The Public and Private Politics of Care: An Ethnography of Young Carers, Family Life and Policy Presence

by

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Abstract

This study addresses the question of what an ethnography of family life contributes to understandings of young carers. It considers the methodological and intellectual contribution that can be made by developing an ethnographic description of young carers' family life and care practices. Exploring this gap is important at a time when new public policies are changing the relationship between young carers, their families and the state. The study is informed by an interest in the ways that young carers and their families are social located, at the intersection of disability, 'race'/ethnicity, class, gender, sexuality, citizenship-status and age. The theory of the Public and Private Politics of Care is developed and used to analyse ethnographic data on how families negotiate a family care work settlement in the context of inequalities. Working within this theory we can better understand children's involvement in care work, how families experience the implementation of policies and the implications of understanding family life for policies on young carers.

Dedication

I dedicate this thesis to the five families that made it possible with their generosity, wisdom and creativity.

Aidan, Joey and Marie
Alia, Amber, Kaya and Ben
Rosie, Poppy and Dominique
Sapphire, Luke, Jane, Becky and Chris
XD and Tizzy

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1. Introduction

This thesis is an ethnography of family life. The word, ‘ethnography’, indicates a type of research that uses observation and participation at its heart. It has another meaning because ethnography also refers to a particular way of writing research, which aspires to recreate a set of recorded experiences on the page, through which we can engage in thinking about an important world, full of life. The focus here is the lives of the five families who participated in a study and the ways that they cared for one another. Placing this on the page, I am sharing my stories of what took place, drawings created by participants, their book recommendations and my interpretations of that information using the contributions of a wider community of researchers and theorists.

To present an ethnography of family life we must consider what it means to put this subject on the page in this way. Families are familiar, both when we are absorbed in our own or when we compare notes with others. Yet, they also have a strangeness, a profound complexity that makes their workings elusive. The method of ethnographic research, applied here, encouraged the technique of making social processes appear strange, even when I have reached of point of them being deeply familiar (Hammersley and Atkinson, 2007, p.231). However, we should apply some restraint to this task because other people’s families can already appear strange. This is particularly the case for the families participating in this study because they experience the gaze of others and potentially the judgement of strangeness. They are singled out as families that include a young carer and have the presence of disability, which can lead to them being questioned, scrutinised and, sometimes, censured. This approach, therefore, requires us to simultaneously cultivate and moderate the strangeness in a representation of families. It works with an awareness of this tension and the risk of families slipping out of our empathetic reach.

1.1 New methodological and theoretical responses to the study of young carers

Starting off with this tension puts into context the research question for this thesis:

> **What does an ethnography of family life contribute to understandings of young carers?**
>
> > **What consequences does this have for the conceptualisation of young carers as a social group?**
> >
> > **To what extent does ethnographic research design build an understanding of family life and what methods can be applied and developed to gather observational and visual data?**
> >
> > **Are policies on young carers reaching families and what is the impact?**

This thesis argues that in the context of the changing role of policies on young carers, we need new methodological and theoretical approaches to the study of young carers. An urgently needed contribution is one that can explore and analyse the complexity of family life as a primary site of children’s care work and as an object of policy. By framing the relationship between families, young carers and social policy through the theory of the public and private politics of care we are better placed to understand young carers.

In the thesis the argument is developed, firstly, by reviewing the literature on young carers and, secondly, describing an ethnographic methodology through which the empirical work was carried out. The families that participated in the study are introduced. This is followed by four findings chapters which address the negotiation of care across and at the boundary of ‘public’ and ‘private’ in the context of intersecting inequalities. A final chapter reflects on the theorisation of public and private politics of care and considers the ways this can facilitate conversations about policy as an instrument that impacts the lives of young carers and their families.

Before embarking upon the literature review in Chapter two, this introductory chapter provides background information. I will explain how this line of questioning developed in a practice context. I provide an overview of the policy area and explain how recent changes make this study particularly urgent. The location of the study and the importance of connecting the data to the location in which it was gathered and its economy of care is set out. I conclude this chapter with a brief comment on the approach to writing about care.

1.2 The study origins

I started the research project after encountering a gap in knowledge about young carers through my professional work, one that seemed to have consequences for the ways that policies were being formulated and implemented in the UK. A crucial time for thinking about this problem was during the two years that I worked for a carers charity that advocated for carers, people who provided unpaid care for a friend or family member. My job was to research, critique, discuss and seek to shift policies on young carers and young adult carers in England. When thinking about young carers, this group were understood through an array of sources, including case studies and survey research findings (Sempik and Becker, 2013), face to face discussions and colleagues bringing their own experiences from different professional and personal backgrounds. I was interested in understanding the population of young carers and also seeing how their experiences were changing. They emerged from this mix as isolated figures, both as carers and as children unjustly cut off from other people.

For example, David Mowat MP, the then Minister for Community Health and Care, issued a statement in connection with Young Carers Awareness day on 25th January 2017 (Mowat, 2017). His contribution advocated for a better informed relationship between the general public and young carers, but excluding family members as active participants in this potential for change. He said: “most young carers are happy and proud to care for loved ones, but too often this important role goes unnoticed. Young people not only have to cope with the complexities of growing and learning, but also that of their parents or siblings’ health conditions, preventing them from enjoying childhood in the way other children do. It’s a challenge no one, regardless of age, should face alone - especially if they have their own health concerns.” The concern about children facing these circumstances alone illustrates the way that parents, siblings or other family members are not taken seriously as crucial figures in the lives of young carers. They are especially disregarded as those who might help young carers manage at present or fare better under different circumstances. Another reflection on this problem is the way that disabled people in receipt of care from family members were also individualised, overlooking their collective experience and socially structured circumstances (Keith and Morris, 1995, Priestley, 2000). Family was missing and the research that follows seeks to sketch it back into the picture of young carers lives.

My colleagues and I would speak about young carers as a group in the abstract but they were represented as undifferentiated group members who needed to be better served in their own individual situation. This was reinforced by concern about a central problem of public agencies routinely not identifying these young people in terms of being young carers. They therefore continued to be carers, to do care tasks, without connections to formal sources of support.

Young carers connected to this system of support reported that they benefited from local youth groups that brought them together with their peers (Cheesbrough et al., 2017). However, the majority, it was feared, would remain cut off as young carers unless more action was taken (Children's Commissioner for England, 2016, Carers Trust, 2016).

The representation that predominated about young carers missed a particularly interesting and important set of relationships - those of family (Banks et al., 2001). Families are an important element of the way we can understand young carers and it could also provide important insights into what policies on young carers are doing, because we can see their operation or presence within family life, where care work is so often situated. When I was putting together a case for a research project on young carers, the idea of family life became central to my thinking. It helped me explain something that was quite clearly important but it was something we could not use existing research to say much about.

1.3 The changing relationship between children, their families and the state

1.3.1. The global context of young carers

The research question for this study takes as a starting point an assessment of contemporary public policies on young carers as establishing a significant change to the relationship between those children, their families and the state. By bringing family life into the picture, this will be an important site in which to study the localised and personal consequences of evolving policies on young carers at a national level.

This localising approach is situated within a global picture of children's care work. Young carers are well established as one perspective on children's care practices in the Minority World (Morrow, 1994, Evans and Becker, 2009, Banati et al., 2017, Camilletti et al., 2018), This is a particularly dominant perspective for the Minority World, a term that I use to signify a generalisation about the global north in which a minority of the world's population live but nevertheless is over-represented and continues to be culturