how he would describe herself to a stranger, i.e., by declining to say, “I used to be a young carer”, Iwan also made clear his preference in identifying himself. He would not actively choose to identify as a young carer in presenting himself to another person. Iwan illustrates the sentiment expressed by American novelist and social critic James Baldwin: “Language, incontestably, reveals the speaker. Language, also far more dubiously, is meant to define the other – and in this case, the other is refusing to be defined by a language that has never been able to define him” (Baldwin, 1997, p. 5). Baldwin (1997) asserts that language has the power to convey who you are. The words used by an individual can serve as a descriptor for the listener or reader. When young people use language that differs from the language used by social care professionals, i.e., “young carers” or “young adult carers”, they are, as Baldwin suggested, revealing the speaker. The use of different language indicates explicitly that these two groups of people are in fact different, and moreover, it demonstrates that they have a different internal thought process and conceptualization of the situation at hand, i.e., family caregiving at young age. To use the language of Baldwin, when we reflect on young people who provide care as “the other”, we can observe that their refusal to embrace the young adult carer label is their way of refusing a language that does not accurately define them. Such language, in fact, has not been created by them, rather the labels young carer and young adult carer have been created and co-opted by researchers, social care professionals, and policy-makers. The label of young carer did not accurately conceptualize how Iwan saw himself, and therefore she would not elect to use such language to describe himself. Iwan further expressed that caregiving is a “really weird thing to put a label on”, indicating the awkwardness that many young people feel with labelling their contributions to their families.

The following statement from Joe also serves to demonstrate the discomfort young people may feel in putting labels on their caring role. When asked in the interview whether he chooses to call himself a young carer, he highlighted his uncertainty regarding the reaction of non-caregiving peers to his admittance of being a young carer. The act of caregiving is “normal” to him, yet he recognizes that other people may not understand certain aspects of his caring experience if they did not also engage in caregiving at a young age.

“It’s weird because a. it feels normal to you but that the same time you’re aware of the gap when talking to people who aren’t young carers.... because I forget sometimes that other people haven’t by necessity had to learn these things, but, I guess I take it for granted at first, but then sort of I realised the differences. And that affects how I react to people and how I talk to them, I look at them differently and think how I talk to them because there are certain things that I don’t know whether they’ve had to deal with, I don’t know how they would react to certain conversations. So for instance like if I was to talk to half a dozen of my friends about having to care for someone from a young age, I’ve no idea how they would react. I’ve no idea if they would be really interested or enthusiastic in the conversation or if they feel really awkward and backed out. And so, I do err on the side of caution”

Joe, age 20. Alton/London, England, United Kingdom. Cared for mother who died of cancer, and currently cares for brother with a rare chromosomal disorder

In this statement, Joe demonstrates a progression in his self-awareness. The act of caregiving during childhood is normal to him to the extent that he sometimes forgets that other young people have not had that same experience. Over time, he has become more aware of the differences between himself and his non-caring peers. These differences revolve around certain things that he has had to manage as a young carer, and moreover, the death of his mother from cancer during his early adolescence years. These experiences set him apart from his peers—and notably, the death of his mother at a young age further sets him apart from some other young carers—and therefore he expressed a reluctance to share with others about his caring experience. While the issues of associated stigma and subsequent wariness of young people to identify as a young carer have been mentioned previously, Joe’s statement brings attention to the nuances of “outing” oneself as a young carer. His concern over the reaction from his peers influenced the way he guided conversation with others. He also engaged in an element of code-switching by consciously staying aware of his audience and their background experience and consequently, selecting to communicate information about himself accordingly. Here again, we observe that young people like Joe exercise a particularly high level of maturity and competence in cognitively understanding their audience, their own personal experience, and the social norms that govern situations. Joe’s decision to “err on the side of caution” when speaking to non-

caregiving peers illustrates the lack of a conversational script when attempting to share his experience as a young carer.

While numerous studies with young carers have previously found that young carers may decline to mention their caring role with others out of fear of bullying, fear of social services involvement, discrimination in the workplace, or a general sense of discomfort of feeling different from peers (Banks et al., 2002), no previous research to the author's knowledge have viewed statements such as Joe's through a socio-linguistic perspective of the lack of a conversational script about young caring leading to code-switching. In the research of Hall and Sikes (2017) with young people who have parents with early-onset dementia living in the United Kingdom, they found that those young people find it difficult to talk about their experience of their parents' condition because unlike other health conditions such as cancer, they do not have a conversational script. A conversational script refers to the acknowledgement that there is a generally accepted way to discuss a subject; participants in a conversation understand what language was socially acceptable. Young people in the research of Hall and Sikes (2017) acknowledged that there are social conventions to other health conditions: there is a generally accepted way of speaking about them, and others understood how to ask questions and how to respond appropriately. Yet with early-onset dementia, young people found that many people did not understand how their parents could have an "old person thing", i.e., disease, at such a relatively young age (Hall & Sikes, 2017, p. 1207). As a result, the young people felt that their experience with their parent's illness was misunderstood and they were further stigmatized. Similarly, caregiving during childhood and young adulthood may not have a script or preconceived social conventions. People may not know how to respond and react to young people with caregiving responsibilities. The young people in this research study like Joe were acutely aware of this possibility, and thus their code-switching is their response to adapt to a world that does not understand their life experiences as young carers. Thus, using certain language within a particular context functions as a creative response: young people have created their own scripts. When the young people in this research use the label young carer or young adult carer during the times that they are participating in services dedicated to their caring role, e.g., attendance at a young carers project, but do not use those same labels when around their friends and family, they are functioning in response to the social conventions we have about family, care, and illness. Young people with caregiving responsibilities are reacting to their own

conceptualizations about family, health conditions, and the activities that they do for their family. Conversely, these young people are in a perpetual position of navigating how the outside world perceives them. There are social conventions to how non-caregiving people respond to both carers and young people and thus, young people with caring roles. Joe expressed the sentiment that people do not know exactly how to respond to young people with caring responsibilities as the experience of caregiving at a young age feels foreign, unexpected, and unfamiliar to them. As Burke (2010, p. 1696) found in his research with children who have siblings with disabilities in England, “living with disability causes reactions”. The reactions from other people reinforce a social construction of disability, as “the social elements of stigmatisation are evident, in the negative sense, reflected in family dynamics and social interactions” (Burke, 2010, p. 1696).

Excluded from this consideration are young carers project staff, as by the nature of their practice, they have already categorized these young people as “young carers”, and likely filter their interactions with them through the accepted conceptualization of the young carer identity. Conversely, non-caregiving peers do not typically view these young people as young carers as young caring is an experience unfamiliar to them. Social conventions would preclude that young people with caregiving responsibilities *should* be treated as “normal” young people by other non-caregiving individuals, yet when others are presented with their caring experience, they may respond inappropriately, offering stances that are unsupportive, invalidating, or perhaps even silence. Young people who provide care have learned this through their encounters with others, so they use code-switching language as a social lubricant and to ease their interactions with non-caregiving individuals.

A final note regarding context and the identification process for young adult carers: some young adult carers may experience identity confusion as they consider which contexts they should embody the young carer identity. Throughout this work, I have suggested that the young carer label can be a distinct identity for young people, to the extent that I use the word “label” and “identity” interchangeably. I assert that it may also be true that young people may experience confusion over their identity in various settings. Some may begin to reflect, as the following statement from Lynn indicates, that they may inhabit a carer identity only in certain contexts, and there is uncertainty surrounding when the carer identity is salient:

“I think I act differently away from my family. So when I’m with my friends from uni or work or wherever, I act differently because, I’m in a different situation. Now I’m not quite sure which of the two people I am. I’m either the person who I am when I’m with my family and caring for them and more serious, because I have to be. Or am I the person that I am when I’m with my friends or at work or wherever, because I can act differently around them. I don’t have to kind of check in, you know, ‘do you want a cup of tea’? Things like that. My friends and I can go out for a meal, but that means for me I don’t know who I am out of them two people.”

Lynn, 21, Newtown, Wales, United Kingdom. Cares for brother with Cerebral palsy

Lynn expressed that she feels like she is two people: the person she is when she is caring for her family, and the person she is when around non-caring individuals at work or at university. For her, caring feels like two different personas that function prominently when she is in the relevant setting. However, internal confusion arose and she debated over which identity she embodies in various settings. Lynn is attempting to navigate the embodied identity of young carer and her other understandings of her identity, dependent upon her social context. This is a nuanced difference from code-switching, as it appears that young adult carers who engage in code-switching remain aware of their multiple identities in each instance; they do not report confusion in their identity as they shift their language. Lynn may be experiencing what Settles (2004) referred to as *identity interference*. Recalling from the literature review chapter (Section 2.5), identity interference is the difficulty one may experience in navigating from one identity to another in various contexts. The experience of multiple identities can be distressing in some instances, such as with Lynn, but it also can serve as a buffer from uncomfortable social situations as with Joe, Iwan, and Allison.

This subsection discussed the experience of young adults with caregiving responsibilities who identify with the young adult carer label yet do not openly refer to their caring role. These young adult carers expressed that the young adult carer label accurately described themselves and their contributions to their families. However, they often chose to communicate their caring role through familial language rather than using carer-related terminology. This research study found that young adult carers may be reluctant to openly associate themselves with the young adult carer label because of courtesy stigma and the threat of mistreatment from others. To avoid negative treatment, they also engaged in a form of code-switching by consciously selecting which terms they would use to talk about their lives as young carers in certain settings. Typically, the young adult carers reported that they felt more comfortable expressing that they

were carers within the confines of their young carers project or in the company of other young carers. Amongst the general public, they preferred to use familial language or not to discuss their caring role at all. Through this discussion, we understand that young adult carers can maintain their identification with the young adult carer label while also actively considering the appropriate time, setting, and audience to use the label verbally.

The following section will focus on the perspectives of those who completely reject identification with the young adult carer label.

5.3.7. ON NOT IDENTIFYING AS YOUNG ADULT CARERS

A very small number of young adult carers in this research study reported that they did not identify with the young adult carer label. These young people were officially identified by another individual and their official identification led to their receipt of a formal support service in connecting to their caring role. However, when asked if they identified with the label, these young adult carers reported that they did not possess a self-perception of themselves as carers. They presented a variety of reasons to explain their disassociation with the young adult carer label: they view themselves as family members; the carer term does not define their overall sense of identity; and finally, the act of care exists as a function of their normal daily activities rather than a distinct role. We will first examine the perspective of a young adult carer who declines to identify as a carer because of their sense of familial duty:

“I don’t see myself as a carer because it’s a family member, you’re meant to look after family, so why would you get praise for doing what you’re meant to do? Family is family. And that’s what God put us on the earth for-- to take care of home. I don’t see myself as a hero or anything. If your family needs you, you’re there--that’s what family is for.”

Sinead, age: 19, Newry, Northern Ireland, United Kingdom. Cares
for mother who uses a wheelchair.

Sinead expressed that she did not identify with the young adult carer label because she viewed her caring activities as an extension of her membership in a family. By questioning why an individual would “get praise doing what you’re meant to do”, she alluded to the notion that the term carer provides its user with recognition of their caring role. Her statement implies that she does not view

herself as a hero, recalling the assertion promulgated by Smyth et al. (2011, p. 147) that young carers often do not “regard their responsibilities as unusual or exceptional in any way”. Indeed, the work of Aldridge and Becker (2002, p. 218) suggested that the media narrative of young carers as “little angels” has been successful in upholding notions of childhood vulnerability and exceptionalism instead of a more balanced, normalized view towards multigenerational caregiving. It may also be true that Sinead’s notion of doing “what you’re meant to do” may fit within the wider narrative promoted by earlier research that challenged whether young carers were performing roles different from other children in households in which there was not a family member with an illness or disability (Olsen, 1996; Olsen & Parker, 1997; Parker & Olsen, 1995).

In congruence with other young adult carers in this research study, Sinead’s understanding of her caring role was centered in her performance as a family member rather than as a distinct role as carer. Sinead presents an example of a young adult carer who does not identify as a carer, yet is in receipt of a formal support service. Her involvement in a young carers project began through the referral from someone external to her family, i.e., she was officially identified as a young carer. Her association with the young carer label did not appear to influence her identification as a participant in her family; her sense of self was centrally aligned with her family membership. In addition to the belief that caregiving is performed by reason of their obligation to their family, young adult carers may also report that they do not identify as carers because caregiving has become normalized. The following statement from young adult carer Lillian reveals that young adult carers may feel that caregiving ceases to feel distinct as it becomes a part of daily life:

“When I was younger before I had my son, yes, but now I just kind of feel like it’s a daily thing and fits in to daily life. So there’s not that much change I think I find I’ve just got into a big routine and I don’t really see it as caring anymore. Just see it as daily life.”

Lillian, aged 20. St. Ives/Cambridge, England, United Kingdom.
Cares for mother with a genetic condition.

Lillian indicated that she did not identify as a carer because the act of caregiving had become enmeshed within her activities of daily life. Lillian had provided care for her mother since her earliest memory, and she began caring for her son at his birth when she was 17 years old. Her

statement may show that when caregiving has taken place over a long period of time, caregiving feels ordinary and no longer feels distinctive. It may also be true that the act of care may cease to feel distinctive once young people begin caregiving for multiple individuals. The final excerpt will explore the view that young adult carers may avoid identifying with the young carer label out of concern that the label will define their overall sense of identity and limit their worldview:

“I think you shouldn’t call people anything because I never let being a carer define me, because I am a young person first and I’m a person first who had caring responsibilities and I refused to let that be all of who I am. There’s so much more to me than there was then and by labelling everyone in one group, I know you need to for like statistics and like filling in forms and identifying them and stuff, but I think it should be careful about doing it too much because if you’re putting them in this group, and then they can feel like they have to care because they’re called a young carer or a young adult carer. And they can feel like they can go off and do other things and do their own lives because you get put in to that box and you don’t feel like you can get out of it, because you feel the guilt. And some yeah controversial to what people probably normally say, but – It’s like if someone has a mental illness you won’t just say oh that’s the depressive or that’s the schizophrenic, that’s insulting, you wouldn’t say that.”

Jeffery, age: 18, Edinburgh Scotland, United Kingdom. Cares for mother with Bipolar disorder, epilepsy, partial blindness, brain injuries, & alcoholism

In Jeffery’s excerpt, we see the power of labelling. Jeffery advocated for the use of person-first language when referring to young caring, in place of the prioritization of care-related language, as he felt that his sense of self was broader than the identity of young carer. Terms like young carer, young adult carer, and carer felt too restrictive for his sense of identity, and he preferred that others avoided using those labels. His support for person-first language is reminiscent of the perspective encouraged by some in the field of disability studies in the United States (identity first language is typically preferred in the United Kingdom) (Olkin, 2017; Peña, Stapleton, & Schaffer, 2016). His preference for person-first language may also allude to the issue of stigma facing young carers. Earlier in this chapter, the prevalence of courtesy stigma provided a rationale for why young adult carers may choose to talk about their caring role and their families with other language

disassociated from caring. In a similar manner, the young adult carer label itself may possess a level of stigma; if a negative perception of carers exists, then not only do young people face stigma from their mere association with their family member's illness or disability, they may also face stigma for *providing* care for their family member. Alternatively, avoiding the use of the young carer label may unintentionally reinforce negative stereotypes about young caring, causing, as Collier (2012, p. 1977) indicated in his disability work, the stigmatization of "words that were never considered derogatory or pejorative in the first place". To avoid stigmatizing language on disability, some had advocated for identity-first language, e.g., disabled person rather person with disabilities (Gernsbacher, 2017). Similarly, an identity-first perspective to young caring may work to combat unintentional stigmatization of carer-related language.

In addition, Jeffery warned that when young people are officially identified as young carers or young adult carers, they may become bound by the perceived expectations of the label, preventing them from seeking autonomy away from their family. Previous research in the United Kingdom has confirmed that guilt in connection with their caring role is a central feature in the lives of young people with caregiving responsibilities, including the sentiment that they feel tied to their families and hindered from exploring other life paths (Dearden & Becker, 2000; Becker & Becker, 2008; Carers Trust, 2015). The research of Hamilton and Adamson (2013) with Australian young carers found that young carers may experience "bounded agency" and feel restricted in their ability to explore life paths because of their responsibilities to their family. The young adult carers interviewed in the United Kingdom sample of this research study reflected similar sentiments regarding their ability to explore various aspects of their identity.

The cases of Sinead, Lillian, and Jeffery present the perspective of young people who were officially identified as young carers and have been engaged in a young carers project since their childhood, yet they report that they do not identify as carers. Their reasons vary: caring is an expected aspect of membership in a family, caring over long periods of time become normalized, and the carer identity may reinforce notions of bounded agency. Their reasons do not differ widely from the sentiment shared by other young adult carers in this research, yet conversely these young adult carers express that they do not identify with the carer label. Because of their sustained involvement in young carers projects, it appears evident that young adult carers may choose to associate themselves with the young carer label to receive formal support services, even if they do

not internally identify with the label. Therefore, a young adult carer's engagement with formal support services may indicate their prioritized need for support, rather than their identification with the young carer label. This does not mean that young adult carers do not view their caring contributions central to their sense of identity, rather it means that young adult carers may refer to their caring contributions as a function of the role they play in their families. The *act* of caring for their family likely remains critically important to their development and understanding of their sense of self, but the *identification* with the young carer label may be of lesser importance.

The following section will feature the young adult carer identification process for young adults providing care for siblings. The total sample of interviews in both the United Kingdom and United States significant featured young adults providing care for siblings, and it was revealed that those young adult carers generally conceptualized their young caring experience differently than those caring for parents or grandparents. Thus, a separate section closely examining their experience will be provided.

5.4.1. THE SIBLING PERSPECTIVE ON THE YOUNG CARER IDENTITY

The definition of young carers in common usage within the United Kingdom has been expanded to include siblings of those with a condition requiring care (Children's Society, 2013). Despite this inclusion, Meltzer (2017) and Newman (2002) accurately recognize that most young carer focused research has primarily focused on children who are providing care for their parents, so there remains a dearth in knowledge about the position of children and in particular, young adults who provide care for siblings. Historically, research on young people providing care for a sibling with a disability or health condition has shed light on the types of care that they provide siblings but without examining the effect of their relationship onto care, e.g., what is it like for siblings to provide care to another sibling rather than a parent (Meltzer, 2017). Likewise, as this research study is the first of its kind in the United Kingdom to focus on the identity development of young adult carers, it is also the first research in the United Kingdom to consider the perspectives of sibling young adult carers as they reflect on their identification with the young carer label and on their overall sense of identity. Fitting within our larger discussion on young carer identification for young people, this section will focus on identification for sibling young adult carers. Two

major findings will be examined: first, sibling young adult carers may find it difficult to self-identify as carers because they share caregiving duties with their parents, and second, young adults are more likely to self-identify as carers if they provide care for multiple family members and if they are the primary and sole carer in the family.

5.4.2. ON NOT IDENTIFYING WITH THE YOUNG CARER IDENTITY

Like other young adult carers, young adults providing care for siblings understand that they are supporting their families through their provision of caregiving tasks, however they may not think of their activities as “care”. They may not view themselves as young carers or young adult carers, instead they view themselves as siblings simply helping out or assisting their parents. The interviews with sibling young carers in this research study revealed that young adults providing care for siblings were less likely to have been officially recognized as young carers when they were children. It follows that the sibling young adult carers in this research study were less likely to have received a formal support service in connection to their caring role. Therefore, the sibling young adult carers in this research study either had a rather late realization of their status as a young carer, i.e., their understanding of their family contribution as young caring, or that realization came fairly recently, as through the recruitment for this research study. In the excerpt below, Najmeh exemplifies the experience of sibling young adult carers who have not been officially identified as carers, as well as the experience of a young person who has considered her caring role in light of simply “assisting” her parents.

“When I think of a carer I think of my mom because she is genuinely the primary carer. So it’s kind of like I don’t really fit in to the carer – even though I care so much and there is this obviously different kind of lifestyle. Maybe [I] “assist”, because when you said “young adult carer”-- that’s not me, because I’m not officially a carer. But when I read the email [call for research participants] like “assist someone without support or without money or so a sibling or with a mental [illness] or another thing” I was thinking “does a mental disability count as well?”, because when I think of “carer”, I think of somebody in a wheelchair. Somebody assisting someone in a wheelchair or with some physical ailment. I know that my mom is a carer, she takes care of

my brother because he is disabled. He is classed as disabled, but I wouldn't have thought young, when I saw young adult carer I didn't class me as one, until I read the rest of the email."

Najmeh, age 20. Hall Green, Birmingham, England, United Kingdom. Cares for brother with severe autism

When asked if she identified as a young adult carer, Najmeh revealed an internal indecisiveness regarding whether that label fit her experience. She thought of her mother as the primary carer because her mother provides aid to her brother who is "classed as disabled". In an earlier part of the interview, Najmeh described the care that she provides for her brother, which included helping him get dressed, bathing, sitting with him, and helping him calm down during times of emotional distress. Under our traditional understanding of young caring, it is acceptable to classify Najmeh's activities under a young carer definition. However, Najmeh questioned whether she was a carer because she did not have sole responsibility for her brother; her caring activities were shared with her mother. In addition, Najmeh reported that her mother received formal governmental support in connection with her care provision, thereby officially classifying her as a carer. The receipt of official recognition of her mother as a carer arguably solidified in her mind that her mother was the carer, and that she was not. This further indicates that formal recognition from external individuals or services can play a role in influencing one's perception of their identification as a carer. Najmeh reported that the label of young adult carer did not readily feel applicable to her when she encountered this research study's call to participants. It was clear that she had not been referred to as a young adult carer or a carer prior to her encounter with this research study by an external individual, nor had she ever considered herself in light of this identity. Najmeh appeared more comfortable with the term "assist", as she felt that she assisted her mother in providing care for her brother. Najmeh also expressed uncertainty about whether her brother's condition qualified to make her a young adult carer. She referred to her brother's diagnosis of autism as a "mental disability", and was uncertain if his condition should be viewed as one that she could provide care for. In her mind, she thought a carer would be one who provided care to someone in a wheelchair or with a "physical ailment". Najmeh's perception of the care activities of a carer and the condition of a care recipient strongly reflects the perception reported by others in societal discourse. Because siblings often share the care with their parents, they may decline to see themselves as carers because they view their parents as

primary carers. This belief may be reinforced when their parent(s) receives formal support for their caring role and are officially recognized as carers. Thus, it is also probable that siblings may feel that their perception of themselves as carers is *negatively* reinforced by their parent's carer identification. Some young people may feel that they are precluded from being classified as a young carer or young adult carer because their parent(s) are formally recognized as carers.

I suggest that a more inclusive understanding of young caring is encouraged, one that recognizes that siblings who provide care in conjunction with their parents are may also be carers and warrant the opportunity to be officially recognized as carers and directed to formal support services. It is also worth noting that the research study was the first time that Najmeh had been introduced to the label of young adult carer, and while she expressed that she was comfortable with that label, future research should consider the effects on a young person's well-being when the young adult carer identity is introduced so recently. Finally, for Najmeh, while she did not readily identify as a young adult carer, she could readily express that providing care for her brother affected her identity and the way she saw herself both presently and as she looked to her future choices in life. Najmeh's experience heightens our understanding of the nuances between identification and identity. She demonstrates that it is possible to not identify with the young adult carer identity (in her case, because she was unfamiliar with it), but still find that her overall identity is impacted from caregiving.

While this research study was not designed to ask participants explicitly about their perspective on varying types of care and care relationships, Meltzer (2017, p. 2) posed a relevant question in her work with young adult carers providing care for siblings in Australia: "Do different types of care feel different or have different relational implications?" Najmeh would appear to provide an affirmative answer; caring for a sibling has different implications for her role in the family, but also to her own characterization of herself as young carer. Conversely, Joe appears to be able to distinguish less from his role as young carer to his brother and his role as a normal older brother. Clearly, Joe can point to nuances in differences towards in his actions towards his brother, however, he himself wonders how much different his experience with his little brother would be if his brother did not have a disability. For Joe, especially regarding emotional support, he surmises that he would behave the same way regardless of his brother's health condition because of his role fulfillment as an older brother.

“Well to me a lot of it does feel normal like [my brother] having a problem with girls, I’ll talk to him, I’ll advise him. If [my brother]’s being silly when he shouldn’t be, I’ll turn round to him and say ‘stop it we’ve got to be serious now’. I’m doing work on sort of trying to get [my brother] involved so he’s got the skills. If someone is being a pain to him, I’ll “do the big brother thing” if he wants me to. I’ll step in and make sure he’s ok. And sort of try and scare the other person into being less of a pain. They don’t feel exactly conducive to being a young carer, it’s something that I’d have thought any older brother with any consideration for their younger brothers or sisters would do the same. I mean I don’t think if [my brother] had his learning difficulties I don’t think that I would, I guess I would treat him slightly differently in that for instance I’m conscious of his difficulties, I’m conscious of the fact that he is at a disadvantage and I want to make sure he is at as little of a disadvantage as he can be, but at the same time I’d still be there to support him, I’d still be there to sort of help out, I’d still be, try to watch over him and make sure that he knows it he’s in trouble or if he has issues, he could come to me. I’d still want to sort of hang out with him, I’d still try and advise him where I can because to me that’s being an older brother.”

Joe, age 20. Alton/London, England, United Kingdom. Cared for mother who died of cancer, and currently cares for brother with a rare chromosomal disorder

It appears difficult for sibling carers to make delineations between activities they would do as “normal siblings” and what they would do as carers. Heyman and Heyman (2013, p. 564) affirmed that it may difficult to differentiate between care, noting that helping a family member with disabilities may be seen as a “burden”, while taking care of a younger sibling without disabilities typically is not viewed as caring. For young adults caring for their siblings, their caring role is especially encompassed into their perception of their role as a member of a family. The notion that older siblings help younger siblings is one that society would view as a “normal” part of participating in family life. This helps explain why young people like Joe and Najmeh find it difficult to view themselves as “young carers”, as their perception of themselves is founded upon societal and perhaps in addition, familial expectations that they are doing what siblings should do for each other, especially as an act of performance between older sibling to younger sibling.

The concept of expected behaviors within the participation of the family can make it difficult for young people to distinguish the types of behaviors that they assign to their carer role

and their role as siblings. Olsen (2000) suggested that the way we view the activities of caregiving are grounded in context; in certain contexts, caregiving tasks are acceptable for young people to do perform, in other contexts, we view it as problematic and inappropriate. He points to the instance of a child having significant chores within a home as “normal” and appropriate and we would not classify that child as a young carer. If that child had a sibling with a disability and, additionally performed a significant level of housework, we would likely give that child the young carer label. Therefore, Olsen (2000) asserts that “we see young carers defined not simply by the type and quantity of tasks that they do, but also by the fact that their activity is directed towards the ‘care’ of a ‘dependent’ disabled person” (p. 391). To this end, Meltzer (2017) asserts that we do not give enough weight to the reality that for sibling carers, they engage in many tasks that they consider normative within the context of a sibling relationship, especially ones with significant age differences. We can see this complexity reflected in the experience of young people caring for siblings, like Joe, who expressed uncertainty about whether the emotional support that he provides to his brother should be classified as young caring or alternatively, the expected and typical level of involvement for an older brother. His relationship to his brother with a disability and his perception of the normal activities that occur within an older-brother-younger brother relationship served to construct the extent to which he self-identified as a young carer. Further layered in between Joe’s social construction of his role as an older brother, he, like many other young people, also grappled with whether emotional support qualifies as care.

In addition, one’s living status may matter deeply to young people as they consider whether they can identify as a young carer or young adult carer. As the following statement from Joe indicates, it is possible for young people to question if they are young carers if they spend limited time in the family home:

“I don’t feel so much like a young carer for [my younger brother] now though, because I’m not there full time anymore and because it’s not so it’s not as intense, it’s mainly just sort of being there for him. And sort of just trying to insulate him when things get a bit rough and it feels a lot more now like things that should just be done anyway, rather than – being a young carer. So I don’t feel so much as a young carer now and also I guess because I’ve been, since university I’ve gained a lot of independence. I’ve always wanted to sort of break free and get my independence, if I have it my way once I finish university I will remain in London and just live my own life. It

doesn't feel so much like being a young carer because sort of when I was more of a young carer so I was more tethered to one person or one place. Whereas it's not so much now in sort of if I have my way I won't be at all.

Joe, age 20. Alton/London, England, United Kingdom. Cared for mother who died of cancer, and currently cares for brother with a rare chromosomal disorder

Joe's interpretation of a young carer identity is defined by the notion of the young carer living full-time in the home and in possession of a diminished sense of independence. We can deduct from Joe's statement that some young people may believe that the identification as a young carer necessitates being "tethered to one person or place". For Joe, the young carer identity is wrapped up in notions of diminished autonomy. The perception that Joe maintains regarding young carers is critical as it helps to guide our understanding of how young people conceptualize young caring. This consideration matters because conversely, for those young carers who do live away from home and have a sense of independence, either others may not perceive them as young carers, or they may not see themselves as young carers.

5.4.3. ON IDENTIFYING WITH THE YOUNG CARER IDENTITY

Meltzer (2017) noted that some of the young adult carers interviewed in her research on sibling carers felt that their parents only allowed them to do certain types of care, i.e., caring tasks that did not involve personal intimate care like bathing, toileting, or dressing, because their parents wanted to preserve their *sibling* relationship versus a relationship that was solely centered on caring. This desire to keep "normalcy" intact as much as possible in the maintenance of their sibling relationship could also have bearing on their sense of identification as young carers and young adult carers, as well as their understanding of their family identity. If parents protectively shield their children from certain aspects of caregiving—and the child is conscious of their parent's act of protection, does it have an impact on their sense of identification with the young carer label? It is possible that a child may identify more as a sibling who merely assists, rather than a sibling who is a care provider. Notably, a sense of a conscious move from their parents to maintain a normative *childhood*, rather than necessarily a normative sibling relationship only appeared as an emerging theme from one of the young adults caring for siblings

interviewed in this research study. Samuel is one such young adult carer; he revealed that his mother was not comfortable with his caring role in the family because she wanted him to have a childhood. It is therefore implied that his mother did not feel that acting as the family carer would allow him to have a childhood:

“She wanted me to not be an adult at that age. She wanted me to be a kid and she knew that at some point I would be an adult and she didn’t want me to see her like that. At one point she refused to let me push the wheelchair. She said, ‘I don’t want kids seeing that, nobody seeing me like this. My mum hated the fact that I was a carer for the family. My mum never, ever wanted me to do this. She always hated me doing it, because she wanted me to have a childhood and I said to her no way in hell....I said to myself, I would rather rot away inside than let this family rot away. And I just ended up nearly killing myself for this family...I think after a while you just become numb to everything really. That’s when [social services] kind of stepped in and really gave me the childhood that my mum wanted me not to lose.”

Samuel, 18, Birmingham, England, United Kingdom, cares for father with schizophrenia, four siblings, and previously cared for mother who died from cancer

In this excerpt, Samuel expressed that his mother hated that he was a carer for the family because she wanted him to preserve his childhood. She felt strongly about not wanting Samuel to help and did not want Samuel (or anyone else) to see her in a state of needing care. It is clear that Samuel’s mother communicated a message that children should not provide care; caregiving is reserved for adults to perform. We recall the work of Morris, Parker, and Clarke with disabled parents; they may not want to be seen as dependent upon their children as they maintain that they are loving and capable parents. Samuel spoke of his mother not wanting his help and would often decline his help, however he continued to provide care for his family. The involvement of social services was targeted to supporting Samuel’s siblings and their needs (various undisclosed mental illnesses and substance abuse issues), rather than towards Samuel or his needs as a young carer. Whilst social services involvement helped to salvage Samuel’s sense of childhood, it did not completely ameliorate his often negative experience of caring, nor did he cease to identify as a young carer:

“when I was a kid, being a young carer was the worst labour and I hated it, I hated that I’m at home...at one point you just sort of think ‘am I really 15 or am I like a 40 year old bloke who is actually a trained social worker in his head to deal with all these problems?’...Can you imagine a 45 year old man going into Parents’ Evening [at his siblings’ school], but a 15 year old? That’s really unheard of, and teachers giving me funny looks.”

Samuel, 18, Birmingham, England, United Kingdom, cares for father with schizophrenia, four siblings, and previously cared for mother who died from cancer

In this excerpt, Samuel referred to young caring as “the worst labour”, explicitly stating that he viewed caregiving as *work*. This word choice feels very different than the language used by Joe and Najmeh in which they used words like “assist” and “helping out” to describe their caring role. Furthermore, this is work that he “hated”, and he hated that caring required him to be at home. He felt like he was a “40 year old bloke” working as a “trained social worker”, rather than a 15 year old boy. In this statement, we see that Samuel understood that his experience of providing care as non-normative for his age and, in addition, position in life; he implied that he wasn’t trained to deal with the kinds of issues he was responsible for resolving within his family, in comparison to the way a social worker twice his age would be prepared to handle. Samuel also described his experience of being 15 years old and attending Parents’ Evening at his siblings’ school on behalf of his parents. He recognized that his presence at Parents’ Evening was unusual and did not fit within the expected behaviors for a child *nor* a sibling. I assert that sibling young adult carers, such as Samuel, who not only function as the primary carers for their family but also as young people responsible for making major decisions and serving as the crisis mediator for the entire household, possess a higher likelihood of not feeling like they are in a “normal” sibling relationship. As sibling relationships are often deemed as the first interpersonal relationship that young people may experience in life, the question requires further study as to how sibling young adult carers who do not feel like they are “traditional” siblings process their identity in life (Aronson, 2009). Of the young adults living in the United Kingdom in this research study, Samuel came the closest to explicitly stating that he no longer felt like he was acting as an age-appropriate sibling in performing his caring role. Similarly, Samuel was the only sibling young adult carer interviewed in the United Kingdom for this research study who served as the primary or sole carer. He was also the only sibling young adult providing care for family

members with substance abuse or mental illnesses. The sense of responsibility he felt as the sole carer, coupled with the unstable home environment he experienced as a result of caring for his parents and siblings with complex needs, likely bear weight to his experience of feeling distant from his role as sibling *and* as a child. For young people who are the sole carer for their family, providing care for conditions that can affect a parent(s)' ability to be cognitively present, like what can occur within substance abuse issues and certain mental illnesses or developmental disorders, they may feel that they are shouldering a greater sense of responsibility in household management, problem-solving, or involvement with social services than young people engaged in practical care tasks like cleaning, cooking, or helping with mobility aid. Different kinds of health conditions lead to different kinds of caring tasks which can lead to different kinds of perceptions of identity associated with caregiving. Therefore, it remains very possible that young people, like Samuel, feel distant from their identity as a sibling and feel closer to their identity as a carer. Their high level of involvement within their family in conjunction with the type of care that they perform (for example, household management, crisis resolution) can lead them to identify more strongly as carers, rather than siblings. This goes beyond the expressed feelings of not feeling like a "normal" sibling or correspondingly, a sibling that "does a little more" than other non-caregiving siblings. Conversely, it is also possible that a sibling may not fit the aforementioned criteria and still identify more saliently as a carer rather than sibling—the caring experience is not one-size fits all. As we noted with Joe and Najmeh, they expressed that they participated in various kinds of caring tasks for their siblings, including intimate tasks but excluding household management or crisis resolution—those kind of tasks were performed by their parents. In all, their level of involvement does not appear to diminish their perception of their sibling relationship, rather they stressed the complexity of feeling like "normative" siblings yet while in possession of significant caring roles.

5.4.4. CONCLUSION

This research study produced two major findings in relation to sibling young adult carers. First, young adults providing care for siblings may not readily self-identify with the label of young carer or young adult carer, yet they recognize that they contribute care to their families. Sibling young adult carers may grapple with seeing their contributions to their families as care,

particularly if they have not had the early intervention of a social services or any other contact that identifies them as young carers. They recognize that their identification as a young adult carer may be dictated by time and space, i.e., whether they live with the person that requires care, or how much time they may devote to providing care. I assert that part of the identification issue for young adult carers is dependent upon if they share caregiving responsibilities with another family member. Regardless of whether a young person lives in the family home or not, young people providing care to support their siblings may not identify as a carer, if they share caregiving responsibilities with their parents or other siblings.

Second, young people are likely to identify as young carers or young adult carers if they provide care for both a sibling and their parent, or alternatively, if they serve as the family's sole carer. Responsibility for multiple family members across generations may lead young people to feel as if they possess more responsibility, thus strengthening their identification as a carer. In circumstances when the ability of parents to provide care is limited, some siblings without disabilities were in more extensive care roles as the primary carer. Such extensive care roles could not adequately be described only as 'help' or 'looking after' and therefore those sibling young adult carers were more likely to frame their contributions in their family as caregiving. Primary carers may feel their caring role is especially heightened and therefore more salient to their identification as a young carer or young adult carer.

5.5. CONCLUSION

This chapter explored the recollections of young adult carers in the United Kingdom as they recalled their encounters with the young carer label for the first time. This chapter discussed their feelings of discovery as the term young carer provided them with a language to describe their contributions to their family. This research study found that young adult carers did not view their contributions to their family as care, but rather as a function of their membership in a family. The expectations of duty to one's family and reciprocity in care played a significant role in the rationale of young adult carers who decline to perceive as their actions as care. The young carer identity was a new identity given by another individual, typically a social care professional. It is clear that young adult carers understand that they are significantly helping their families, but they think about provision of aid as a fulfillment of their familial role. In addition, some young adult

carers reported that during their childhoods, they believed that their family life was “normal” in comparison to the lives of their non-caregiving peers. Therefore, they were not aware of the uniqueness of their role as young carers until they were identified by another individual. Their age, coupled with their perceived maturity level and competency in handling the challenges in their home life also served as a barrier for them receiving official identification. In sum, the interviews with young adult carers across the United Kingdom reveal that despite ongoing efforts from the social care sector to identify young carers, there is still work to be done on reaching young people whose caring roles remain hidden from view. To better target more young people with caring roles, I suggest that formal support services should utilize the proximity of the young carers’ families for identification. As the care recipient engages with health and social care professionals on their needs, inquiries could be made to the care recipient on whether their child has a caring role in their home. Implications for improved practice will be further discussed in the Conclusion Chapter.

I suggest that once young adult carers are presented with the young carer label, they must then decide whether to adopt and associate themselves with the young carer identity. In this research study, most young people chose to readily accept the label of young carer. The label of young adult carer had a specific benefit of indicating their maturity level as legal adults, while also demonstrating their continued need for support as a young person transitioning into adulthood. Many felt that the young carer label was beneficial, as it often prompted the opportunity to receive an assessment for a formal support service. The label of young carer provided them with recognition of their caring role and many felt that the label entitled them to formal support. Nevertheless, the reality facing most young adult carers in the United Kingdom is that they will not be officially identified at any time during their youth. This was the experience for some of the young adult carers in this research study. Some reported that they should have been identified because social care services were already involved with other members of their family. Others reported that they were overlooked by teachers and school staff even when displaying visible signs of young caring. I assert that there is a potential for narrow definitions of young caring to hinder young people from the receipt of official identification and therefore, leading to the denial of formal support.

Next, the findings revealed that young people may partially accept the young carer identity out of concern for negative consequences, like bullying and discrimination in connection to their caring role. There were numerous reports of courtesy stigma for the young adult carers in this research study. I argue that the label of young carer itself may carry stigma and this may discourage young people for associating with it. Because of the experience of stigma, many young adult carers engaged in what I called “code-switching”. They carefully selected the language they used to talk about their caring role with non-caring individuals, choosing more informal words to describe their support to their families. They often avoided using the young carer label with those unfamiliar with the experience of young caring. Many felt that they could only use carer-related language in the presence of other young carers or while attending a young carers project. I argue that it may be problematic for young people to have to adopt an identity to receive a formal support service that they may not identify with, or conversely, may unintentionally cause them harm.

In the final consideration of a young carer identity framework, I discussed young adult carers who did not identify as young carers yet were in receipt of a young carers service. As with many other young adult carers, some felt that care was enveloped in their sense of family membership and therefore the young carer label felt unnecessary. They preferred language that alluded to their familial role, such as child, sibling, or grandchild, as they felt that they did not need special recognition for doing the tasks that they expected family members to do. For others, they did not identify as young carers because the act of caring had blended into their perception of everyday life; it had ceased to feel distinctive. Care had become normalized because they had provided care for many years. The last case presented the experience of a young adult carer who felt that the young carer identity did not define his overall sense of self. This young person avoided associating with the young carer label because he did not want to be confined into the young carer identity.

Finally, I presented a special section on the conceptualization of young caring by sibling young adult carers. This research study found that young adult carers providing care for siblings were less likely to be engaged in a formal support service. Sibling young adult carers often split care responsibilities with their parents, and therefore, their parents were seen as the sole carer and the persons in need of formal support. The parents’ receipt of formal support reinforced

notions that the young people in this research study were not carers. Sibling young adult carers also found it difficult to distinguish actions of care as a *carer* and actions that would be typically performed within a sibling relationship. In addition, I suggest that the type of care they provided hindered their identification as carers, as they provided significant emotional care. Emotional support often felt like typical sibling behavior to the sibling young adult carers. Finally, I argue those most likely to identify as carers are those who are aiding their families as the primary, sole carers and those who are caring for multiple family members.

In the following chapter I will turn to the identification process for young adult caregivers in the United States, drawing comparisons where possible to the findings on young adult carers presented in this chapter.

CHAPTER SIX: IDENTIFICATION WITH THE YOUNG CAREGIVER IDENTITY IN THE UNITED STATES

6.1. INTRODUCTION

This chapter explores the experience of young people with caregiving responsibilities in the United States with the identification of the young caregiver identity. In the previous chapter, I discussed the ways young people in the United Kingdom may come to identify as carers, young carers, and young adult carers. The moment a young person is first identified as a young carer, called the “official identification moment” in this thesis, was revealed to possess critical importance to young people. The young carer label and subsequent ‘young carer identity’ was a new discovery to nearly all of the participants in the United Kingdom; before their official identification moment, their caring role was encased into their understanding of their familial role. I primarily focused on their decision process to associate with the socially constructed young carer label and the ramifications of their decision upon their ability to receive formal support for their caring role. As this research study is comparative in scope, this chapter will now examine the identification experiences of young adult caregivers in the United States.

As I discussed in the literature review, the first issue of note in a consideration of young caregiver identification is the absence of an agreed-upon language to refer to young caring in the United States. The experience of young caring is rarely addressed in public spheres, and there is a vast gap in knowledge about the prevalence, needs, and experiences of young adult caregivers in the United States. Indeed, even as a small-scale exploratory study, this research stands as the largest qualitative study of young adult caregivers in the United States to have yet be conducted. As discussed in the Methodology chapter, a significant barrier to the recruitment of participants for this research study was the lack of commonly accepted language to characterize young caring in the United States. The absence of care-related language also had a significant influence upon the identification moment for young adult caregivers in this research study. The sheer “newness” of the young caregiver label meant that participants were often contemplating a newly discovered understanding of their family contributions for the first time during the research interview. Therefore, some of the themes discussed with young adult carers in the United Kingdom did not arise with the young adult caregivers in the United States, namely, the

potentially negative effects of an association with the young caregiver label, i.e., bullying and courtesy stigma. This does not mean that bullying and courtesy stigma in connection with one's caring role is not a part of the young caring experience in the United States—it likely is, however, I suggest that the composition of the United States sample may contribute to the difference in findings. The participants in the United States sample tended to share caregiving responsibilities with another family member, and specifically there was a slight skew towards a higher proportion of participants providing care for siblings and grandparents. In contrast, a higher proportion of the young adult carers in the United Kingdom were caring for parents and served as the primary carer. Some of the more detrimental effects from young caring—chronic tardiness and absences from school—were reported more frequently in the United Kingdom sample. Therefore, it may mean that the more visible adverse effects of young caring, particularly those that may provoke bullying in school, found in the United Kingdom sample may help to explain why there were differences in the treatment of young adult carers and caregivers across the respective countries. In addition, there was also a patent difference in the two country samples with regards to sheer brevity of perspective during the research interview. This will be discussed in greater detail in Section 6.2. There was a greater level of content shared by the young adult carers in the United Kingdom in relation to the identification process in the research interview. I suggest this difference can be explained by the comfortableness and familiarity possessed by the young adult carers in discussing their caring role, whereas a dialogue on young caring was a new experience for nearly all of the young adult caregivers in this research study. With an understanding of the contextual differences in an examination of a young caregiver label, I shall now proceed to an exploration of the official identification moment for young adult caregivers.

6.2. IDENTIFYING AS A YOUNG ADULT CAREGIVER

How did the identification process occur for the young adult caregivers in the United States sample of this research study? Firstly, the majority of the sample had never identified as a caregiver before, so therefore, their recognition as a caregiver was relatively recent. Of these, some had been identified by gatekeepers to this research study and they had not previously considered themselves as caregivers.

“I hadn’t thought of myself as a caregiver until [a mutual friend] told me about your research study. She said that I would fit, since I moved in to take care of my grandma. This is the first time anyone has ever asked me about my life, taking care of her. Nobody ever has ever asked me about me.”

Michelle, 22, Nashville, Tennessee, United States. Cares for grandmother with intestinal problems

Michelle’s statement illustrates a common experience for the majority of the interviewees in this research study: they were unfamiliar with the young adult caregiver identity until their participation in this research. They had not thought of their family contributions as caregiving, nor had they ever associated with the label of caregiver. Similar to the majority of the young adult carers in the United Kingdom sample of this research study, most of the interviewees’ first introduction to the identity of young adult caregiver took place when an external individual told them that their activities within their family could be classified as caregiving. However, the participants in the United Kingdom reported that they were first identified as carers during their childhood years, or at the very latest, during their late adolescence. By the time of their participation in this research interview, they had associated with the young carer identity in various capacities for several years. This is in contrast to the experience of most of the young adult caregivers in the United States sample; their consideration of themselves as caregivers had only occurred a few days to mere hours before the research interview. Thus, their reflection on their young caregiver identification took place in early adulthood, which is late in life compared to the United Kingdom sample. In the previous chapter, I asserted that the receipt of a formal support service in connection to one’s caring role likely serves as a significant factor in the development of one’s identification as a young carer or young adult carer, as well as one’s overall sense of identity. Because the majority of the participants in the United States did not receive a formal support service in connection with their caring role, I am unable to make a strong assertion regarding any potential differences in the experience of those who were introduced to the young carer/caregiver identity earlier in life in comparison to those who were introduced to the young carer/caregiver identity relatively recently. The receipt of a formal support service in connection with one’s caring role, in addition to the age that official

identification occurs may be significant mitigating factors in the determination of the strength of one's association with the young carer/caregiver identity. To feel confident in distinguishing any potential significance, I suggest that future research with young caregivers in the United States should endeavor to recruit more individuals who were identified as caregivers early in life, preferably early to mid-childhood. At this juncture, I surmise that an official identification during childhood years may allow for more time for a young caregiver identity to be deeply rooted into one's overall sense of identity, especially if identification is coupled with the receipt of a formal support service in connection with one's caring responsibilities.

Michelle also stated that this research interview was the first time that anyone had inquired about her caring role in her family. Nearly all of the other participants in the United States sample reported that they shared her experience; this study was notably the first time they were provided the opportunity to voice their perspective about their caregiving responsibilities. The small number of participants who had engaged in some sort of formal support service, e.g., involvement in the AACY, were excluded from this finding. This was in contrast to the participants in the United Kingdom sample, who reported that the research interview was not the first time that they had spoken to someone about their caring role. Many, in fact, considered themselves well-versed in discussing their caring role in various settings with various audiences, e.g., in school, at work, with social care professionals, and with other young carers. In reflecting upon the interview responses of the participants in the United States, firstly, it is critical to recognize that the research interview itself possessed great importance to their self-perceptions as caregivers. Their involvement in this research study represented the first time they were recognized as caregivers, as well as the first time that anyone had inquired of their caring role in their families. It is here that I recall Olson's (2017) statement on the use of the term "youth caregiver" as an "impossible anachronism" in the context of the United States; the notion that young people do not 'care' has rendered young caregiving invisible in the United States. Secondly, I suggest that the relative "newness" of their consideration of their family contributions as caregiving may have influenced the nature of their responses during the interview. Overall, I found that the young adult caregivers in the United States sample of this research study expressed more responses of "I don't know" or "I'm not sure" when asked about their identification as a young caregiver or young adult caregiver, in comparison to their counterparts in the United Kingdom. The brevity and uncertainty found in their responses will be

evident in this chapter; the content presented in this chapter will be of less magnitude than the previous chapter featuring the responses of the young adult carers in the United Kingdom. I believe that their brevity and uncertainty can be attributed to the different “context” of the yet-to-be socially constructed young caregiver identity in the United States. The experience of young caregiving and the various characteristics encompassing the young caregiver identity is not a part of the public discourse in the United States. There is an absence of research, policy, supportive organizations and interventions specifically related to young caregivers. This is the context that the young adult caregivers in this research study live their daily lives providing care for their families. A consideration of a young caregiver label, and subsequent conceptualization of a young caregiver identity is relatively new within the context of the United States, and therefore, it was also new for the participants in this research study.

A very small number of the United States participants (around 10%) had previously self-identified as a caregiver, usually through their own awareness of the characteristics of caregiving, and of these, the majority reported that their paid employment in the health and social care sector had reinforced the notion that they were caregivers. The statements from Angela and Savannah demonstrate that it is possible for young adult caregivers in the United States to self-identify as caregivers, despite the lack of public discourse on young caregiving:

“Yeah, I mean, I’ve known what I’ve been doing is caregiving. Nobody had to tell me. I’m the only one taking care of her, and the only one in my family willing to take care of her. So it’s kinda obvious...I saw your flyer on an Alzheimer’s list I’m on. I saw it and was like, ‘yep, that’s me. I’m a young adult caregiver’. And no, no one has ever talked to me about being a caregiver before. No one.”

Angela, 25, Silver Springs, Maryland, United States. Cares for mother with late stage early onset Alzheimer’s disease

Angela voiced that she understood she was acting as the caregiver for her mother. Because she served as the sole person providing care, this solidified her belief that she was a caregiver. She discovered a flyer for this research study through her connection with a local Alzheimer’s disease non-profit organization email list-serve, noting that when she saw the flyer,

she immediately recognized herself as fitting the criteria for “young adult caregiver”. A copy of the flyer used to advertise this research study can be found in Appendix. Like most of the other United States participants, Angela had never spoken to anyone about her role as a caregiver until her participation in this research study. The following statement from Savannah illustrates the experience of a young adult caregiver who reported an “instinctive” understanding of herself as a caregiver:

“I knew I was a caregiver. That’s what I’m doing, taking care of my husband and children. I don’t go home too often but when I do, I help with our grandfather as he’s near end of life. So I think I just instinctively knew I was a caregiver. And plus, my work is with other military caregivers. I’m surrounded by caregiving!”

Savannah, 25, Boston, Massachusetts, United States. Cares for husband with traumatic brain injury, hearing and vision loss, sleep apnea, post-traumatic stress disorder, knee pain, and epileptic seizures and three daughters with normal development

Savannah reported that she “instinctively” knew that she was a caregiver. Her awareness that she provides assistance to her husband and children, and occasionally grandfather, led her to understand herself as a caregiver. Her self-perception as a caregiver was further reinforced by her paid employment working as an advocate for military caregivers—she considered herself to be a military caregiver, as well. Her husband was a military veteran and sustained injuries during his service in the Iraq War. As she was her husband’s sole caregiver and he was a veteran of the military, she often referred to herself as a “military caregiver” during her interview.

Savannah and Angela both became caregivers during their early twenties. I suggest that the sudden uptake in caregiving served to influence their self-perception as caregivers. Those who have been providing care since early childhood may not feel that their caregiving role feels distinctive and separable from their understanding of normality. This can be observed in the discussion of young adult carer Suzanne in the previous chapter (Section 5.2.1); she had provided care for many years and care was normalized for her. In contrast to Savannah and Angela, Suzanne did not self-identify as a young carer until she was officially identified by someone else. Drawing from these cross-country experiences, it may be true that an unexpected start into caregiving, such as a diagnosis of early-onset Alzheimer’s disease or injuries sustained

in military conflict, may aid a young person to identify more readily as a caregiver. Identification by another individual, typically through formal support remains the principal way a young person comes to identify as a young caregiver. The remaining participants in the sample had been identified through their engagement with the American Association of Caregiving Youth in South Florida:

“[AACY] is how I came to know that I was a caregiving youth. They came to my school and I remember filling out this form, it asked questions about what kind of things I did at home for my family. I guess I qualified cause here I am!”

Mitchell, 19, Lantana, Florida, United States. Cares for mother with schizophrenia and partial vision loss

Mitchell demonstrates the role of a formal support service in identification for a young caregiver. He used the term “caregiving youth” promoted by the AACY to describe a young person under the legal age of 18 providing unpaid care for a family member. His story of identification reflects the experience of the young adult carers in the United Kingdom sample of this research study who were identified by a social care professional and began involvement with a young carers project. Like many others, he did not understand his family contributions as care until an assessment from a social care professional. Mitchell and the four other participants identified by the AACY represent the extremely small minority of young caregivers in the United States who are identified by a young caregiver dedicated formal support service. We also observe in Mitchell’s excerpt the significance of ‘doing’ in the formation of an identity. To assess whether or not he was a young caregiver, he was asked what he *did*. Those activities help shape the notion of a young caregiver identity; this is what young caregivers do. Again, we see the usefulness of the concept of performed identity, as we reflect on how young people can embody the identity of young caregiver through their actions.

In addition, one participant was previously identified through her work supervisor:

“When I was very young, I don’t think I knew that it was a caring act, I was just kinda doing what needed to be done... I really hadn’t identified myself as a caregiver, so in that conversation

at the gym [with her current boss], she helped me self-identify to say wow that's actually what I did. That's part of who I am."

Jennifer, 21, Seaside, New Jersey, United States. Cared for father with alcoholism and liver and colon cancer [deceased]

Jennifer's statement echoes the experience of most young caregivers: when care provision begins in early childhood, young people may not understand their responsibilities as care. While exercising at her local gym, Jennifer's now current work supervisor heard her family story and pointed out to her that she was a caregiver. Jennifer's work supervisor was employed by a caregiver advocacy non-profit organization, thus she was familiar with the characteristics of caregiving. Jennifer's identification with the young caregiver identity arose through her contact with an individual who possessed an awareness of caregiving. This identification did not prompt the receipt of any formal support services in connection to her caring role, recalling the experience of young adult carers in the previous chapter (Section 5.3.4) in which young caring may not always elicit formal support, even when in contact of those who are aware of young caring. Nevertheless, Jennifer's identification with the young caregiver identity led her to recognize that caregiving was a part of her overall sense of identity. Similar to our discussion on Mitchell, 'doing' care led to the development of a part of her overall identity.

This section addressed the ways young adult caregivers experienced their first encounter with the young caregiver identity. For most of the United States participants, their introduction to the label of young caregiver was relatively recent, and for some, their introduction took place through the gatekeepers to this research study. The majority of the participants also reported that this research interview was the first time that someone had specifically inquired about their caring role in their families. Only 10% of the participants reported that they self-identified as caregivers. I suggest that unexpected and sudden uptakes in care provision, like what may occur with accidents, injuries, or new health diagnoses may prompt self-identification. Finally, the involvement of a formal support service for young caregivers led a small number of the United States sample to identify as caregivers. It is understood that young people may identify with the young caregiver identity in theory, yet they may not use the young caregiver label in practice, highlighting once more that labels are necessarily interchangeable with identity. The following

section will explore the perspectives of young people and their choice to accept or reject the young caregiver label.

6.3. USING THE YOUNG ADULT CAREGIVER LABEL

The United States participants in this research study were also asked if they would use the label of young adult caregiver to describe their caring role. This also included other related words such as “caregiver”, “young adult caregiver”, “young caregiver”, or “caregiving youth”. The research interviews revealed that young people believe the care-related terms accurately describe them, yet they do not frequently use those words in practice. Instead, the participants use action words to discuss their caring experiences, like “looking after”. They also frequently referred to their presence with their care recipient as an allusion to their care provision: for example, the phrase “when I am with my mother” was used to describe the times a young person would provide care to their mother. Conversely, participants in the United Kingdom also used action words to describe their caring role, but they also used care-related words, including “carer” and “young carer” regularly. This discrepancy can be explained through an understanding that the United Kingdom has a greater public representation of carers, and in addition, the majority of the United Kingdom participants were in receipt of a young carers support service, allowing care-related terminology to feel more familiar. Thus, it is unsurprising that the respondents in the United States sample were less likely to speak about their experiences using care-related language. An understanding that the participants in the United States may express their caring role differently than their counterparts in the United Kingdom will guide the rest of our reflection. In the following excerpts, I will present the responses to the question “Do you call yourself a caregiver or young adult caregiver?”. The notion of family centrality was a commonly reported rationale for their self-description as a caregiver:

“I always describe myself as a mom and a caregiver, because I’m always caring for someone. Family is so important to me.”

Heidi, 23, Minneapolis, Minnesota, United States. Cares for husband who is a triple amputee and two sons with normal development

Young adult caregiver Heidi provided care for her husband who had undergone the amputation of both legs and an arm because of injuries sustained during his military service in the Afghanistan War. She also noted that she provides care for their two sons who are healthy with normal development. Heidi voiced that she identified as both a mother and a caregiver, indicating that she distinguishes her caring responsibilities for her husband and children. Care for her healthy children may feel normative and representative of the type of behavior typically undertaken by a mother. Her use of the word “caregiver” to describe her spousal caring role suggests that providing care for the needs of her husband may warrant an additional descriptor than simply “wife”, “partner”, or “spouse”. Like other young adult caregivers, she stated the centrality of her family. The maintenance of her family’s well-being through her care provision is the defining feature of her life.

“I would definitely describe myself as a caregiver. I care for my family, I care for my friends, I care for the environment. And I care for my dog and hamster.”

Robert, 21, West Palm Beach, Florida, United States. Cares for sister with asthma and
close friend with leg pain

The statements from Heidi and Robert demonstrate that the act of care can feel all-encompassing as they consider the various people in their lives for whom they provide care. Much of this research has focused on young people’s experiences providing care for ill or disabled family members, yet the responses in this study indicate that a broad, inclusive approach to care is needed. I suggest that there are a variety of ways young people may provide care. Providing care to friends, caring for healthy children, and caring for the natural world can help to conceptualize the young caring experience, in addition to their care provision for family members with health conditions. A more holistic understanding of care can also aid us in having a more complete picture of the care responsibilities of a young adult carer/caregiver. Notably, many of the respondents in the United Kingdom sample and the United States sample chose to include their pets when asked to name those in their family for whom they provide care. My choice to exclude the mention the participants’ family pets was not meant to indicate a devaluation of the pets in this consideration of the influence of caregiving upon identification and identity. On the contrary, as many had several pets in their family home, I chose not to

include the listings of family pets in the Methodology chapter to maximize the limited space available in the thesis. Previous research has established the deep bonds that children and young people may have to animals in the family home, to the extent that they include pets in their consideration of family composition (Cain, 1983; Mallon, 1992). Research with young carers in England has found that young carers may include their pets into their description of their family, and they describe that taking care of their pets is a part of their overall caring responsibilities (Aldridge & Sharpe, 2007). Therefore, it is unsurprising that young people in this research study consider their care for family pets as a part of their understanding of their identity as young carers/caregivers. The interconnectedness of young people to living things in their world, both human and animal, can influence their identification as carers and caregivers.

Young people with caregiving responsibilities may find that the language of “young adult caregiver” may be too formal for practical, everyday usage. Brooklyn provides an example a young person who identified with the term of young adult caregiver yet preferred not to use the term in its fullness:

“I guess young adult caregiver is the best word for it, it kind of sums it up actually, you’re a young adult giving care. But I would probably just say ‘I’m a caregiver to my grandma and my dad or my family’. I don’t know if would say “young adult”, just a “caregiver”. The entire phrase together sounds a bit much, too formal for me. At [AACY], we said caregiving youth”

Brooklyn, 20, Boca Raton, Florida, United States. Cares for grandmother with heart disease and father with paralysis from stroke

Brooklyn felt that the term young adult caregiver was an accurate description of herself; she is a young adult and she provides care. However, she noted that she would likely not use the entire phrase, preferring instead to simply state that she is a “caregiver”. The formality of the term young adult caregiver led her to use the shortened word of caregiver. In the previous chapter (Section 5.3.6), I asserted that young adults with caregiving responsibilities may engage in a form of linguistic code-switching by carefully selecting when to use the label of young adult carer. Brooklyn alluded that she may choose to use the word caregiver in certain settings, but noted that during her participation with the AACY, she would use the phrase “caregiving youth”. This phrase, “caregiving youth”, is the preferred word of choice with the AACY. Because the

term “caregiving youth” is meant to describe those under the age of 18, it is understandable that Brooklyn and other young adult caregivers may decline to use that term once they reach the age of legal adulthood; they may prefer to use a term that indicates their increasing maturity. However, most young adult carers in the United Kingdom sample tended to use “young carer” interchangeably, with an observable frequency in the usage of “young carer”. I argued that this was because they were typically identified as young carers during childhood, and they also began participation in young carers projects in childhood. Some social care professionals and project workers may also include 18-24 year olds into their description of young carers. Thus, young adult carers in the United Kingdom may have the language of young carer imprinted on their mind to use since childhood. Conversely, the United States lacks a strong foundational context for any care-related term for young people with caregiving responsibilities. Recalling that United States participants were less likely to use care-related language during the course of the interview, when they did use care-related language, the word “caregiver” was the most frequently used. Thus, a nonspecific word like “caregiver” may feel more accessible amongst young adult caregivers in the United States.

Of the young adult caregivers providing care for parents or grandparents, only one individual responded that they rejected the label of young adult caregiver. Some of those providing care for siblings did express uncertainty using care-related terminology. I include his statement to present the reminder that it is possible that young adult caregivers may feel tension using care-related labels, and commonly accepted language may not feel accurate to all:

“As a child, if someone has called me a ‘young adult caregiver’, I would have looked at them like they were crazy. I kinda don’t like the term ‘caregiver’. I like ‘teammate’—it’s a different term, but that’s kinda the way it is. Whenever you’re caring for someone with a disability or illness, it’s not me just doing stuff for them. It’s always dual sided. There’s stuff that I get out of helping her and there’s stuff that she obviously gets out of me helping her. It’s not a one-sided, me just giving and giving. It’s for sure, anything I give, I get 10-fold back. I think ‘caregiver’ gives it more of a sense that I have to do something out of obligation, because it’s my parents. ‘Teammate’—cause it is. If the person you’re caring for isn’t compliant, then nothing you do is of any significance. But if you’re working together for their goals and what they need. That’s kind of a teammate relationship. You’re working towards one goal to get them better.”

Ethan, 18, Cleveland, Tennessee. Cares for his mother with fibromyalgia, lupus, arthritis, and father with multiple sclerosis

Ethan felt that the language of “young adult caregiver” or “caregiver” did not correctly describe his experience of young caring. He preferred the term “teammate” because he believed that he and his parents were working together to accomplish their care needs. He also expressed that his chosen word of “teammate” indicated the mutuality of care between he and his parents. Previous research has found that young people with caring roles often report that love and close family bonds are the benefits of young caring (Becker & Becker, 2008). Ethan was clear that care-related language implied a sense of obligation to him that he felt did not accurately depict his sentiments towards his parents. In the previous chapter (Section 4.2.2), I have referred to the felt obligation and duty that young people with caring responsibilities may feel towards their family members. I asserted that feelings of obligation may cause young people to decline to identify as carers because their caring role is “masked” by their familial role. The case of Ethan presents an alternative view: it may also be true that young people will not identify as caregivers because caregiving is “masked” by the notions of mutuality of care found in the ethics of care approach. The sentiment that blurs the line between caregiver and care recipient may also invalidate language suggesting that caregiving is a distinct identity. As Ethan was the only young person in this research to issue such a statement, future research is needed to establish whether mutuality of care can influence the identification process of young people with caregiving roles.

This section examined the ways young people with caregiving responsibilities in the United States consider using the label of young adult caregiver. Overwhelmingly, the participants reported that they would describe themselves as caregivers. Of the young people providing care to parents and grandparents, only one participant in the United States reported that he would not describe himself as a caregiver, preferring instead to label himself as a “teammate”. This young person emphasized the notion of mutual care between he and his parents to explain his position. For others, their families also remained central in their lives, but their sense of family centrality led them to consider themselves to be caregivers. In addition, the young adult caregivers promoted an inclusive conceptualization of care by including their friends, family pets, and the environment into their self-awareness as caregivers. At this juncture,

I will now discuss the young adult caregivers' perspectives on the value of the young caregiver identity.

6.4. UNDERSTANDING THE VALUE OF THE YOUNG CAREGIVER IDENTITY

To be clear, most young people in the United States will not be told by another individual that they are young caregivers. This is due to the general lack of public consciousness about young caring within the United States. There is a greater likelihood for young people to be identified as young carers in the United Kingdom, although it is also true that most young people in the United Kingdom will not be identified or assessed for a formal support service. The hidden nature of young caring remains pervasive throughout both the United States and United Kingdom. Within the United Kingdom, it is possible that young people may self-identify, however, most young carers' experience of "so that's how I knew I was a young carer" typically occurred through the intervention of a social care professional. It became clear that the primary function of identification is to prompt assessment for formal support. This differs drastically in the United States, as the majority of health and social care professionals will not recognize the signs of young caring because of an endemic lack of awareness. There is also a scarcity of formal support available, specifically dedicated to supporting young caregivers. When the young adult caregivers in this research study were informed of the stark contrasts in recognition and formal support for young caregivers between the United Kingdom and United States, they expressed feelings of anger and offense. Their recognition of their state as young adult caregivers in the United States led some to question if the young caregiver identity possesses meaning and value for their lives. This section will discuss their perspectives and reflections on the implications of the young caregiver identity.

While a discussion of the stark contrasts of the public representation of young caring in the United Kingdom was not an explicitly designed (nor intended) part of the research interview with participants in the United States, the interviewees often inquired about the state of young caring in the United Kingdom either before or at the end of the formal research interview. I chose to respond to their questions at the end of their formal interview (rather than at the start) and emphasized that I was principally interested in hearing their views about their lives in the United States and valued their opinions on their experiences as a caregiver. I acted this way firstly to

honor the agreed upon time commitment to the research interview; as a part of the informed consent process, I stated that my interview questions were designed to take no more than an hour of their time. Secondly, many of the participants were curious about my life as a former young caregiver and my experiences living in England. To avoid focusing the research interview on my personal story, I responded that I would be happy to share details about my young caregiving experience and life in England after the completion of the formal research interview. A more detailed reflection on my efforts to center their caregiving experiences during the research interview was previously discussed in the Methodology chapter. The participants wanted to know what life was like for young carers in the United Kingdom, and they were specifically interested in learning about the supportive resources available for young carers. I explained that most young carers were not receipt of a formal support service in connection to their caring role, yet that once a young carer was formally identified, their identification often led to an assessment to receive formal support. I also explained about the various means of formal support for young carers and young adult carers available in some local areas, including young carer/young adult carers projects, the carer's allowance, and bursaries to help attend college and university. The interviewees in the United States expressed visible shock, anger, and confusion that the United States was so far behind in the development of public awareness, policy, and supportive services for young people with caring roles. Many felt that it was unfair that young caring in the United Kingdom was met with greater recognition and support than what was offered in the United States. I present some of their statements here with their consent:

"I'm actually upset listening to you tell me about England. Wow. I didn't even know I could have support."

Brielle, 23, Washington D.C., United States. Cares for father with stroke complications

Brielle stated that she did not realize that it was possible for young people to have support in connection to their caring role. Hearing the availability of formal support in England and elsewhere in the United Kingdom angered her, as she was not aware that young caring could be supported—the idea of formal support for caregiving was a new discovery. For nearly all of the young adult caregivers interviewed in this research study, learning of the formal support developed in the United Kingdom for young carers was a new discovery. A small number of

interviewees who had received support services from the American Association of Caregiving Youth in Florida were minimally aware that their counterparts in the United Kingdom were often entitled to formal support, but they were largely unaware of what kind of support was available. Generally however, it was a novel concept that children and young people could receive support for their caregiving responsibilities. Providing unpaid care for their families without direct assistance, aid, or support was seen as an expected way of life. The reality that caregiving could elicit practical, financial support was often surprising to them:

“Like, they can get a scholarship [to go to university] just because they are caregivers? Do you know how much I needed help to go to college? Man, we need that!”

Logan, 21, Boston, Massachusetts, United States. Cares for grandmother with dementia and younger brother with Down Syndrome

Logan expressed surprise to learn of bursaries such as the 16-19 bursary in England or bursaries at some universities specifically for young adult carers. He reported that he needed financial help to attend university and a bursary would have been greatly beneficial. While Logan and other young adult caregivers were unaware of the various eligibility criteria in place to award young adult carers in the United Kingdom with bursaries, they were astonished to learn that young people could receive financial assistance for education “just because” an individual possessed a family caring role. To those young adult caregivers, it was a revelation that caregiving could be recognized to such an extent to prompt financial help. Similarly, young adult caregivers were also surprised to learn that it was possible for national laws regarding children with caregiving roles to exist:

“So there’s laws about kids who are caregivers? Like to make sure they can get help? Good for them, but damn. What about us? Can we get some help?”

Joel, 20, Greenacres, Florida, United States. Cares for mother with Bipolar disorder and migraines

Informing Joel and other young adult caregivers about the Care Act 2014 in England and of the legal duty extended to local authorities to identify and assess young carers for formal

support was also met with astonishment. Currently in the United States, there is an absence of legislation, on both state and national levels that specifically address children or young adults with family caregiving roles. If children seek formal support, such as the help of a social worker, social services involvement generally raises inquiries of parental neglect or abuse. Concerns of parental neglect may still occur in the United Kingdom, particularly amongst adult social care professionals who are under-educated about the experience of young caring. However, the advancement of laws such as the Children and Families Act 2014 and the Care Act 2014 in England, the Carers (Scotland) Act 2016 in Scotland, the Children Order 1995 and Carers and Direct Payments Act (Northern Ireland) 2002 in Northern Ireland, and the Social Services and Well-being (Wales) Act in Wales have been put in place to better ensure children are recognized correctly for their caring roles. Upon the revelation that the supportive policy exists in various forms in the United Kingdom, the interviewees in the United States sample of this research study believed that they should be entitled to the same level of recognition within governmental policy.

Nearly all of the participants were also largely unaware of the prevalence of young caring in the United States. When I informed them at the end of the research interview of the estimated millions of children and young adults providing care in the United States, the participants expressed amazement that the figures of young caring in the United States could be that large. For the majority of the young adult caregivers interviewed in this study, I was the first young caregiver they had the opportunity to meet, at least to their knowledge. They described that the revelatory knowledge of millions of other young adult caregivers in the United States served to help them feel less abnormal in their caring role.

“I mean, it’s nice knowing that I’m not alone. You kinda go around thinking that you’re the only one. I would have never known that there were so many other people looking after their parents, or grandparents, or whatever—until you told me. It’s kinda like whoa, you know? It’s just not a thing that’s ever talked about.”

Ethan, 18, Cleveland, Tennessee. Cares for his mother with fibromyalgia, lupus, arthritis,
and father with multiple sclerosis

The statement from Ethan further demonstrates the hidden nature of young caregiving in the United States. Like most of the other young adult caregivers participating in this study, this

research interview was the first time that anyone had ever asked him about his family contributions, particularly through an acknowledgement of his contributions as care. As Ethan indicated, young caring is not a subject that is discussed widely in the United States, and there is a sheer absence of a public representation of young caregivers. This provides rationale for his gratitude in knowing that he was not alone as a young adult caregiver. At the end of the research interview, I informed Ethan of the prevalence of young caregivers. If I had not done so, Ethan would have been unaware that other young people in the United States possessed caregiving responsibilities to their families. He and other young adult caregivers expressed that it was beneficial to know that other young adult caregivers existed, as it may help them feel like less of an oddity:

“Yeah, I had kinda heard that there was more stuff to help people like me in other countries, like I had Googled one time and all this stuff came up in Australia. But I didn’t know that there was so many of us in America. Young adult caregivers, I mean. If it wasn’t for the Caregiving Youth Project, I wouldn’t have met any other caregivers. It is nice knowing you’re not alone, cause you feel so weird all the time, and I think younger caregivers are very isolated. You feel a bit more normal knowing there’s lots of other people like you, your own age. That’s why I had this idea of a YouTube channel or some kind of website to help other caregivers, like doing video blogs about what life is like—it could connect young caregivers across the country and they could feel less alone and less ‘odd man out’.”

Lourdes, 19, Lake Worth, Florida. Cares for mother with mobility issues and grandmother with Alzheimer’s disease

Lourdes had participated in a support service offered by the AACY in her local high school, and her participation allowed her to meet other young caregivers. If not for her participation, she would not have met other young people with caring roles. However, she was unaware that of the high numbers of young adult caregivers in the United States until I disclosed the statistical figures to her at the end of her research interview. As with Ethan and other interviewees, the lack of public representation of young caregiving in the United States has shielded them from the knowledge that other young people with caring roles exist. She and other young adult caregivers voiced that they found comfort in knowing of the existence of other

caregivers of their same age. Lourdes expressed her belief that young caregivers are isolated and may feel “weird” because they are different from their non-caregiving peers. In the research of Kavanaugh, Cho, Maeda, and Swope (2017) with child and young adult caregivers of those with Huntington’s disease in the United States, they found that young caregivers were more likely to report that support groups or respite camps with other young caregivers afforded them to opportunity to meet young people with life experiences similar to their own, allowing them to feel more normal. Furthermore, the young people in the research of Kavanaugh et al. (2017) reported that their attendance at a Huntington’s disease youth camp was deeply meaningful for them, as this was the first time that they had met someone with their comparable life circumstances. I suggest that young caregivers in the United States live in a unique juxtaposition: Despite the high prevalence of young caregiving, they often feel like they have atypical lives as young people because they likely have not been introduced to other young people who are caring for family members with a disability, illness, or another condition requiring care. However, it is possible that they have met someone *living* with a family member with an disability, illness, or condition requiring care, but because the act of care is often embedded into the understanding of a familial role, young people may not be aware that they are interacting with other caregivers. Recalling that earlier research in the United Kingdom established that every child living with someone with a health condition, disability, or substance abuse issue may not become a young carer (Becker, 2007; Becker, Dearden, & Aldridge, 2001), it is also true that young people in the United States may come across others who have a family member with a health condition yet they do not have a caregiving role. This may serve to further isolate a young caregiver, leading them to believe that they truly are the only young person providing care for a family member. However, I suggest that it is more likely that young people providing care in the United States have either never met another a young caregiver, or conversely, they have met a young caregiver but unrealized, because the notions of care are so deeply embedded into the fulfillment of a familial role, i.e., sibling, child, or grandchild. In any instance, it has been established that young caregivers will likely feel isolated and may feel like they are different from their non-caregiving peers. The understanding that young caregiver are socially isolated has been established in earlier research in the United States (Kavanaugh et al., 2017; Kavanaugh, Noh, & Studer, 2015; Kavanaugh, Stamatopoulos, Cohen, & Zhang, 2016). Lourdes stated that a greater awareness and connection with other young caregivers (even through online methods) would help resolve some

of the issues of isolation facing young people with caregiving responsibilities. Thus, I assert that the principal advantage to an awareness of a young caregiver identity—at this present time-- is the revelatory knowledge that young people with caring roles exist in large numbers across the United States. Such knowledge may help young caregivers feel less atypical and isolated within their young caring experience. I note that this is the critical advantage presently, as the development of a young caregiver identity in the United States has not progressed forward enough to include the benefit of the receipt of formal support services and interventions. This is in contrast to the United Kingdom, in which one of the principal benefits to the acceptance of a young carer identity is the possible receipt of formal support. Thus, I suggest that a young caregiver identity possesses more meaning for a young person when an association with the young caregiver identity can elicit supportive interventions. Without supportive services or interventions, the young caregiver identity can lack transformative power.

The following statements from Leah and Andrew provide an example of the sentiment held by some young adult caregivers in this research study: their awareness of the young caregiver identity lacks substantive power to alter their daily lives.

“What do you mean, the US [United States] is about 20-25 years behind the UK [United Kingdom]? It’s funny, cause we think we’re the best at everything, like, lead the world. But whoa, like, this just shows that we don’t. I hadn’t ever thought of myself as a caregiver really until talking to you. And just talking about everything, like shit, I see how everything in my life has been affected. And now, thinking of myself as a caregiver, what does it mean? Like in England, it means something. But it don’t mean nothing here, not really. Like, this means what you’re doing is, like, so important. I’m really proud that I got to be a part of this research you’re doing. Cause it could help really change things here. Put that on the record! I think kids and young adults here need help too!”

Leah, 25, Nashville, Tennessee, United States. Cares for younger sister with cerebral palsy

In this statement, Leah expressed her realization that the association with a young carer identity possesses the ability to make a difference in the life of a young carer in England. She is alluding to the belief that identifying as a young carer could serve as a gateway to accessing

formal support. In contrast, she realized that the young caregiver identity does not possess the same level of recognition in the United States as her caregiving counterparts may experience in the United Kingdom. In the United States, an identification with the young caregiver identity will not prompt an assessment for formal support (excluding those living in the South Florida area in which the AACY is located). For her and other young adult caregivers in this research study in the United States, this was a troubling realization. They believed that the introduction to the existence of a young caregiver identity ceased to impact their lives as caregivers:

“Now that I know young caregivers in England can get support, I’ll be honest—it really does feel like nobody cares about us over here. I can identify as a caregiver, and sure, I do, but what good is that gonna do me? It doesn’t change my life, at least not yet. I walk out of here, my life is still the same. My mom still needs help and she can’t get it, we can’t afford it. If there’s help out there for people like me, I certainly don’t know about it. It’s not advertised. It’s not talked about.”

Andrew, 25, Portsmouth, Virginia, United States. Cares for mother with osteoporosis and
osteoarthritis

Like the previous statement from Leah, Andrew voiced concerns that the identification as a young caregiver would not significantly influence his life. He acknowledged that he did identify as a caregiver for his mother, yet he felt that his identification would not prompt any help for his mother nor for himself. Alluding to the lack of public discourse on young caregiving, Andrew stated that he had not been made unaware of any formal support to aid young adult caregivers. For Andrew and some of the other young adult caregivers in this research study, the reality that their identification as caregivers would not garner support demonstrated that the young caregiver identity had minimal benefit. Therefore, I argue that some young adult caregivers may find that an adoption of the young caregiver identity is valuable for their emotional well-being and overall sense of identity. Conversely, other young adult caregivers may recognize that the awareness of a young caregiver identity may provide some emotional benefits, yet believe that the identity has little value since it does not significantly alter their lives. To be clear, I use the phrase “significantly alter their lives” to allude to the receipt of formal support services. It is likely true that a self-awareness of one’s identity as a young caregiver may provide

such emotional benefits for a young person to feel that their life has been significantly changed. However, my usage of “significantly alter” follows the perspective of the young adult caregivers interviewed, as some felt that the discovery of a young caregiver identity would not provide practical support for them or their families. The perception towards the value of the young adult caregiver identity is critical because young people may be less willing to identify as caregivers if they believe the label will not greatly benefit their lives. Understanding that most young adult caregivers in the United States would have been engaged in caregiving roles for several years before they self-identify or receive identification by another individual (if it happens at all), it follows that such young people may find an identification with the young caregiver identity does not massively change their caregiving lives and is simply an unnecessary identity to adopt.

This section provided an overview of the ways young people may determine the value of the young caregiver identity. The most notable finding presented in this section is the acknowledgement that young adult caregivers in the United States may believe that an association with the young caregiver identity may be of little value to their lives. Some young adult caregivers expressed this belief because they recognized that the young caregiver identity does not typically elicit the opportunity to receive formal support in connection with their caring role. This understanding arose out of the young adult caregivers’ inquiries about the young caring experience in the United Kingdom during the research interview. Once they were made aware of the prevalence of young caregivers in the United States and the increasing number of formal support services and interventions for young carers in the United Kingdom, they felt markedly angry and resentful. This awareness led some of the young adult caregivers to express that they believed the young caregiver identity possessed minimal value as it did not greatly alter their lives or the lives of their families. They reported a strong desire for practical, formal support and it remained clear to them that their status as young adult caregivers in the United States would not afford them the opportunity to receive significant aid. However, they did report that knowledge of the young caregiver identity had the positive effect of diminishing their sense of isolation as young people with caring roles, as well as helping to foster their sense of normalcy. These emotional benefits, while important, may not be enough for some to place great value on an adoption of the young caregiver identity.

The following section will feature the young adult caregiver identification process for young adults providing care for siblings. As presented in the previous chapter (section 4.4.), the

experiences of young adults providing care for siblings appeared to indicate that sibling young adult carers/caregivers may generally conceptualize their identification differently than those caring for parents or grandparents. A significant number of the United States sample provided care for siblings, heightening the need for a critical reflection on their experience

6.5.1 INTRODUCTION: THE SIBLING PERSPECTIVE ON YOUNG CARING

Our understanding of young caring in the United States remains rather limited and neglected in research. This is particularly true for young people providing care for siblings. Aronson (2009, p. 49) asserts that “sibling relationships are crucial to our social-interpersonal development” and represent our “first social relationship”; yet, the effect of those relationships on the personhood of children and young adults remains under-studied. In the only large-scale, national research study in the United States on children with caregiving responsibilities, it was found that approximately 154,000 children (11%) of the estimated 1.4 million child caregivers in the United States were providing care for siblings (National Alliance for Caregiving, 2005). More recent research suggests the potential for significantly higher numbers of children supporting siblings with their health care needs; as data from the 2011 United States Census revealed that there are approximately 2.8 million children living with a disability (United States Census Bureau, 2011). However, research in the United States rarely frames the experiences of children with disabled or ill siblings as caregiving, and therefore, we know little about sibling young caregiving (East & Hamill, 2013). Of the modest existing research, much has tended to focus on educational impacts on children: for example, the findings of East and Hamill’s (2013) research with Mexican-American children propose that young caregiving has the potential to positively affect children’s educational aspirations, while negatively impacting their ability to attend school.

Young adults providing care for siblings has been long ignored in academic scholarship in the West. There is a small but growing collection of scholarly literature on the experience of young adults providing care for siblings in Australia. In the United Kingdom, the experience of siblings in young adulthood is not typically made distinctive from within broader research on young adult carers. Within the United States, there is a complete dearth of research on young adults with disabled or ill siblings, particularly guided within the structures of care and caregiving. In the only national scientific analysis on young adult caregivers in the United States,

Levine et al. (2005) only briefly mentioned the existence of sibling young adult caregivers in the context of their assertion that the majority of care recipients in their data were grandmothers and mothers. It follows that there is non-existent research on the perspective of identity and identification with sibling young caregivers. As discovered with this research study's sample in the United Kingdom, it was also revealed that young adults providing care for siblings in the United States possessed a unique and nuanced perspective of identification and identity. This section will offer increased understanding on whether young adults come to identify as caregivers, how the identification process may take place in the context of a society that lacks a discourse on young caring, and finally, the ways sibling young adult caregivers create their own language to describe their caring role and how our understanding of their preferred language can be used to develop more targeted formal support systems.

6.5.2. THE TYPES OF CARE PROVIDED BY SIBLING YOUNG ADULT CAREGIVERS

This research study revealed that the types of care young adults provide to their families influences their perception of their identity as a caregiver. Within a traditionally accepted young carer identity, certain caregiving activities, such as physical care, medicine administration, and intimate care are often thought as the types of activities that constitute young caring. Conversely, caregiving tasks like emotional support may not always be seen as care, both by the young adult caregiver themselves and society at large. Therefore, this research study demonstrated that when young people find themselves engaging in emotional support for their family members, they may not view themselves as caregivers. This is especially true for sibling caregivers, as they reported that much of their caregiving responsibilities focused on the provision of emotional care. The young adult caregivers in the United States sample of this research study who provided care for siblings report engaging in the same nature of caregiving tasks as their counterparts in the United Kingdom sample. Tasks related to emotional care featured prominently in their description of their caregiving experience:

“I would say a lot of like emotional support, a lot of emotional support, because when he is processing things or he has like girl problems-- he'll talk to me about that. Sometimes in the evenings he will sometimes talk about his country music career. A lot of emotional support, that's even when I'm out of town, if I'm not here to drive him around, he'll call and we'll talk

and he'll start talking about this happened at [his social club for young adults with disabilities]. I'd say our relationship is like a friendship- a big friendship. I don't know if that counts [as caregiving] but it should."

Mia, 21, Brentwood, Tennessee, United States. Cares for older brother with Down Syndrome

Mia expressed that her relationship with her brother felt similar to a friendship in the ways that she provided him with conversation and helpful advice. This mirrors the experience of other sibling young adult carers in the United Kingdom such as Joe, whose experience of care strongly featured emotional support. The provision of emotional support can make it difficult for young people to distinguish their care tasks from the activities that they consider normal within a typical sibling relationship, e.g., giving romantic relationship advice or discussing their interactions with teachers at school. Young people may also encounter uncertainty over knowing whether the emotional support that they provide to their siblings "counts" as caregiving, particularly if they have not been officially identified as a young caregiver by someone else. Mia's excerpt demonstrates this uncertainty, as she was unsure if her emotional care towards her brother could be classified as caregiving although she felt that it should. Therefore, we understand that the types of care that young people provide towards their siblings influences the way they consider their identification as a caregiver. Some young people may not feel like a caregiver because the nature of emotional support feels very similar to the types of support that siblings would typically be expected to provide in sibling relationships with those who do not have health care needs. It is also true that some young people may possess some understanding of their contribution of support as caregiving, as Mia demonstrates. Nevertheless, the perception that emotional care may not be caregiving persists within both the internal experience of young adult caregivers and also within society itself. This has significant implications for the ways that young adults consider themselves as caregivers.

6.5.3. WHY SIBLING YOUNG ADULT CAREGIVERS MAY NOT IDENTIFY AS CAREGIVERS

The involvement of parents in providing care for a young adult's sibling with a health condition or disability served to influence the perception of a young caregiver identity. Based upon the sample of interviewees living in the United States, this research study found that young

people providing care for their siblings can find it difficult to identify with the labels of young adult caregiver or more broadly, caregiver, because they share caregiving duties with their parents. Some young adult caregivers perceived that they were different from other caregivers because their sibling has other family members upon which they can rely on for support. This recognition that they are not like other caregivers who have sole responsibility for caregiving likely serves as the foundation for their oft-held belief that they are not caregivers if they share caregiving duties with their parents. In the following excerpt, one such young adult caregiver, Leah, reported that she is different than other caregivers because she has joint caregiving duties with her parents for her sister. She felt that other caregivers have a stronger sense of responsibility because they are solely responsible for the care of their family member:

“I have a situation that’s different than most probably care givers like –I grew up with a sibling with a disability, and I do feel a sense of responsibility to make sure [my sister] is okay, but my urgency in doing so is not as strong as maybe someone who say like their sibling with a disability is all that they have, like they only have that person. Right now [my sister] has my dad and my mom and [my step-mom], and yes [my step-mom] is getting up in age, both of them [my parents] they’re getting up in age.”

Leah, 25, Nashville, Tennessee, United States. Cares for younger sister with cerebral palsy

Leah understood her sense of responsibility within her caring role in context to other “imagined” caregivers who act as sole caregivers, and she believed that her responsibility was lessened because she shared with her parents. She also noted her parents’ increasing ages by alluding that one day she will be become solely responsible for her sister’s care when her parents die. I have chosen to include Leah’s statement on her sense of responsibility as I suggest that it demonstrates the mindset that young adults providing care for siblings have regarding their understanding of their caring role. As discussed in Chapter Four, this research study found that those young adult carers in the United Kingdom caring for siblings tended not to see themselves as carers, and this finding can be largely attributed to their experience of sharing caring duties with their parents. This major finding with young adult carers in the United Kingdom is reflected with their counterparts in the United States: those caring for siblings found it difficult to identify

as a caregiver because they felt that viewing themselves as a caregiver would take acknowledgment away from their parents, who they believed shouldered the primary responsibility for caregiving. One such young adult caregiver is Sebastian, who believed that he could not take full “credit” for providing care for his brother, as he viewed his father primarily responsible for caregiving. Sebastian recognized his own contribution to his brother’s care as a form of “helping”, yet felt that recognition of the role of caregiver rested principally with his father. Thus, as the following excerpt demonstrates, Sebastian declined to see himself as a caregiver.

“I will eventually have to be [a caregiver]. But I feel like I should give more credit to my dad, for being the real caregiver for the past 24 years. I feel like I helped, but it wasn’t totally me. It was more my dad—my parents.”

Sebastian, 19, Brentwood and Nashville, Tennessee, United States. Cares for older brother with autism

For Sebastian and the other young adults caring for siblings in the United States sample of this research study, a constant theme emerged: while they undeniably engaged in a caregiving role presently, they understood that their caregiving role would increase to the point they would become sole caregivers of their siblings upon their parents’ death. Previous research in the United States (Begun, 1989; Chambers, Hughes, & Carter, 2004; Grossman, 1972; Stoneman & Berman, 1993) has found that young people are socialized from their family to expect that they will be required to take care of their siblings with health conditions in later life, with Krauss, Seltzer, Gordon, and Friedman (1996, p. 92) going so far as to assert that siblings are “the next generation of family caregivers”. In this research study, it was demonstrated that this understanding had a profound effect on their sense of identity both presently and as they looked to their future self. In the present day, they tended to consider themselves as partial caregivers—if caregivers at all—but they clearly and deeply understood that they would be caregivers in the future. As a result, these young adult caregivers made intentional choices in present day that they believed would influence their ability to serve as sole caregivers for their siblings in the future. For some like Sebastian, this meant that they felt the pressure to perform well in school presently so that their academic success would lead to a financially secure career in the future, ensuring

their financial stability to act as sole caregivers. For others, this understanding had a direct impact upon the types of romantic partners they currently sought out.

Young adults providing care for siblings may feel that they are *more* than simply siblings because they feel that their activities within their family may feel atypical in comparison to other siblings who do not have siblings with health care needs. They recognize that they are different from their peers without family caregiving roles yet because caregiving duties are balanced with their parents' acts of care, they do not feel entitled to the label of caregiver. Mia is one such young person:

“I don’t think I’m responsible enough for the right to be considered the caregiver. If there was like a middle ground word between those two I feel like I would fit that role better, because there’s more, I have responsibility for [my brother] to my family that I wouldn’t have otherwise and a lot of things to consider as I plan, that I wouldn’t have to consider otherwise. But I think I’d be taking too much credit if I call myself – a “caregiver”. Like I do think I give care in some capacity, but as far as taking full care of him I don’t do that. Yet.”

Mia, 21, Brentwood, Tennessee, United States. Cares for older brother with Down syndrome

Mia expressed a tension in self-identifying with the label of caregiver. She did not feel that she was “responsible enough for the right to be considered” her brother’s caregiver. Mia does not use the word “responsible” to indicate maturity, but rather she alludes to the secondary position she possesses regarding her brother’s care. Mia’s parents remain in command as the primary decision-makers despite Mia needing to make personal adjustments to her life in order to facilitate care for her brother. Similar to Sebastian, she understands that she is going to be the primary caregiver for her brother at some point in the future, most likely upon her parent’s old age or death. Through Mia’s statement, it is also clear that young adults caring for siblings may feel that they lack accurate language to describe themselves. They have a sense that they have greater responsibilities and different relationships with their siblings than their non-caregiving peers, yet, they are also unsure if they can fully classify themselves as caregivers. Their uncertainty is further complicated by the realization that one day they will have the opportunity to consider themselves fully as caregivers as through the old age or death of their parents. In the meantime, they maintain a sense of “semi-possession” of a young caregiver identity, while

believing that one day, when they are solely responsible for the care of their siblings, they will be allowed the right to call themselves caregivers. The label of caregiver appears to represent a title that must be earned; not just anyone can call themselves a caregiver. Firstly, the title must be merited through the full-time labor and responsibility of caregiving tasks, and secondly, the title should be recognized and acknowledged out of respect to the hard work performed. This gives credence to the notion that the label of young adult caregiver has tangible meaning that can be defined. While it is necessary to understand the meanings that society has ascribed to young caregiving, I assert that it is absolutely critical that we seek to understand the meaning that young adult caregivers themselves give to such labels. This approach enables us to create a young caregiver identity that is primarily driven by the perspectives of young people. Therefore, we can add the view that the label caregiver is one that young people believe must be secured through sole responsibility of care to our understanding of a young caregiver identity.

Part of the experience of young people feeling like they cannot consider themselves as caregivers because they also share caregiving responsibilities with their parents can also be influenced by their parents *actively* shielding them from a more intensive caregiving role. In the following excerpt, Mia expressed that her parents explicitly told her that they desired her to have a separate life from her relationship with her brother requiring care:

“I think I was very fortunate to have my parents. They were very strong advocates for [my brother] and they provided a lot of support so that I wouldn’t have to worry about that. They told me that they worked really hard so that I could kind of have my own life separate from being [my brother’s] sister...They worked hard for me to not need support because they had taken care of [my brother].”

Mia, 21, Brentwood, Tennessee, United States. Cares for older brother with Down syndrome

Mia expressed gratitude that her parents provided the majority of care required by her brother to the extent that she felt that she did not need support in connection with her caring role. The active, intentional role of her parents in advocating for her brother’s care needs meant that she did not need to be concerned about how her brother’s care needs would be met. The knowledge that her parents have intentionally tried to lessen her caring role within the family could contribute to her disassociation with the identity of caregiver. Her parents have attempted

to deter her from caregiving, and this has led to a congruent self-perception that she is not quite a caregiver, especially in the same manner as her parents. In some ways, this mirrors the experience of young adult caregivers looking after siblings in the United Kingdom. Recalling the experience of Samuel in the United Kingdom, he reported that his mother explicitly expressed that she did not want him to provide care, and that as a young person, he shouldn't be exposed to caregiving at such an early age. However, Samuel reported that he felt that he had no choice to be a caregiver for his siblings and his parents. What can we learn from the experience of young adult caregivers like Mia and Samuel? Their experiences help us better understand how young adult caregivers come to view themselves and specifically, the understanding of their self-perception (identity as it relates to their larger self-concept) in light of their caring role (identification with a young caregiver identity). Those like Mia, whose parents do not require care themselves, may find it difficult to identify as a caregiver. Firstly, because they shared caregiving responsibilities with their parents and secondly, because their caregiving role is not as intense *because* their parents have actively shielded them from care. This is in contrast to caregivers like Samuel who provide care for both siblings and their parents—he depicts a self-described intense caregiving role as the sole provider of care and the complex nature of his family, e.g., his siblings and his parents both required care. Samuel reported that he needed support at an early age, but was not identified as a young carer and therefore did not receive support. Through the contrasting experiences, Mia and Samuel depict sibling young adult caregivers across a continuum of caregiving. Young people themselves are expressing what may seem overtly evident: it is easier to identify as a caregiver if they are the sole caregiver, caring for multiple family members across generations, and in receipt of services in support of their caring role, and finally, aware of the terminology of young carers or young caregivers. Conversely, it is much harder for young people to identify as a caregiver or carer if they are providing care in conjunction with other people, caring for siblings, and not in receipt of services in connection to their caring role, and again, not aware of the terminology of young carers or young caregivers.

The experience of having parents share in caregiving responsibilities may also lead others to hold a false view that siblings do not participate in caregiving. Society maintains a view that when young people live in families with parents who *appear* to be able to provide care, they

falsely believe that caregiving will solely be the responsibility of the parents. This belief causes young people like Harper and other sibling young adult caregivers to be overlooked:

“I think that people don’t often get that and they think ‘oh yeah your parents should have done everything’, like yeah they did but you know as [my parents] got older, my mom had to work and my dad had to work and [my mother] was able to be there only sometimes”

Harper, 23, Bowling Green, Kentucky, United States. Cares for older sister with cerebral palsy

This false perception can be precarious because it helps to perpetuate the myth that siblings of children with health conditions requiring care will not be caregivers. This persistent myth in society influences the understanding that young people themselves have regarding their caring role. Young people like Harper may find it difficult to identify as a caregiver because they have received messages from society that their role as a sibling caregiver should not exist because their parents should be responsible for the entirety of their siblings’ care needs. As Harper illustrated, siblings take on caregiving roles within their families for a variety of reasons. When society is unaware of this reality facing siblings, not only will sibling young caregivers find it frustrating that society has disregarded their contribution to their families, but it also has serious implications for their ability to identify as caregivers.

While siblings spoke in uncertain terms regarding the labeling of themselves as caregivers, they also used a common language when describing the activities they performed to support their siblings. Many of the young people reported that carrying out their caregiving tasks made them feel like mothers to their siblings. This sentiment was not dependent upon gender, as male young adult caregivers also reported that they felt like a mother to their siblings. This was also observed in the interviews with sibling young adult carers in the United Kingdom (see statements from Samuel). In following excerpts from Mia, Leah, and Hunter, they express that they equate their caregiving tasks with mothering and thereby identify as “mothers” to their siblings:

“Right now feel like sister is an over simplified word, because like I feel like my role maybe when you ought to see [my brother] and I interact, they’re like not in a condescending way, but

it's mainly motherly like, it's just different like that – if [my brother] was a typical twenty six year old male, like it would not be that way. Feel like sister is too simplified.”

Mia, 21, Brentwood, Tennessee, United States. Cares for older brother with Down Syndrome

Mia felt that the label of sister did not sufficiently explain her role towards her brother who has Down syndrome and required emotional care. To her, the label of sister oversimplified her experience of living with her brother as a sibling and also providing care to him. Instead, she felt that she behaved more like a mother towards her brother. Mia explained that her brother wasn't a “typical 26 year old male” and that his condition required her to supervise him in ways that would normally not be required from a “26 year old male”, causing her to feel “motherly”.

Young adult caregiver Leah also expressed that she did not feel like she had a normal sibling relationship with her sister because of many caregiving duties she performed on behalf of her sister. Just as Mia acknowledged in the previous excerpt, Leah felt that there was an abnormal aspect to her relationship with her sister, and she indicated that caregiving was the root cause of her feeling as if her sibling relationship was not typical. Instead of a normal sibling relationship, Leah felt like her sister was more like a child to her, even to the point that Leah felt like an only child:

“With my sister, I look at her as a child even though she is my little sister. I'm so used to doing so much for her, just knowing how she is, that it's not your normal sister relationship. I'm like a mother. So to me in my sense I still feel like I'm the only child.”

Leah, 25, Nashville, Tennessee, United States. Cares for younger sister with cerebral palsy

Similarly, Hunter felt that his caregiving tasks were the type of activities that a mother would perform, and this influenced the way he viewed his own caregiving role:

“I'd watch over her, make sure she was fine. She was having seizures at the time, those kind of things might happen. I just needed to make sure that she wasn't getting too tired. Allowing her to get rest, checking on her when she slept and you know just kind of do the mom thing.”

Hunter, 26 (birthday within 1 month of the research interview), Bowling Green, Kentucky, United States. Cares for twin sister with cerebral palsy

Mia, Leah, and Hunter reflect the other experience of other young adult caregivers caring for siblings: they often express that they don't simply feel like the parent to their sibling in need of care; they feel like they are their siblings' mother. Their sibling role can feel like they have also taken on the role of their mother, as self-reflectively, they observe how their mother cares for their sibling in need and in turn, they can mirror those actions. They can serve as substitute caregivers for their parents in their absence and perform the care-related tasks that their parents are normally responsible for.

I suggest that the messages young people receive from within their home and from outside of their home help shape their views towards their caring role as "motherly" siblings. Notably, all the siblings in the United States sample of this research profess that they come from "two parent homes", in which there is a mother and a father. Furthermore, these young people confirm that both parents contribute to the care of their sibling. Yet, in describing their role as a "more than a sibling", they use words and phrases like "motherly" or "I am sort of like a mom" about themselves. This language was also observed with sibling young adult carers in this research study in the United Kingdom. References to feeling like a "mum" to their siblings occurred frequently over the course of the research interview, and such language could be attributed to those who live with both a father and a mother who perform caregiving duties for the sibling with a health condition. Whereas one might assume because these young people have observed their both parents provide care for their sibling, that they would feel like the *parent* or alternatively, the mother *and* the father of their sibling, it is notable that these young people choose to describe their caring role towards their sibling in reference to motherhood. What we don't know is what types of care they have observed their parents perform for their sibling. For instance, the mother may provide intimate or emotional care and the father provides physical care like lifting or mobility aid. The types of care performed by their parents may have an influence on their perception of their role as a sibling and the caring tasks they engage in. If a young person has observed their mother provide emotional care to their sibling, and subsequently the young person becomes responsible for care provision, the sibling may feel that their caring experience is best reflected by their mother's caring experience; therefore they feel like the

mother to their sibling. This research study was not intentionally designed to ask young people about their perceptions of their parents' caregiving role; rather, this research was primarily interested in the perspective of the young adult in relation to their own caring role. Therefore, future research should consider the types of care parents provide as a potential influencing factor in the ways that young people perceive of their own caring role to provide greater depth to our understanding of a young person's caregiving experience. Even if young people haven't observed a gendered negotiation of roles within their family, the external socialization of motherhood remains a strong influence in the way they view themselves. The gendered nature of caring and the ways that society regards the emotional and mental labor that women perform in their families likely influences the views that the young people in this research study have towards their mothers' caring role and their own caring role.

Some siblings in the United States sample of this research study echoed the words of their counterparts in the United Kingdom: they don't feel like they identify with the label young adult caregiver because other words that allude to their familial attachment feel more accurate. They reported to prefer other descriptors like "loved one". In the following statement from Hunter, he declines to call himself his sister's caregiver, but rather her "loved one":

"I was always kind of like her protector. Not only was I her protector, but I was a provider kind of like so very early..... I guess I take the time to pause because I wouldn't say 'caregiver' I would probably just say 'loved one', like I'm just loving her. I didn't do it because I was getting paid to do it. I didn't do it because it was my major and this is a great way to jump into a field. It was just because I loved her and I just gave her everything that, you know, had I been in her situation I'd have want someone to give to me."

Hunter, 26 (birthday within 1 month of the research interview), Bowling Green, Kentucky, United States. Cares for twin sister with cerebral palsy

When asked if he identified with the label of young adult caregiver, Hunter rejected the label in favor for other descriptors, such as "protector", "loved one", and "provider". He made it clear that he provided care for his sister because he loved her, rather than because of paid employment or a requirement for his university courses. His sentiment of caregiving as a performance of love was reflected by other young adults in this research study, siblings or otherwise. This is also congruent with other research in Australia specifically focusing on sibling

caregivers; they often identify more strongly with words that indicate their familial relationship, e.g., brother or sister, or their attachment bonds, e.g., “loved one” (Meltzer, 2017). The labels that young people feel describe their relationship with their siblings is understandable when their caregiving duties are viewed as an expression of love and familial bonds. Nonetheless, the lack of young people describing themselves as caregivers is troubling when we consider that the labels of carer or caregiver are the primary way health and social care professionals recognize young caring and seek to target young people for formal support.

6.5.4 WHEN SIBLING YOUNG ADULT CAREGIVERS IDENTIFY AS CAREGIVERS

Similar to the sibling young adult carers in the United Kingdom, there were a few young people interviewed in the United States part of this research study that readily identified as a young adult caregiver, and expressed that viewing themselves in such a way was not a black-and-white issue, but rather involved significant complexity. In contrast to the sibling young adult carers in the United Kingdom who felt like they identified as a carer who may or may not have received formal support services in connection with their caring role, the sibling young adult caregivers in the United States sample who reported that they felt like caregivers did not receive a formal support service. For sibling young adult carers in the United Kingdom, it was observed that even for those who did not receive a formal support service, the existing societal discourse on young caring allowed for them to be familiar with a young carer identity. The context shifts remarkably for sibling young adult caregivers in the United States; there is not an existing national awareness or understanding of young caregiving. Therefore, the majority of young people providing care for their families who identify as caregivers do so without the reinforcement of both a formal support service and a societal awareness. If young people in the United States identify as caregivers, they adapt this identity because of their own personal framing of their family contributions, or because someone else has introduced the identity to them, e.g., most commonly, a gatekeeper to this research study. It is also possible that there is an influence of both factors; young people have already considered their activities as caregiving, and their understanding was only reinforced through their contact with an external individual who viewed them as such, again, namely a gatekeeper. The following sections will further discuss the issues surrounding the identification process of young adult caregivers in the United

States, particularly the experience of a recent introduction to the term young adult caregiver. For this discussion on the experience of sibling young adult caregivers, it is contextually important to understand that these young people understand themselves as caregivers in spite of a society that does not.

Some young people reported that the label of young adult caregiver is an accurate descriptor of their activities within their family, but they struggled to think of themselves as caregivers. Because they have been providing care for their entire lives, caregiving has been normalized. Young people like Harper lack a word or a label for caregiving because it ceases to feel distinctive from their sense of normal activities within their family:

“Yeah I’m a caregiver, in the sense of actually providing care and that I care and I give that to everyone that I come in to contact with. Yeah I think caregiver is the best word to describe me. I think sometimes I don’t really think of myself in that way. Of course from years of just having that be a normal presence, a normal activity. But I think in terms of trying to explain to other people that’s where it would fit. And then when I think of what I would list myself, I don’t have a word for it, it’s just the normality of it all. And I think if I try and put a word to it and I don’t really have a word for it, it’s our normal for us.”

Harper, 23, Bowling Green, Kentucky, United States. Cares for older sister with cerebral palsy

This excerpt from Harper represents the experience of many sibling young adult caregivers. When asked or prompted—for instance, during a research interview, they may readily identify as a caregiver. However, they would not normally use that label to describe themselves because they have been caring for their siblings for several years, and for many, as long as they can remember. The act of taking care of their siblings was their understanding of normality within their family home, similar to the experience of young adults providing care for other family members who report that caregiving is normal to them because it is all they have ever known to do in their family. Harper also indicates that she would use the term caregiver to describe her relationship to her sibling when speaking to others. Her understanding that other people require clear and dedicated language when talking about her family contributions strongly mirrors the experience of young adult carers in the United Kingdom: British young adult carers engaged in a formal support service reported that they would only use the term carer when

discussing their caring role with social care professionals, otherwise, they preferred to use words that alluded to their familial relationship, e.g., sister or daughter. Harper's statement demonstrates that the act of "code-switching" using caregiver-related language is not only relegated to the United Kingdom, but is a common experience across young adults engaged in family caregiving across nations. Harper uses the term caregiver to help others understand her role in her family; it serves as a succinct way to explain how she supports her sister and her health care needs. She does not use the term caregiver to gain easier access into a formal support service, or to fit in with other caregiving peers—this is a drastic difference from the experience of young adult carers in the United Kingdom, who reported that they did use carer-related language within the context of their receipt of a formal support service and additionally, in the presence of other carers. As there is not a formal support service for the majority of the young adult caregivers in the United States to access, using the word caregiver or other care-related terms in reference to their caring role may help others more easily categorize their experience, but such usage will not lead to receipt of a formal support service. Instead, using the term of caregiver serves a different purpose: increasing understanding and awareness from those around them. This is critically important in a society in which understanding of young caregiving is essentially non-existent. Terms like "young adult caregiver" can help other people understand who they are and what they do in their families. This is both true for sibling young adult caregivers and those caring for other family members like parents or grandparents.

Young adults like Harper may find it difficult to articulate, assess, and form distinctions between their activities as a caregiver, sibling, and overall participant within their family system for a variety of factors, with the notions of temporality and normality serving as a dominant influencer. Young adults caring for as long as they can remember, i.e., the temporality element, can often feel that caregiving is their ordinary way of life, i.e., the normality element. This is particularly true for young adults whose relationships with caregiving and the care recipient exist for a great deal of time, as such is the case with young adults and their siblings. For some, caregiving for their siblings may begin during their early childhood years, and for others, it may begin as they themselves grow older and able to take on more responsibility. In either instance, caregiving has the potential to feel normal, either because it is all they have ever known or because it has grown to feel normal over time. Once caregiving exists in their life as a familiarity, it becomes difficult—or perhaps even impossible, for them to make distinctions

about their caregiving role in their family. Their caregiving role and their sibling role often feel intertwined. Furthermore, the lack of societal discourse on young caring has not readily provided them with a language to discuss their activities within their family. Terms like “caregiver” may feel foreign to their own self-perception, yet can serve a vital purpose for articulating their experience to others. In the following statement, sibling young adult caregiver Simone expressed that the term of young adult caregiver was an accurate descriptor of her personhood because it indicates that she is different from her non-caregiving peers:

“I identify with being a young adult caregiver. I’m definitely not normal at my age. A lot of other people are in school or graduating or they wouldn’t be caring for someone unless they wanted to be in that field.”

Simone, 21, Antioch, Tennessee, United States. Cares for older brother with cerebral palsy, schizophrenia, and multiple undisclosed developmental disorders

Simone feels that she is not normal for her age because she believes that the majority of her peers are not engaged in family caregiving tasks. To her, there is the expectation that young adults should either be in education or completing university and therefore would not be serving as a family caregiver. She also acknowledges that most young adults would not engage in caregiving tasks unless they were working as paid caregivers as a source of employment. Therefore, caring for her sibling makes her different than others in her age group. In comprehending the statements from Simone and Harper, it is possible to draw a distinction in the understanding of normality and how terms like “young adult caregiver” may be utilized. The act of caregiving may feel customary within their own self-perception and their perception of their family, i.e., it is “their normal”. Because of this, it may be difficult for young adults to identify with a distinctive label such as “caregiver”. However, young adults may simultaneously feel that the act of caregiving has made them atypical young adults in comparison to their peers. Therefore, young adults like Simone may find caregiver-related language beneficial for articulating their unique experience and encapsulating their identity.

Those caring for siblings may also find that other words in addition to caregiver-related language can help explain their relationship with their sibling. This is not unlike the experience of other young adults caring for other family members, e.g., parents or grandparents, nor, is it unlike the experience of young adult carers in the United Kingdom. Generally, young adults

providing care for family members may use a variety of words to help define their caring role and their sense of identity on a whole. Understanding that young adult carers and caregivers often communicate their caring role using language that reaches beyond the scope of “carer” or “caregiver” allows us to better comprehend their framing of both the act of caregiving and their identity as a carer/caregiver. In this research study, it has been observed that those caring for siblings are particularly more likely to consider themselves in a diverse set of descriptive language, largely in part because of their tendency to disassociate from the identity of carer or caregiver, as they typically believe that the carer/caregiver identity can only be attributed to their parents. In the following statement, Jaclyn, a sibling young adult caregiver living in the United States, provides an example of the various types of labels a young adult caregiver may feel accurately describes who they are and what they do within their relationships with others:

“I can definitely identify with the word ‘caregiver’. I think there is a multitude of different words that fit though: caregiver, friend, assistant. But [“caregiver”] is a really generic term—cause when you get to being a caregiver of friends and family, that’s kinda built into being a friend and part of a family.”

Jaclyn, 24, Nashville, Tennessee, United States. Cares for younger sister with cerebral palsy and autism; younger brother with autism; 3 year old son with normal development

Jaclyn expressed that she identified as a caregiver, but also felt that other words could describe her role with her family and friends, such as “friend” and “assistant”. The notion of assisting in a sibling’s care is one that has been reflected in other interviews with sibling young adult carers/caregivers in the United Kingdom and the United States, as they feel that they are assisting their parents in providing care for their siblings. Her understanding of friendship and family has also been echoed by other young adult carers/caregivers; the meaning of duty, responsibility, and mutuality of care in familial and interpersonal relationships may make an identity of carer/caregiver indistinguishable from their broader concept of what it means to participate in a family and to engage in friendships.

6.5.5. HOW SIBLING YOUNG ADULT CAREGIVERS RECEIVE SUPPORT

Of the entire United States sample of young adults caring for siblings, there was only two young adult caregivers who reported that they received a formal support service. Of those two young people, only one, Maria, received a formal support service that was specifically designed to support young caregivers; the other young person, Mia, received a formal support service for siblings living with individuals with health conditions that did not use the any caregiver-related terminology within the program. Maria received formal support through the American Association of Caregiving Youth (AACY), the only official organization in the United States dedicated to supporting children who provide care to their families. Maria reported that the organization was fundamental in identifying her as a caregiver and introducing her to the term caregiver:

“I didn’t really see myself as a caregiver until I met up with AACY. I just saw myself as an older sister helping. I didn’t know what “caregiver” meant. Until they described it and said ‘this is what you’re doing.’ To me, those are very good terms. But because I was younger, I didn’t know what a caregiver was. But once it was explained to me, I’m like ‘yeah I am a young caregiver and I say it proud!’”

Maria, 19, Stuart, Florida, United States. Cares for younger brother with Cerebral palsy and her 2 year old son with normal development

Maria’s participation in the AACY acquainted her with the label of caregiver to describe her contribution to her brother’s healthcare needs; previously, she simply saw herself as an older sister helping her brother. Maria was officially identified as a young caregiver during her late childhood by the staff at the AACY and she subsequently began receiving support services as a result of her official identification. This mirrors the experience of other young adult carers in the United Kingdom: while aware of their contribution to their family, they were unaware of their status as a young carer, this was an unfamiliar term to them. In addition, their official identification by a young carers project worker led to the receipt of a formal support service. As with the young adult carers in the United Kingdom, similar concerns regarding identification and receipt of formal support are present in the context of the United States. If young people with caring roles do not view themselves as caregivers, but rather associate their caring role with familial language, there is a danger that they may not self-identify as caregivers and will not seek out caregiver-specific services. Conversely, it may be problematic that young people must

subscribe to the term caregiver in the receipt of a formal support service when it does not originate from their own self-perception nor the language they use to describe themselves. Nevertheless, it remains constructive that young people like Maria find official identification and the introduction of a label to describe their family role advantageous in contributing to their sense of self-worth.

The other sibling young adult caregiver Mia, reported an experience in formal support that did not address any identification as a caregiver. Mia reported that during her childhood, she attended a support group for siblings of individuals with chronic health conditions, developmental disorders, and mental illnesses called Sib Shops. Sib Shops take place in dozens of locations around the United States and also has a strong international presence, although none of the young adult carers in the United Kingdom interviewed in this research study reported that they participated in Sib Shops. In the following excerpt, Mia describes her involvement in Sib Shops:

“I attended a lot of Sib Shops. Sib Shops is for siblings of people to get together and talk about their experience. And that was fun when I was in elementary school but then I outgrew that.”

Mia, 21, Brentwood, Tennessee, United States. Cares for older brother with Down syndrome

Mia provided positive experience of her participation in Sib Shops, although she indicated that she matured beyond the social aspects of Sib Shops as she grew older. In our consideration of identification and identity, it is noteworthy that her participation in Sib Shops did not officially identify her as a caregiver. Through her experience in receiving support, she was able to only think of herself as a sibling of an individual with a developmental disorder as she reported that the curriculum of her Sib Shops program did not use the terminology caregiver. This is an important point to consider, as Mia received a positive formal support service experience, however, it was not one that identified her a caregiver. Principally, it is advantageous that Mia received positive support, regardless of whether she was officially recognized as a caregiver. However, it does provide a confirmation of the ways society continues to view young adults caring for siblings as merely siblings, rather than caregivers. Why is a critical lens towards the identification of young adult caregivers providing care for siblings important? With their counterparts in the United Kingdom, I asserted that the difficulties that they may have in

identifying as a carer can also serve as a barrier to their ability to access formal support services as young adult carers. If they discredited their caring role because they viewed their parents as primary carers or if living outside of the family home or attending university meant that they no longer considered themselves to be carers, despite maintaining an active caregiving role with their siblings, there is a strong likelihood that they may not seek out formal support. It is also true that supportive services or those who could serve as gatekeepers to formal support services may not view them as carers as therefore, these young people miss out on receiving support that they may be eligible to receive. In considering the identification process of young adult caregivers in the United States who provide care for siblings, the most glaring reality necessitates acknowledgment principally: excluding the South Florida area of the United States, there is not a dedicated formal support service for child or young adult caregivers. This means that regardless of whether or not young people identify as a caregiver, their self-identification as a caregiver will not serve as a gateway to accessing formal support services in connection with their caring role as younger age caregivers. This research study demonstrated that young adults caring for siblings have a much decreased likelihood to receive formal, dedicated young carers services in the United Kingdom, in comparison to those young adults caring for parents. The reality facing these young adult carers in fact mirrors the experience of young adults caring for siblings in the United States. In the United Kingdom, there is a substantial, growing national awareness of young adults caring for siblings yet this awareness is solely lacking by those who could serve as gatekeepers to services, e.g., social and health care professionals, and educators. As a result, formal assessment for support services alludes these young people and they remain hidden from view. In the United States, there is an extremely limited--or arguably, non-existent--national awareness, of young adults caring for *any* family member, sibling or otherwise. There is also an absence of dedicated support services for young caregivers. Thus, like their counterparts in the United Kingdom, young adults caring for siblings do not receive formal support and they remain hidden from view. So while a discussion on identification for young adults caring for siblings in the United Kingdom is warranted because of the implications on their ability to access formal support services, it is also true that within the United States, this discussion will likely not impact their ability to receive services (as young caregiver support services are virtually non-existent. Instead, a focus on the identification of young adults with the labels “caregiver”, young adult caregiver”, and even “caregiving youth” are beneficial as the discourse on the language we use to

describe young people with caring roles has yet to be fully developed in the United States. In the United Kingdom, the research debate on the terms of ‘young carer’ is still ongoing, particularly in the tension between the carers rights movement and the disability rights movement. Furthering societal awareness and understanding that the terms young carer or young adult carer includes those caring for siblings or those with substance abuse issues remains a major part of the ongoing advocacy work in the United Kingdom, and thus, so does the inclusion of such young adults in assessing for formal support services. In the United States, this work is in the preliminary stages, and therefore, the young people’s own uncertainty on whether they should call themselves “caregivers” sits within a larger context in which a societal discourse on young people with caring roles in any form or fashion is wholly absent. Because the awareness of young caregivers remains introductory, there exists an opportunity to shape the inclusion of young adults caring for siblings into the creation of the accepted terminology and definition of young caring in the United States, perhaps more firmly than what has occurred in the United Kingdom.

6.5.6. CONCLUSION

This section began with a discussion on the types of care that young adult caregivers provide to their ill or disabled siblings. Their caregiving tasks center around the provision of emotional care, such care involves giving advice, serving as an active listener, and general supervision of daily tasks, e.g., reminding a sibling to pack lunch. Because many felt that it was challenging to distinguish between tasks as a caregiver and tasks that a sibling would ordinarily be expected to provide, many expressed uncertainty over whether they could classify themselves as caregivers.

The following section explored the reasons young adults looking after siblings tend to find it difficult to identify as caregivers. All of the sibling young adult caregivers in the United States sample of this research study reported that they shared caregiving responsibilities for their sibling with their parents. Their notion of split responsibilities led them to believe that they could not refer to themselves as caregivers, instead, they believed that the title of caregiver exclusively belonged to their parents. It is also possible that parents may actively attempt to shield young people from taking on a “full-on” caregiving role in the family, and this may lead young people to feel as if they are not entitled to the label of caregiver. Other people may decline to view them as caregivers, reinforcing their self-perception that they are not caregivers. Finally, young people

in the United States function within a society that does not have readily available language to define their role in the family; “young caregiver” or other related words are not a part of their typical discourse. While young adults caring for siblings may be reluctant to call themselves caregivers, they are deeply cognizant of their contribution to their families. They fully understand that they are different from their non-caregiving peers, leading some to describe themselves as more than siblings but instead like mothers to their siblings.

In Section 5.4, I address the rationale of the few young adults providing care for siblings who do express that they identify with the label of caregiver. Some may feel that the word caregiver can serve as a succinct term to describe their caring role to others unfamiliar with young caregiving. While recognizing that as caregiving feels personally indistinctive and has become normalized, they also express that caregiving at a young age is not a typically expected mode of living. Therefore, the label of caregiver can serve to highlight their different way of life and distinguish them from young people who do not possess caregiving roles. Finally, some young adults providing care for siblings may also prefer other words to describe themselves, particularly words that emphasize their interpersonal bonds.

In the final section, I presented the statements of the two sibling young adult caregivers interviewed in the United States sample of this research study who had received a formal support service. While both sibling young adult caregivers expressed positive experiences with their receipt of formal support services, they revealed that the services had very different approaches to their experience providing care for their families. One sibling young adult caregiver received a formal support service that officially identified her as a caregiver, and services were provided to her in acknowledgment of her role as a caregiver. The other sibling young adult caregiver received a support service that did not use any caregiver-related language, not did it encourage her to view herself as a caregiver. It was noteworthy that the service did not officially identify as a caregiver to her sibling, nor did the program use this language to describe her relationship with her sibling. Filtering the experience of the young adult caring for siblings through the lens of a sibling relationship, rather than also a caregiving relationship poses a real danger that those young adults will be overlooked from being identified and accessing formal supportive services for caregivers. While the United States has extremely limited resources for young caregivers, a pervasive view that “siblings are not caregivers” is one that will prove to be detrimental to an

inclusive definition of young caring in the United States. As dedicated formal support services for young caregivers continue to develop in the United States, children and young adults who need support as caregivers may not receive adequate support if they are only viewed as siblings. While the United Kingdom has made significant headway in including siblings into a young caring framework in comparison to the United States, this research study indicates that young people providing care for parents may receive official identification and access formal support services in disproportionately higher numbers than young people providing care for siblings. Indeed, with the exception of one individual, the young adult carers interviewed in this research study who provided care for siblings did not receive formal support in connection with their caring role, even as their sibling and parents received social care assessments and subsequent social care benefits. The push for health and social care professionals to ask parents of the presence of children and youths in the family as a way to help identify siblings as carers remains essential. For both countries, the inclusion of siblings into strategies for young carer/caregiver identification and assessments for formal supportive services is critical to ensuring that relationship of the carer/caregiver to the care recipient does not serve as a barrier to receiving support.

While the previous sections discussed in greater depth how young adults in the United States more generally identify with the label of young adult caregiver, a separate discussion on the ways young adults providing care for siblings explore their identification process was deemed necessary because this research study's findings revealed that the relationship of the care recipient, i.e., sibling versus parent-to-child, possessed great significance to not only their ability to identify as caregivers, but also their ability to receive official recognition from others as caregivers. This discussion on identification and language remains critical in helping us better understand how young adult carers/caregivers experience care and how they see themselves in light of their caregiving responsibilities. It is useful for academics and health and social care professionals to use caregiver-led language, as young people may be more responsive to programs, initiatives, and formal support services that accurately address their perspective on their caring role.

6.6. CONCLUSION

In this chapter, I have explored the identification process for young adult caregivers in the United States as they encounter the young caregiver label. I sought to compare the experiences of young adult caregivers and carers in the United States and United Kingdom with the understanding that the identification with the young carer/caregiver label has the potential for profound effects on their overall sense of self. The United States does not have the public representation of young caregivers, legislative policy, formal support services and interventions specifically dedicated to addressing the needs of young caregivers. There is also a lack of a universal language to describe young caring in the United States. Thus, there is a vastly different national context underlying the discussion on identification with the young caregiver label and how that label can be transformed into an identity. An awareness of those differences and the implications they have on identification served as the fundamental principle guiding this discussion.

For nearly of the participants in the United States sample, their participation in this research study was the first time that they had ever spoken to anyone about their caring role in great detail. They were typically unfamiliar with care-related language, and for many participants, this was the first time they associated their family contributions with the labels of care. It follows that most participants had a relatively recent identification moment, including those who were identified through a gatekeeper for this research study. Other participants were identified through their contact with the AACY and this identification led to the receipt of formal support services with AACY. 10% of the participants reported that they self-identified as caregivers without the intervention of someone else. I suggest that those who begin caregiving later in life, through a sudden or unexpected accident, health diagnosis, or injury to their family member, are more likely to self-identify. For others, caregiving may feel normal and a part of their standard routine as a family member, so it ceases to feel distinctive.

Young adult caregivers reported that they felt that the label of young adult caregiver was an accurate term to describe their caring role, yet I observed during the research interview that they often did not use care-related language. Instead, they used action words like “looking after”, and they referenced the moments spent with their care recipient, e.g., “when I am with my mother”. This may be a form of code-switching, but I suggest that it is more likely that young adult caregivers are unfamiliar with care-related language and therefore it is not their language of choice. When the participants did use care-related language, they tended to use “caregiver”. The

participants reported that they felt that they could identify with the label of caregiver because they felt that providing care for their family, friends, pets, and the natural world enabled them to perceive themselves as caregivers. Family remained central to the lives of young adult caregivers and they reported that the importance of family led them to identify as caregivers. Only one participant reported that he did not agree with the term “caregiver”; he referenced the notion of mutuality of care to explain his relationship with his family members.

In their consideration of their identification with the young caregiver identity, the respondents sought to understand the young carer experience in the United Kingdom. At their request, I informed the participants of the current position of young carers and young adult carers in the United Kingdom. Upon the knowledge that there are greater opportunities for practical support for young carers in the United Kingdom, many of the participants expressed feelings of anger and resentment. Young adult caregivers’ understanding of the prevalence of young caring, coupled with the reality that there was a dearth of dedicated, supportive young caregiver services, further reinforced their belief that the young caregiver identity lacked transformational meaning. In comparison to the interviews with young adult carers in the United Kingdom, there was a marked difference in how the young adult caregivers in the United States considered the benefits of the young caregiver label. Several young adult carers interviewed in the United Kingdom sample of this research study expressed that an understanding of themselves as young carers significantly altered their lives. Firstly, the official moment of identification typically served as a gateway to an assessment of formal support. No young adult carer in this research study received formal support without first receiving official identification as a young carer. Secondly, the recognition of their family contributions as care helped to validate their experiences of young caring. Finally, the label of young adult carer specifically acknowledged that they were different from their non-caring peers in young adulthood, in addition to acknowledging that they were different from children and older adults with caring roles—their age signified greater maturity and competency yet they still needed extra support. While the benefits of the young carer label emerged clearly from the interviews with the young adult carers in the United Kingdom, this did not occur as evidently with the sample in the United States. At most, the interviewees in the United States were relieved to know that many other young people in the country also possessed caring roles; they gained a sense of normalcy in their unique identity as a young adult caregiver. Some reported that they appreciated the knowledge of the

prevalence of young caring in the United States, as it made them feel less isolated as young adult caregivers. They also reported that knowing there were millions of other young adult caregivers in the United States allowed them to feel “normal”. However, several other participants began to question the value of the young adult caregiver identity in the United States. They expressed the sentiment that the young adult caregiver identity did not possess meaning, as an association with the label would not typically elicit practical support. I suggest that while an awareness of a young adult caregiver identity may provide great emotional benefits, without the coupling of practical support, an adoption of the young adult caregiver identity may feel unnecessary.

In the final section of this chapter, I sought to address the identification process of sibling young adult caregivers in the United States. Those providing care for siblings are typically overlooked in research and in the public representation of caregivers. It was revealed that most of the sibling young adult caregivers provided significant amounts of emotional care. The young people were often uncertain if emotional care could be characteristic of young caring. Because many sibling young adult caregivers split caregiving duties with their parents or other family members, they tended to question if they had the “right” to call themselves caregivers. It was also difficult for sibling young adult caregivers to distinguish acts of care from expected, typical behavior in sibling relationships because their care provision had been normalized since early childhood. Others may prefer other labels to describe their caring role, such as “friend” or “assistant”. Whilst sibling young adult caregivers did not typically view themselves fitting within the young caregiver identity, they did express that their family contributions made them feel like they were the “mothers” to their siblings. This finding indicates that young people may be influenced by gendered notions of care as they consider their own identification as caregivers. The few participants who agreed with the young caregiver identity noted that the identity allows them to regain a sense of normalcy during young adulthood. Most young adults providing care for siblings in this research study were not in receipt of a formal support service. Of the participants who had been engaged in a formal support service, one participant reported that their involvement with the young caregiver support organization caused her to identify as a caregiver. The other participant to receive formal support noted that her service involvement did not identify her as a caregiver, nor did the support service use care-related language. I suggest that young adult providing care for siblings are more likely to identify as caregivers if they receive a formal support service that promotes care-related language.

This research study affirms that young adult caregivers in the United States may also undergo a process of identification with the young caregiver identity, similar to their counterparts in the United Kingdom. However, because of the absence of young caregiver awareness and formal support services in the United States, the experience of identification can be vastly different from those in the United Kingdom. Identification as young caregiver in the United States will not typically lead to an opportunity to receive supportive services. The majority of young carers and young adult carers in the United Kingdom are hidden from the view of health and social care professionals and therefore have not been identified as carers. This reality is shared by young caregivers and young adult caregivers in the United States, as most will not receive formal identification by another individual nor are they likely to self-identify. However, because the majority of the United Kingdom sample in this research study had been formally identified by social care professionals and had engaged in a young carer project, I was able to clearly observe differences in the pathways of identification in the two national contexts. Thus, we can see how identification in the United Kingdom may lead to the receipt of formal support services, conversely, identification in the United States will typically not lead to a receipt of formal support services. Future research should continue to examine the benefits and meaning of the young caregiver identity within the context of the United States, a country in which an adoption of the young caregiver identity will not lead to practical support. In the following Conclusion chapter, I will provide further implications for future research.

CHAPTER SEVEN: CONCLUSION

7.1. INTRODUCTION

This research study sought to explore the identity development of young adult carers in the United Kingdom and young adult caregivers in the United States. It utilized 55 qualitative semi-structured interviews with young adult carers/caregivers in the United Kingdom and United States. With a qualitative, inductive, interpretative approach, this research sought to prioritize and center the perspectives of young adult carers/caregivers in the generation of new theories. A thematic analysis was performed, using codes primarily focused on identity and identification. This research found that the identification moment is a critical point in time in the life of a young adult carer/caregiver. Before the identification moment, young people with caregiving responsibilities tend to believe that they are fulfilling their familial role and helping their families because of love and a sense of duty. Once identified, the young carer/caregiver identity can feel revelatory. This research recognizes that most young carers and caregivers in the United Kingdom and United States will not be formally identified by another individual, rather they remain hidden from the view of social care professionals and other service providers. Because of this, young carers in the United Kingdom will likely not receive formal support. In the United States, it is evident that even once a young person identifies as a young caregiver, because of the lack of dedicated formal support services, they will not receive formal support. Therefore, in contexts in which there is no formal support available for young carers, a young carer identity may lack meaning.

I will now present a brief overview of the discussion found in this thesis, revisiting each chapter. I will then proceed to a presentation of the major contributions to new knowledge that this research study provides. Next, a consideration of the limitations of this study will be addressed, as well as a reflection on the work that was not able to be included in this thesis. This thesis will conclude with an examination of the implications and directions for future research.

7.2. REVIEW OF THE THESIS

In the Introduction chapter, I discussed the initial presentation of the positionality of young adult carers in the United Kingdom and young adult caregivers in the United States. I presented a first look of the contextual basis for this international comparative research study. In

the following section, I disclosed the motivations for my chosen direction with this research, in light of my personal young caregiving experience.

In Chapter 2, I presented the definition of young caring from the work of Becker (2000) in the United Kingdom. As previous research has established that the characteristics of young caring are thought to be universal across countries, I surmised that the young carer identity in the United Kingdom and the young caregiver identity in the United States possess similar characteristics (Kavanaugh et al., 2016). I next explored the difference in contexts between the United Kingdom and the United States; the United Kingdom is classified as an *advanced* country in young carer awareness and policy, whereas the United States is classified as an *emerging* country (Leu & Becker, 2016). I established that there is a tremendous difference in the scale of awareness, recognition, policy development, and supportive formal supportive services and interventions for young carers between the two countries. I argued that there are several reasons to explain why the United States is far behind the United Kingdom in young carer awareness and policy: first, the United States has a strong parental rights rhetoric within its culture, and therefore, the country has not signed the UN Convention on the Rights of the Child; second; the strong reliance on the for-profit market in health care delivery and structural inequality has meant that children and young adult serve as the safety net for their families with care needs; third, the fragmented government in the United States has made it difficult to work across state and federal government branches to push young caregiving legislation forward; and finally, there remains a mis-conceptualization of young caring as parental neglect. Next, I presented our current understandings of young adult caring in each respective country, noting that there is little existing research on young adult carers/caregivers. In the United States, current discourse revolves around Millennial caregivers which is a broader age range than is traditionally included in a conceptualization of young adult caring. There is only one large-scale, national prevalence study of young adult carers in the United States. In the United Kingdom, there exists a heightened understanding of the lived experience of young adult carers, due to the three major research studies on young adult caring (Becker & Becker, 2008; Sempik & Becker, 2014).

In the first half of the subsequent chapter, I presented the rationale for a study of young adulthood, focusing on the theory of emerging adulthood. In critiquing the theory of emerging adulthood, I addressed its usefulness for understanding young adulthood as a special, distinct stage in life, while also remaining critical of its implications for young people whose social

mobility is limited. Finally, I introduced the theories of identity in young adulthood. First, I reviewed the personal identity literature, highlighting the seminal work of Erikson and Marcia. Next, I considered the implication of the social identity theory for the consideration of identification for young adult carers/caregivers. I concluded the literature review by noting the usefulness of the theories of multiple identities and roles in helping to understand that young people may have think of their self-concept in a variety of ways.

In the latter half of Chapter 3, I engaged with two major areas of theoretical work: how we understand ‘care’ in the lives of young people, its contested nature, and their lived experiences of family practices; the social construction of identities through the study of sociological and sociolinguistic theories, with a consideration of labelling, performance, embodiment, and code-switching. I established that care, in its gendered, classed, and racialized nature, consists of a variety of meanings and levels (macro, meso, and micro). With a narrowed focus of ‘care’ onto those young people who undertake caring activities in the home, I discussed the ways care can shift from “caring about” to “caring for”, which is the realm in which young carers/caregivers execute their daily lives. The contested nature of ‘care’ for young people and their families arose, and the historical debates of the disability rights movements and the carers movement were reviewed. In agreement with the stance of the disabled mothers’ movement, I suggested that young caring is a socially constructed phenomenon with significant implications for policy and practice. The usefulness of ethics of care in re-thinking ‘care’, whilst understanding the complexities of the distinct “cared-for” role for young people was also addressed. In thinking of how identity can be conceptualized through language, a post-modernist and post-structuralist view of sociology and sociolinguistics was articulated. The subjects of performance, labelling, and code-switching were particularly relevant for a consideration of identity development for young people with caring responsibilities. Finally, a recognition of the Foucauldian approach to power was recognized, especially in light of the imposition of the socially constructed label ‘young carer’.

In the following Methodology chapter, I presented my chosen methodological approach and methods for conducting this research study. This international comparative research study took an inductive, interpretative, qualitative approach. I provided the research aims and the research questions which guided this research study. I next established the rationale for conducting an international comparative research study, focusing on the implications on

identification within country contexts with stark differences in young carer awareness and supportive interventions. This was followed by a review of the ethical issues, participant vulnerability, confidentiality, and informed consent process. I provided a significant account of the difficulties encountered in the recruitment process. Finally, in a discussion of the methods, I presented the sample composition of the pilot study and main research study, and described the chosen method of data analysis: thematic analysis.

The next chapter presented the first set of major findings from this research study, describing the identification process to the young carer identity in the United Kingdom. In this chapter, I first discussed the moment of discovery experienced by nearly all of the young adult carers in this research study. Nearly all were told by another individual that they were young carers. Before this instance, they were aware of their contributions to their family but they did not view their contributions as care. Thus, the young carer identity was a new, revelatory experience for them. This research study revealed that young adult carers often think of their caring role as a fulfillment of their familial role, and their sense of duty, obligation, and felt reciprocity motivates them to care for their families. The notion that they should provide care as a fulfillment of their familial role was shown to hinder their perception of their young carer identity.

Next, I presented a framework for understanding the identification process for young adult carers in the United Kingdom. I established that young adult carers may either accept the young carer identity when presented, or they may accept it in part, or they may reject it fully. Most of the young adult carers in this research study chose to accept the young carer identity in fullness. This newfound identity was beneficial to them as it typically lead to the opportunity to receive formal support services in connection to their caring role. The young carer identity also affirmed that their age as young adults was a distinct time in their transition to adulthood, noting that they had different needs and experiences than their younger (child) and older adult caring counterparts. Finally, some reported that the young carer identity was empowering to their sense of self, as the label provided them with recognition of their significant contributions to their families. However, it was revealed that the experience of providing care at a young age does not always lead to an assessment for formal support. Young adult carers reported that their older age served as a barrier to accessing support, as they believed potential gatekeepers to formal support services viewed them as capable because of their increased maturity. They also reported that

potential gatekeepers (e.g., teachers and social workers) overlooked visible signs of young caring and they were not offered the opportunity to receive support.

Young adult carers in the United Kingdom indicated that they may only adopt the young carer identity in certain contexts. This was partly due to the experience of stigma, in which they revealed that they experienced both courtesy stigma and stigma attached to the young carer identity itself. Other young adult carers expressed that they engaged in what I referred to as *code-switching* by selecting when to use the label of young carer. Typically, they reserved the use of the young carer label when in the presence of other young adult carers or when they were within their young carers project. Amongst family, friends, and strangers, they preferred to use language that de-associated them from caring. It may be that carer-related language can create social bonds with other young adult carers. It was also revealed that code-switching can act as a social lubricant with interacting with non-caregiving peers. Notably, young adult carers reported that the young carer identity remained salient even as they shifted in their language usage.

There were a small number of young adult carers who disclosed that they rejected the label of young adult carer. For some, they felt that the label did not apply to them as they did not seek special recognition for their family contributions. Others found the act of caring had become so normalized that they were no longer able to distinguish between what constituted caring and what constituted normal, daily life. Finally, there were young people who felt that the young carer identity could restrict their life opportunities by creating a sense of bounded agency.

In the final section of this chapter, I presented a special consideration of the experience of young adults providing care for siblings. Sibling young adult carers found it difficult to identify as carers because they felt they merely “assisted” their parents with care for their siblings, and they felt that they had not “earned” the right to call themselves carers. Those who provided care for multiple family members and were the sole carers for their families were more likely to identify as young adult carers.

In the following chapter, I examined the identification process for young adult caregivers in the United States. The first major contrasting difference between the identification process within the United States and United Kingdom is that young adult caregivers in the United States had a relatively recent identification moment. For many, this research study served as their first introduction to the label of young adult caregiver. For nearly all of the participants in the United States sample of this research study, this research study was the first time that they had discussed

their caring role openly. They were also less likely to use carer-related language during the interview; when they did use caring language, they chose to use the word “caregiver”. This is in contrast to the young adult carers in the United Kingdom, who reported that they had spoken of their caring role in various settings and audiences. Secondly, it was revealed that the recent identification with the young caregiver identity meant that they had not had ample time to reflect upon this identity, and their answers in the interview demonstrated a brevity of discussion that did not occur in the interviews with the young adult carers in the United Kingdom. Generally, this research study found that a very small number of young adult caregivers in the United States may self-identify if they had a sudden uptake of caregiving later in life, such as through a new health diagnosis, an accident, or injury. Their self-identification as caregivers may be further reinforced if they had paid employment in the health care sector. For those who received the formal support services of the American Association of Caregiving Youth, their identification process followed the same path as those in the United Kingdom: they were identified as caregivers by the AACY and they accepted the identity and began receiving formal support services.

A major finding revealed in the interviews with the young adult caregivers in the United States was the question of the true value and meaning of the young caregiver identity. When informed of the stark contrast in positionality of young caring in the United Kingdom, many of the United States participants expressed anger and frustration. While reporting that the young caregiver identity may help them feel less alone (in addition to knowing the prevalence of young caring in the United States), they felt that an adoption of the young caregiver identity would not significantly impact their life, as it did not lead to formal support for themselves or aid to their families.

In the final section of this chapter, I presented the perspective of young adults providing care for siblings in the United States. There exists little research on the experience of sibling young adult caregivers in the United States. Similar to the sibling young adult carers in the United Kingdom, they often found it difficult to identify as caregivers. Some reported that they did not believe their provision of emotional care to their siblings constituted caregiving. Others felt that because they shared their care responsibilities with their parents, they did not deserve the title of caregiver. This is congruent with the perspective of sibling young adult carers in the United Kingdom. Notably, the sibling young adult caregivers in the United States often

described a relationship to their sibling that alluded to motherhood and mothering; some felt that their siblings were like their children. Finally, some expressed that they could not identify as caregivers because care had become normalized as a part of daily life, whilst they felt abnormal in comparison to their non-caregiving peers.

7.3 NEW CONTRIBUTIONS TO KNOWLEDGE

I will next consider this research study provides new contribution to knowledge.

The first major contribution of this work involves its multidisciplinary approach to its theoretical underpinnings, by drawing from developmental psychology, sociology, and sociolinguistic perspectives to better understand the identity development of young adults with caring responsibilities. Previous research involving young adult carers in the United Kingdom has generally focused on prevalence, daily tasks, or impacts on school or mental health in connection to one's caring role. This research sought to build upon previous work by recognizing a gap in the literature for more theoretical and conceptual understandings of young caring. In essence, research has established what young carers 'do', but we understand far less on the whys, hows, and the meanings of their lived experiences. In the United States, this research study has sufficiently acknowledged that there is a dearth of scholarly research on young adult caregivers in comparison to the United Kingdom and other countries in the West. Research in the United States has certainly not yet transitioned into addressing theoretical approaches to the lived experiences of young adults with caring roles. We understand the significant role research has played in the United Kingdom to render "visible" the experiences of young people with caring responsibilities through the way it has both socially constructed the young carer identity, and also how it has informed the creation of policy and community care practices. In the United States, therefore, it is abundantly clear how the lack of scholarly research and embedded policy has further rendered young caregivers invisible in American society. While small-scale in scope and indeed exploratory, this research study functions to solicit our gaze to the experience of young caregivers in America. Nevertheless, for both country contexts, I recognize the importance of adding new theoretical understandings of care, family, identity, and identification in respect to young adulthood. By providing the first foundational layer of an consideration of multidisciplinary perspectives, we can deepen our analysis of their experience and produce new ways of thinking about care and family life.

Secondly, this work revealed the ways young adults with caring responsibilities opt to engage the socially constructed discourse on young caring through the complex use of language (and specifically, labels and codes). The disability rights movement and its critique of the advent of the carers movement in the 1980s and 1990s also brought to light the useful concept of the social construction of the ‘young carer’ label. Both the disability rights promoters and care researchers have acknowledged that the labels used to describe the family practice of “caring for” have been created, refined, and promulgated by academia and professionals, rather than through those in caring relationships. The significance of this discourse is clear, when reflecting upon the access to systemic resources and capital, i.e., formal support services, because of this distinct and politicized social grouping of ‘carers’. This research study contributes new knowledge, through its approaches to identity development from developmental psychology, that the socially constructed label of ‘young carer/caregiver’ can also produce the ‘young carer/caregiver identity’. Such a view recognizes the post-structuralist understanding that socially constructed labels, if performed and/or embodied, can enact identities. This is shown through the examples of young people expressing that the term ‘young carer’ gave them a new way to see their entire sense of self, i.e., identity. We can see this identity performed through the oft-heard statement, “*I am a young carer, that’s who I am*”. The adoption of the young carer/caregiver identity can be an impactful, revelatory moment in their life. The young carer/caregiver identity can exist as an identity in the midst of other identities; and for many, the young carer/caregiver identity is a central part of their overall sense of identity. This research also revealed that the navigation of the both the label of young carer/caregiver and the young carer/caregiver identity was contextually based. Those in receipt of formal support in connection to their caring role are more likely to accept an adoption of the young carer/caregiver identity when the label is introduced. Conversely, for those in locations in which formal support for young carers/caregivers is not available, the introduction of the young carer/caregiver identity may cease to possess meaning and value. Through Foucauldian understanding of discourse and power, it was also observed that young adult carers/caregivers enact and perform and indeed *resist* the socially constructed identities that academia and social care policy and its practices has sought to impose upon them. This research supported previous understandings of ‘doing’ family life and its practices, whilst also advancing our consideration of young adults as active agents in their own lives and in their families. In all, this research study sets the stage for future work on

the implications of the social construction of identities in low and advanced young carer awareness country contexts and the meanings it may have on the actual lived experience of young adults with caring responsibilities.

7.4 LIMITATIONS TO THIS STUDY

The most glaring limitation in this research study is found within the sampling strategy. This research study relied heavily on convenience and snowball sampling through gatekeepers to locate participants. VoonChin (2004, p. 994-996) argued that studies relying on convenience sampling “suffer from the inability to generalize beyond the samples”. Therefore, it is critical to emphasize that whilst this study has produced rich data, this is a *small-scale exploratory study* on young adults with caring responsibilities in the United Kingdom and United States. Furthermore, bias is inherent in this method because gatekeepers could nominate individuals with similar characteristics and only those individuals whom they know well. Furthermore, the United Kingdom sample was largely recruited through young carers projects, indicating the presence of bias in the way the participants may identify as carers. This research study could have also benefited from the inclusion of more young adults providing care for those with stigmatized conditions, such as those with HIV/AIDS and substance abuse issues. Diversity in both samples would have been advantageous, particularly in regards to ethnic diversity within the United Kingdom sample.

In light of the *potential* importance of the receipt of a formal dedicated support service in connection to one’s caring role to the conceptualization of identity and identification, for the United Kingdom sample, this research study could have considered conducting interviews in physical spaces unaffiliated with caring, i.e., young carers projects. When I made the judgement to interview participants in office spaces located within their young carers project, I did so with the understanding that an interview at a familiar place for the participant may ease their burden in participating. In addition, young carers project workers remunerated the participants’ travel costs to the project (this is the standard procedure for many projects—with the available funds—when young carers visit the project). I did not have the available funds to cover participants’ travel costs. Finally, conducting the interview in their young carers projects, usually during occasions when the young people would already be at the project for a group meeting, allowed

me to interview (one-to-one) as many young people who were interested in participating. The project worker exited the room during the interview, leaving me with the participant. Therefore, pragmatic reasoning guided my decision to conduct the interview at the participants' young carers projects when possible. However, because it is now evident that the experience of receiving formal support, particularly through a young carers project, can influence the way a young person reflects upon their identity and identification as a carer, a neutral location may be better suited for the research interview. One United Kingdom qualitative study with young people undertaken in their London community project noted that whilst the researchers practiced ongoing informed consent, i.e., by stating that they were free to withdraw and leave at any time, the young people declined to leave, even though it was apparent that they were uncomfortable with taking part (Curtis, Roberts, Copperman, Downie, & Liabo (2004). To address this, Curtis et al. (2004, p. 169), suggested that "if once in the 'interview setting' it is difficult for young people to leave—even with the reassurance that this is 'OK'—there is an even greater onus to ensure that the child or teenager comes there of their own volition." In this research study, no young person exhibited signs of distress, discomfort, or asked to leave. However, I recognize the potential for young people to feel pressure to participate, or feel pressure to give affirming answers about their receipt of formal support, when the interview is conducted in the very place in which they come for support. Thus, future research with young adult carers should weigh the benefits and drawbacks of the location of the interview, keeping the needs of the participant of foremost importance.

In considering the limitations of the selected methods of this research study, it is important to reflect on alternative methods and their suitability. Co-production is one potential option. Horner (2016, p. 8) defines co-production research as *"research that facilitates equal partnership in research between at least one academic party and one non-academic party (for example a community organisation, charity, museum, or public sector organisation) over all phases and aspects of the research from research design, analysis and output"*.

Co-production often uses language such as "partnership" or "collaboration" and "involves researchers and others with a stake in the project" (Holmes, 2017). It may take the form of traditionally accepted research methods such as surveys or interviews, or participants may elect to use arts-based methods, such as photography, theatre, poetry, videos, and drawings (Horner,

2016). Researchers and the participants make decisions together for the direction of the research and share influence and power. Co-production has also been advocated for use with “hard to reach” groups as it may mean that marginalized groups are present in the research, either physically or symbolically (Durose et al., 2011). As co-production research methods value the co-construction of knowledge and emphasize equal partnership, co-production is seen as highly democratic (Horner, 2016).

Conolly (2008) asserts that participatory methods in research with young people can have variance in meaning between researchers. Some may consider participatory methods to include simply “child-based tasks and activities”, whilst purists emphasis a co-production approach that involves the young people at every juncture in the research process (Conolly, 2008, p. 203). Co-production methods hold that children are active social actors and therefore the experts in their experience (Kellett, 2005). It follows that research should involve young people at every stage (cite). Co-production “recognizes the expertise in everyone” (Horner, 2016, p. 10). Co-production methods may have particular relevance in the research with young carers and young adult carers, as researchers frequently assert that young people with caring responsibilities are experts in their families’ care and experts on their own lives (Aldridge & Sharpe, 2007; Frank & McLarnon, 2008; Moore, MacArthur, & Morrow, 2009; Smyth & Michail, 2010).

The promotion of co-production has extended beyond research to policy. The 1989 United Nations Convention on the Rights of the Child has undoubtedly influenced the rise of participatory and co-production methods, affirming “children’s rights to participation: the right to give and receive information, rights of association and rights to participation in cultural life” (Porter, Townsend, & Hampshire, 2012, p. 131). Holland, Renold, Ross, and Hillman (2010, p. 361) assert that the UN Convention on the Rights of the Child give “political and quasi-legal strength” to the development of participatory research. England’s Care Act of 2014 supports co-production: “Local authorities should, where possible, actively promote participation in providing interventions that are co-produced with individuals, families, friends, carers and the community”. According to the Social Care Institute for Excellence (2015), the Care Act 2014 is one of the first pieces of national legislation to advocate for the use of co-production.

Why aren’t more researchers using co-production? Co-production with children and young people is not without its criticism. Some academics have warned that co-production methods with young people is not a necessarily more “accurate or authentic” account of the

experience of youth (James, 2007; Gallagher & Gallagher, 2008). Still others caution that co-production methods can be undertaken by researchers as a form of tokenism by only involving young people in a cursory manner (Hart, 1992; Holland et al., 2010). Holland et al. (2010) also found that the protection of confidentiality of young people in research required an amendment to their co-production design; instead of allowing the young people conduct data analysis, the researchers chose to take responsibility for this phase of the research process. In research with sensitive subject matters, such as one on care and family life, there must be significant consideration given to the issues of ethics and confidentiality when seeking to use co-production methods.

Durose, Beebeejaun, Rees, Richardson, and Richardson (2011, p. 4) assert that the “timescales, pressures, politics and priorities of researchers may not be shared with communities who may be content to allow researchers to get on with ‘their’ job”. While some academics advocate for training young people to conduct their own research as a part of co-production, this may prove difficult on a timescale dictated by a funding body, or in my particular situation, the timeline of a doctoral research degree (Holland et al., 2010; Horner, 2016). Similarly, Conolly (2008) explains that the shared decision-making process inherent to co-production may prove difficult in the agenda setting stage of research. It may be true that important subjects may not be on the forefront of young people’s minds, yet necessitate research. There is a risk that some topics may not be included in co-production research with young people simply because “they are not interesting or they may not have occurred” to young people (Conolly, 2008, p. 204). If co-production research was undertaken with young adult carers, there certainly exists the possibility that the questions that I as a researcher have set forth as “critical” may not carry that same weight in the perspective of the young adult carers. In such scenarios, I question can we as researchers truly relinquish our control over ‘our’ selected research topics? Indeed, researchers may have spent much personal time and thought to a topic and be entirely attached to the subject and maintain its value. It may also be true that topics rejected or overlooked by young people may be relevant and important research topics, but their proximity to the subject matter may cloud their perspective. Furthermore, as young people with intense caring responsibilities, time demands, and potentially instable daily lives, they may not have yet had the clear mental space to engage in abstract or deeply intellectual topics related to young caring—rather, these are young people simply trying to survive and get through their day. The objectivity and distance

sometimes needed to engage in research may not have been afforded to young adult carers/caregivers. However, such a view may illustrate the elitism and hidden power dynamics within the research process as alluded to by Durose et al. (2011) and Holland et al. (2010). The notion that “participants know *some* things, yet researchers know *most* things” is one that can make it difficult for researchers to trust that young people can fully share in the decision-making process of research from beginning to end. Co-production research, therefore, can restore democratic practice to the research process (Brock & McGee, 2002).

A qualitative co-production research approach may also prove difficult to young people who are not used to expressing their thoughts and feelings about care. For many of those in the United States sample of this research study, this research interview was the first time that they were presented with the opportunity to discuss their views on their caring experience. For many, the interview presented a first-time opportunity to reflect on how care affected all parts of their lives—an activity that their young age, hectic and transient life histories, and intense demands on their time may not have allowed them to do before the moment of the interview. Thus, an expectation that young people with caring responsibilities can quickly articulate not only their lived experiences, but also reflect, think creatively, and make decisions on a research design on the subject of young caring may be unrealistic at best, or distressing for the young people at worst. This does not mean that young adult carers/caregivers do not possess nuanced and detailed views about their experience and their world, particularly as it relates to young caring. Indeed, I assert that such young people are experts in their experience and certainly possess unique knowledge based on their lived experience that is different than the researcher. Nevertheless, if researchers seek to use co-production with young adult carers, researchers should consider the suitability of a *pure* and *complete* co-production design as it relates to the selected subject matter. It may be that in low young carer awareness contexts, a co-production design could give rich and significant revelations, as concepts such as care, identity, identification, and support could be further de-constructed and examined without an pre-existing societal understanding.

A modified approach to co-production and particularly, one that seeks to be participatory, could involve the views of young adult carers/caregivers right from the start of the research by asking their preferences on the research methods. Hill (2006) suggested that children’s preferences can be respected directly by asking them on their preferred way of expressing their

views. Other research with children sought to prioritize their preferences by give them a choice between story-telling, video-tapes, games, drawings, or a semi-structured qualitative interview to share their views (Emond, 2002; Stalker & Connors, 2003). Ali, Ahlström, Krevers, and Skärsäter (2012) in their research with Swedish young adult carers adapted an element of co-production by requesting that participants indicate their preference of one-to-one interviews or focus groups. The majority chose the interview setting. Such an approach could help to relinquish some of the control over the research process when engaging with young adult carers/caregivers, and therefore recognizing their diversity in communication preferences. Young people themselves have also recognized that their peers may appreciate a variance in the ways they can share their views (Lightfoot & Sloper, 2002). A participatory approach to the research methods could also help to lessen any potential feelings of discomfort young people may experience when expressing intimate details of their lives; Hill (2006, p. 76) found that some young people felt that questioning about their home life could feel intrusive as they viewed it as private and “not for public airing”. Still other young people felt that within the understanding of researcher confidentiality, sharing details of their personal experiences could be beneficial (Hill, 2006). With my research with young people with caring responsibilities, no participants expressed that the questions asked during the research interview caused discomfort, nor did I recognize any signs of distress as both a researcher and a nationally certified mental health counselor. However, the potential for young people to find a research interview distressing remains a realistic possibility, and a choice in communication methods, e.g., written or verbal methods, may help alleviate this concern. In essence, a researcher may chose that a full co-production design from start to finish is wholly appropriate, or conversely, that an amended design may be more appropriate, especially in consideration of the emotional capability of the young adult carers.

Retrospectively, I could have positioned myself in a variety of settings where young people are present and live their daily lives, e.g., festivals, coffee-shops, shopping centers, bus stops, city parks, doctor’s offices, and pharmacies. Then invited the public to do an online survey on an iPad. This survey could have consisted of the Multidimensional Assessment of Caring Activities and a series of anchoring questions (to determine if one is a young carer), as the Multidimensional Assessment of Caring Activities was originally designed to assess caring levels, not make diagnostic determinations on young caring. This would have allowed me to

collected a sample of young people who may or may not have attended a formal dedicated support service in connection to their caring role, e.g., a young carers project, thereby providing a stronger comparability with the sample in the United States, i.e., a sample that for the most part has not had contact with a young caregivers project. For those who were determined to be a young adult carer through the survey, I could have invited them to choose their method of participation: an Skype interview at a later date, a quick interview on the spot about their experiences, conduct a drawing, etc. It may also be possible to get the survey within educational setting, such a college or university—following the example of previous research with young carers. This would have the benefit of identifying the numbers of young adult carers in an educational setting—often seen as a finding itself (see Leu et al., 2018). However, such an approach neglects to collect the views of young people who are not in education, which previous research has indicated is a significant proportion of young people with caring roles. Furthermore, Morrow (1999, p. 212) has asserted that school-based research with young people may position them as “objects” and a “captive sample” because of the agreement that between the researchers and the school administrators. It may also conjure up ethical questions of informed consent, as young people may feel pressured to participate in a classroom setting. Photo elicitation could have used instead of drawing---or they could have been given a choice—as photos of what they considered to encapsulate their identity could also help answer the research questions. However, the time constraints of this doctoral research project would have proved challenging to pursue such a method.

After a thorough consideration of possible amendments to the research design, methods, and sampling strategy, it is clear that there is an abundance of ways to conduct research with young people with caring responsibilities. Whilst this present study’s methods did not prohibit the collection of rich data, the study’s limitations due its design and sampling are well-established. It is hoped that future research can seek to address these limitations.

7.5 RESEARCH FINDINGS NOT ADDRESSED

It must be emphasized that this research study is a small-scale, exploratory study on identity development in young adults in the United States and United Kingdom. This is a critical point to reflect upon as its significance is considered. Nevertheless, the sample size of this research study does indicate that this stands as the largest qualitative research study conducted

with young adult caregivers in the United States. It is also the only international comparative study to date involving young adult carers in the United Kingdom and United States. Therefore, the data collected in this research study was substantial. There was not enough space in this thesis to cover all of the findings of this research study. Briefly, I will now present an overview of the findings not addressed in this thesis.

First, nearly all of the participants in both country samples reported that caregiving had impacted their overall sense of identity. Caregiving played a fundamental role in shaping their conceptualization of who they are. Part of this research study involved asking participants to draw on a sheet of paper their responses to the question of “who am I?”. During the research interview, I also incorporated the use of drawings as a creative visual method. Visual methods using the arts have been encouraged in previous research with young people, particularly as a way of using participatory methods (Veale, 2005, p. 265). Visual methods can include drawings, photo elicitation, painting,. Drawings are often chosen as a research method because of its low cost, few resources needed, and the ability to stimulate communication (Mitchell, Theron, Stuart, Smith, & Campbell, 2011). Drawings, especially free drawings, may produce rich data, however the images must be interpreted. Veale (2005, p. 265) found that it was the children’s verbal interpretation of their drawing that produced the data for interpretation—“words about pictures”. Similarly, Mitchell et al. (2011) found that drawing solicitation is typically combined with verbal interviews, as a way to allow the participant to provide interpretation of their drawing. Creative visual methods have been used in previous research with young carers, typically in conjunction with a host of other qualitative methods. Becker and Evans (2005), in their research with children caring for parents with HIV/AIDS in the United Kingdom and Tanzania, reported the advantages of visual methods with their sample. In addition to semi-structured interviews, the work of Becker and Evans (2005) featured drawings, map-making, poster-making, written diaries and stories, and sentence completion exercises. Such task-oriented exercises were shown to facilitate conversation with young children (Becker & Evans, 2005). Aldridge and Sharpe (2007) also employed visual methods in their research with young carers in the United Kingdom. Premised on the belief that interview methods alone were not “adequate nor appropriate” to use with every child, especially with those considered vulnerable, Aldridge and Sharpe (2007) sought to discover another way to encourage the participation of children who may not feel comfortable with verbal discussions. Aldridge and Sharpe (2007) gave disposable cameras to 20

young carers asking them to take photos of things related to their experience of caring over a two week period. Their research found that visual methods can be positioned alongside verbal methods to further capture the experiences of young carers (Aldridge & Sharpe, 2007).

Thus, I elected to use a visual method alongside the semi-structured interview to better capture the views of young adult carers/caregivers in relation to their identity development. I believed that, similar to the work of Aldridge and Sharpe (2007), a combination of approaches—visual and verbal—might help address the diversity in preferred communication styles found within the participant sample. As noted by Mitchell et al. (2011), drawings were selected to help spark communication. I also sought a way to continue to delve deeper into their conceptualization of their identity without the constraints of my semi-structured interview schedule. After asking specific questions related to their educational, employment, and interpersonal life, I desired to shift into a broader consideration of identity. This perspective was grounded in the understanding that whilst identity literature often encapsulates young adults' identity through life domains, young people themselves may understand their identity in a much more abstract and broad way. To solicit the drawing, I asked the participants the following question after presenting them with sheet of paper and pencil: "Let's say there is a circle that represented, 'this is my life and this is who I am'. What would you put in that circle?" After the participant has drawn or written their response, I asked "Do some things in this circle mean more to you than others? Can you show me?" After their response, I asked "Do you think caring has impacted any of the things in the circle?". Throughout this portion of the interview, I asked participants to explain or provide more detail. I also asked at the completion of the drawing if they wanted to verbally tell me anything about their drawing to help me understand.

I positioned the solicitation of drawings towards the end of the interview, so that the young people might have gained a level of comfort in the research interview process, as for many, this was the first time they had participated in a research study before. However, I incorrectly assumed that this may be the first time that they had been asked to think, write, or draw aspects of their identity. It was revealed that in both the United States and United Kingdom, many participants expressed that they had been asked before to perform similar exercises designed to answer the question of "who am I?", usually within a classroom setting. This was the first time, however, that the participants had been asked to answer the question of "who am I?" in relation to their caring experience.

These drawings and subsequent discussions revealed that young adults with caregiving responsibilities possess numerous multiple identities, but caregiving remains a salient feature of who they are. Regretfully, the space confines of this thesis did not allow for the drawings to be included in this work. It is hoped that the drawings and the deep, nuanced analysis they warrant would be utilized in future publications from this research study.

Second, the participants in both countries expressed a common sentiment of feeling more mature than their peers, yet not quite feeling like adults. They felt that caregiving had significantly restricted their ability to explore and pursue tasks that felt normative to their age group, such as partying, drinking, hanging out with friends, traveling the world, and moving away from home. Many felt that because they were not afforded the opportunity to participate in normative tasks of their life stage, they were experiencing a delayed adulthood.

Third, the participants reported that caregiving had impacted their life paths. They demonstrated that caregiving played an influential role in the development of their career identity, educational path, religious identity, and political identity. For some, they felt that caregiving has motivated them to engage in volunteerism and participate in global citizenship. Others, both male and female, expressed that caregiving had shaped their views towards marriage and children; caregiving either eliminated the desire to marry and have children, or it motivated them to delay marriage and children until much later in life.

Finally, young adult carers in the United Kingdom expressed their views of formal support services in great detail. They discussed its usefulness and areas for improvement. Many in the United Kingdom had strong opinions about the current government and the time of austerity and its effects on their families. In the United States, many participants expressed views on what support would have been helpful to them when they were children. In present time, they demonstrated the need for financial support.

It is hoped that the reader will have a fuller picture of the experience of identity and identification for young adult carers and caregivers through the presentation of these research findings. It is with deep regret that the space limitations of this doctoral thesis restricted the inclusion of other rich data and analysis. It is the author's intention to use those findings in subsequent academic publications.

7.6. IMPLICATIONS FOR FUTURE RESEARCH & CONCLUSIONS

It has already been established that future research could improve upon the selected sampling strategy and incorporate co-production methods to better center the perspectives of young people. Future research should also consider the inclusion of *older* young adult carers/caregivers into a study of identity formation. In conversations with caregivers in their late 20s, I discovered that they could readily identify the ways caregiving had shaped their understanding of their identity and their life paths. Similarly, a longitudinal design study may also prove enlightening. I suggest that some of the nuances in identity and identification could be dependent upon the time spent caring. A longitudinal design study could help clarify new understandings. Future research must also seek to include those young adult carers and caregivers who are truly hidden, i.e., those in rural areas, in refugee and migrant families, and those caring for family members with stigmatized identities. A larger-scale study involving mixed methods is advised, as much of the personal identity development work involves survey questionnaires and a quantitative approach.

With an understanding that official identification by social care professionals remains the primary way young adult carers and caregivers receive the opportunity to receive formal support, I suggest that improving the methods of young carer/caregiver identification is a necessary step in practitioner development. Previous research has made clear that there is a persistent notion of the Western construction of a protected childhood from responsibility that undergirds the anxiety parents may feel about revealing the contribution of their children into their care because of the risk of social service involvement, and the shame and guilt they may feel as parents receiving care from their children and young adults (Becker, 2008; Olsen & Clarke, 2003). Nonetheless, the possibility remains that parents and other adult family members, e.g., grandparents, could serve on the frontline for identifying children as young carers/caregivers and directing them to avenues of support. This would require a massive shift in national discourse about disability, parenting, and children's unpaid labor within the family home that would enable parents to reveal the roles their children play in the home without fear of mistreatment. Utilizing family members as the front-line to accessing formal support would also require widespread educational initiatives to parents about young caring. It could be helpful to consider parental involvement, or more specifically, the involvement of any family members requiring care, in the movement to identify young people with caregiving responsibilities and direct them towards formal supportive services. This is not to place undue burden on parents and family members who already function

in marginalized positions because of their condition requiring care provision, nor is it the intention to task already time and resource-strained families with another responsibility to engage with the complex social care system. However, those in positions of authority and those at the point of access for formal support, such as GPs, nurses, teachers, school administrators, and social workers, have contact with the family member(s) with health conditions or disability because of *their* health and care needs. Therefore, these family members are uniquely placed to potentially serve as “identifiers” for the children and young people providing their care. This shift in focus for those receiving care utilizes the agency that adults (and more specifically) disabled parents possess as adults functioning in a society that gives particular weight to the voices of adults. The majority of the scholarly discourse on young caring in the United Kingdom is remarkably distant from the notions of parentification, which arguably can be used to problematize the parent or adult care recipient (Hooper, Doehler, Wallace, & Hannah, 2011). In the effort to avoid placing blame on parents with health conditions, mental illness, or substance abuse issues, I assert that it is also critical that we avoid negating the role parents may have in helping their children access formal support services. Continuing that progression, as practitioners strategically seek ways to identify young carers, I suggest that they target those who are most intimately familiar with the children and young persons themselves. At the very least, this perspective could widen the discourse on young caring to include the voices of parents about what it is like to have their children provide their care. In thinking about the needs of the whole family, this is an opportunity to include the views of every family member in how to best access formal support. A whole family approach would also necessitate the inclusion of those who are in the extended network of the child, irrespective of literal family membership (Morris, 2012). Becker (2008, p. 440) asserts that social workers can play a key role in further identification of young carers and young adult carers by thinking “whole family”. Families are interconnected and dependent on each other, and the complex nature of family arrangements may mean that social workers will need to relax notions of “who is the carer” and “who is the care recipient”, especially in view of an ethics of care approach (Becker, 2008). This also means the inclusion of awareness building for parents to recognize the contributions of their children in the family as *care* and understand that their contributions may necessitate formal support. Thus, we should begin to consider how we can center young people’s experience with care through the inclusion of parental involvement.

In addition, we must begin to reflect on the following question: how could we progress to a society in which it is safe for a disabled parent to notify school staff that their child is their carer in the same manner that it is welcoming, expected, and arguably a responsibility, to get help for their child with dyslexia? To do so would firstly require a recognition of the marginalization of parents with health conditions, mental illnesses, and substance abuse issues, as well as a social view of disability. It would also require a rather intersectional view of disabled parenting, weighing simultaneously that society has poorly treated and placed undue blame onto disabled parents, while also recognizing that disabled parents possess agency as adults in an adults-centric world. A perspective through the lens of intersectionality must consider the privilege adults have in Western society in respect to power and voice--both advocating for others and self-advocacy-- and the ability to be heard, while also recognizing the lack of privilege they experience as individuals with disabilities living in an ableist society. The goal is to remove barriers and reduce stigma and shame to such an extent that it enables parents to openly share that they receive care from their children and young adults. Some might argue that this could be done by appreciating the mutuality of care across families, persons, and society and by taking the perspective that care should be normalized as a natural part of existing in a family system. Certainly, the societal perception of parents with certain conditions, e.g. substance abuse issues, mental illness, and HIV/AIDS is very different towards those parents with physical impairments, chronic or terminal health conditions, or learning disabilities. To properly cause a shift in engagement in young carer identification, societal perception and treatment of these parents with stigmatizing conditions would also need to shift deeply.

There are caveats worthy of mention at this juncture: firstly, not every young person with caregiving responsibilities may desire external former support or intervention in connection with their caring role. This is critical in regards to our recognition of their autonomy and resilience. In addition, young people who have been caring for much of their childhood may not feel that they need support directly related to their caring role because of the practical skills and emotional resilience gained from years of caring (Becker & Becker, 2008). Secondly, we must consider that there are children living in places in which there is no dedicated support for young carers. Parents may indeed recognize their children's caring role and yet, they live in an area in which formal support for young carer is not available. We must also reflect the implications on the entire family when parents identify their children as young carers but there is no formal support

available. Under a whole family approach, future research must examine how a young person's sense of identity towards their family could be affected. It is essential to consider the following questions: how do parents navigate the experience of recognizing their child in a caring role who needs formal support, but there is no support available? How does such an experience affect one's parenting? How is the child's view towards the parent shaped? Previous research has already established that parents feel guilty and ashamed as they consider how their children provide care for them (Aldridge & Becker, 2003). If parents recognize that their children need help in connection with their caring role, and are unable to elicit help for them, this may have reverberating effects in the family relationship. Future research taking a whole-family approach in considering identification is needed.

Furthermore, there remains much room for improvement for the manner in which young people are identified as carers/caregivers. I suggest that identifying young people as young carers must be conducted in a way that young people are more prepared for it and in utmost sensitivity, respecting the potential magnitude this moment in their life and identity this may be. A critical point of reflection for future research: what does it mean when a stranger in a position of authority issues a proclamation onto a young person's identity? How could this affect the psyche of young children and young adults? One must also consider if the young carer identification moment might be better delivered if it took place within the family first, by the person for whom they provide care. Family group conferencing to address the needs of the whole family in regards to receiving support may prove useful (Tew, Nicholls, Plumridge, & Clarke, 2017). Such a consideration cannot assume that every family has the communication skills and comfort level with each other in place to initiate a conversation about young caring. Some young people might prefer to self-identify, or conversely, some may desire to have this crucial moment with an external person not of their family unit so that they may feel free to ask questions and express their feelings about their caring role without guilt or shame. In whichever manner may be true, I assert that treating the identification moment for children and young people with more care and seriousness is needed. This is a critical moment in their identity and the delivery of such an identity must also be treated with gravity.

Until this present research study, there was little existing research in both national contexts that could address the interplay of caring and identity formation for young adults with

caregiving responsibilities, and furthermore, existing research neglected to consider the ways that labels could be used as a part of the identification process for those young people. With this research study's focus on identity development, the use of the labels "young carer/caregiver" have been shown to play an active role in how young people construct and develop their sense of identity in relation to their caring role within their families. In their navigation of socially constructed identities, it is clear that young people with caring responsibilities perform, represent, enact, and even resist both labels and identities, and remain active agents in their own lives and within their families.

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APPENDICES

APPENDIX 1: PARTICIPANT INFORMATION SHEET AND CONSENT FORM



"WHO AM I?": AN EXPLORATION OF THE
IDENTITY DEVELOPMENT OF YOUNG ADULT

CARERS IN THE UNITED KINGDOM AND THE UNITED STATES

PARTICIPANT INFORMATION SHEET

What is this study about?

My name is Feylyn Lewis, and I am doing a PhD at the University of Birmingham. As a part of my PhD, I am conducting a research study. I would like to learn more about the experience of young adults providing unpaid care, support, or assistance for a family member.

You are invited to be in this research study because you are between the ages of 18-25 years old, living in either the United States and United Kingdom, and currently provide unpaid care to a family member. I am looking for young adults whose family member has a health condition that requires care, for example, a physical or learning disability, mental illness, chronic health issue, and substance misuse.

What will happen during the study?

If you consent to participate in this study, you will be asked various questions regarding your experience of providing care to your family member. I am interested in learning about what the experience of providing care has been like for you. I'll also ask you about the pros and cons of providing care and how caring may or may not have impacted the things you do in life—like school or work. This is called an interview. An electronic voice recorder will be used to record your interview. This study will last for one (1) to one and a half (1.5) hours.

If at any time during the interview, you would like to stop the interview, you may do so.

What are the benefits of this research?

By taking part of this study, you have the potential to help other young adults around the world who care for a family member by spreading awareness. By sharing your experience, you can help other people understand what life is like for you and can potentially improve the lives of young adults who provide care.

How will my privacy be protected?

I respect your privacy and confidentiality. By taking part in this research, you can feel safe that I will never identify you by your real name. You will be given a special and unique ID code at the start of the interview. Any reference made to you within the thesis or subsequent publications will have been anonymised. The thesis may include information on your occupation, age, location, and the condition of the person for whom you provide care but such information will be stated only in association with a pseudonym (i.e., a fake name). By signing this consent form, you are agreeing to allow third parties to review the data and/or research findings. By signing this consent form, you are also agreeing for me to analyse the data in the future for further research.

Whilst there will be confidentiality, you need to know that if you tell me anything that puts your safety at risk or the safety of others, I will speak to my supervisors—this is because of my responsibility to ensure that I do not ignore anything that could be harmful to you or others.

I will keep your name, email address, and telephone number separate in a file on the University of Birmingham's secure servers. After a number of years, this will be destroyed.

Do I have to participate?

You do not have to be in this study if you do not want to. This means your participation is voluntary. You have the opportunity to withdraw at any time up to and during the interview, and can withdraw up to four weeks after the interview data has been collected. If you choose to withdraw, the data gathered up to the point of withdrawal will be immediately destroyed.

Who can I contact with questions about this study?

You can contact me:

Feylyn Lewis (Researcher), Tel: [redacted] or Email: [redacted]

I also have 2 supervisors for my research work at the University of Birmingham, Professor Saul Becker and Dr Harriet Clarke. Any questions can be sent to my supervisors using the following contact information:

Saul Becker (lead supervisor),

[redacted]

Harriet Clarke (co-supervisor),

[redacted]

[redacted]

Who else can I contact with questions about my rights as a research participant?

Susan Cottam
Research Ethics Officer, University of Birmingham
Telephone number: [redacted]
Email address: [redacted]

CONSENT FORM

Please ask as many questions as you need to make sure you understand the study before you sign this form.

- I confirm that I have read and understand the information provided regarding this study and that I have had the opportunity to ask questions.
- I know I can decide not to take part before the interview, during the interview or up to four weeks after the interview.
- I understand that my participation is voluntary and that I am free to withdraw without giving any reasons.
- I understand that even if I sign this form, I can decide not to answer some or all of the researcher's questions and that I can have a break at any time.
- I agree to participate in the research study which means I will be interviewed about my experiences as a young person who has care responsibilities.
- I agree for the interview to be recorded on a voice recorder. If you prefer not to be voice recorded, do you agree for notes to be taken? -

PARTICIPANT NAME
(PRINTED)

DATE

PARTICIPANT NAME
(SIGNATURE)

To be completed by participant of 18 years of age or older.

APPENDIX 2: RECRUITMENT FLYER



UNIVERSITY OF
BIRMINGHAM

Are you!

**18-25 years
old?**

**Providing unpaid
care or support to
a family member
with a health
condition?**

**Interested in sharing your
story?**



Let's have a chat!

If you would like to be interviewed as a part of a PhD research project on identity development & young adult carers, please contact Feylyn Lewis



Meet me, hear my caregiving story, & learn more!



APPENDIX 3: RESEARCH STUDY QUESTIONNAIRE/INTERVIEW PROTOCOL

Indicative Interview Guide

***Ongoing consent:

- A. Permission to conduct interview by signing consent form; consent to be audio recorded/ notes taken
 - B. No right or wrong answers. I am interested in hearing your thoughts.
 - C. May stop the interview at anytime. We can take breaks as you like/feel needed.
-
1. Who lives in the home with you? What are their ages?
 2. What does a typical day look like for you?
 3. Who do you provide care for?
 4. Sometimes carers/caregivers help out other people in the home as well as the family member with the health condition. Do you help out anyone else in the home too?
 5. Do you receive any help from others?
 - a. If yes: who helps you?
 - b. What kind of things do they help you with?
 - c. How long have they helped you?
 - d. What would really help you and your family?
 6. Does anyone outside of your home help you, like other family members or friends?
 7. Do you receive any services that are specific to young adult carers/caregivers? Do you attend any young adult carers/caregivers specific projects/organizations?
 - a. If yes: Describe the services you receive. What kind of things does that service help you with? OR How has the service helped you?
 - b. Is there anyone at the service who means a lot to you?
 - c. Is there anyone at the service that you talk to you about what 's going on in your life, e.g., school, job, love, friends, etc?
 - d. What would happen if this service stopped/you didn' t use the service anymore?
 - e. Does this service meet your needs?
 - f. Is there anything this service could do better to meet your needs?
 8. If no, not receiving any carers specific service, do you receive any services from the state or government that helps you?
 9. Do you receive/participate in any service that helps the needs of the person you care for?
 - a. If yes, How has this service helped your family member? Has this service meant a lot to you? How so?
 - b. Are all of the needs of your family member taken care of? What do they still need? How do you feel about that?
 10. If no, the family member does not receive any services or outside assistance,
 - a. What kind of service would help your family member?
 - b. Would this make life easier for you? How so?
 - c. Would this give you a greater peace of mind?
 11. Are you currently in school?
 - a. If yes: what is school like for you?
 - b. Does anyone at school know that you provide care?
 - c. Would you feel comfortable telling anyone?

- d. Do you think anyone would treat you differently if they knew?
 - e. Do you think caring has affected life at school in any way for you?
12. If no, not currently in school:
- a. When was the last time you were in school/last school completed?
 - b. Would you ever want to go to college or uni?
 - c. What would you like to study?
 - d. Do you think caring is part of the reason you' re not in school right now?
 - i. How do you feel about that?
13. Some people have thought about what kind of job they want in life, and some people haven' t. It' s normal to not be sure. Have you thought about what kind of job you want to do?
14. Do you currently work a paid job?
- a. If yes, what do you do and how many hours a week?
 - b. What has working a job and caring been like for you?
 - c. How have you managed?
15. If no, not currently working a job:
- a. Would you like to work?
 - b. What kind of job would you like to do?
16. Who do you spend time with outside of your home?
- a. Do they know that you care?
17. Was there ever a time in your life that you felt lonely?
18. Do you think caring makes it harder to make friends?
19. Are you in a relationship with anyone?
20. Do you think that the type of care (intimate, emotional, etc) you provide has impacted your ability to form romantic relationships?
21. Do you think that the time spent caring has impacted your ability to form any romantic relationships?
22. Have you had any advice about careers, relationships, education?
23. When did you start caring?
24. Why did you start caring?
25. Some people say that those of us who care for a family member are “carers or caregivers” , do you think of yourself as a “carer” or a “caregiver”?
- a. Why yes, why no?
26. Do you think that is a good name for us and for what we do?
27. Do you think there's a better name?
28. Can you tell me about a significant moment in your caring?
29. Has caring ever stopped you from doing anything you wanted to do?
- a. How did that make you feel?
30. What is good about caring? What is bad about caring?
31. What things have happened to you that have shaped the person you are today?
32. When you think about your life right now, how does it make you feel?
33. Is there anything you' d like to change about yourself?
34. What are the most important things to you in life?
35. What would you want people to know about you?
36. How would your friends/family describe you?
- a. Do you think that's true? Would you add anything to what they would say?

37. How would you describe yourself?
38. Are you happy with your life right now?
39. Let's say that there's a circle that represented "this is my life and this is who I am" , what would you put in that circle? ***I envision giving the participant a sheet of paper with a circle and a pencil, and will ask them "what would you put in that circle" ***
40. Do some things in this circle mean more to you than others?
41. Do you think caring has impacted those things?
42. Can you tell me the people who have helped to influence the person you are today?
43. It can be really hard to think about the future when you have a lot going on at home. Do you ever get a chance to think about your future?
44. How do you feel when you think about your future?
45. Do you think caring will be a part of your future? In what ways, if so?
46. Do you see an end to your caring? Or do you think you'll do less caring in the future?
47. What does the phrase "young adulthood" mean to you?
48. How do you know you've become an adult?
49. Do you consider yourself an adult?
50. As we approach the end, is there something I might not have asked, or you want to tell me?

---Identity questions---

- A. Can you tell me about what kinds of things you enjoy doing? Do you have any hobbies?
- B. Do you think caring has impacted those things?
 - a. Yes: In what ways?
- C. Is caring important to your sense of who you are?
- D. Have you felt like you have had sufficient time to think about _? (career/job/work; friends/romantic relationships/education)
- E. Has caring ever gotten in the way/stopped you from doing anything you wanted to do?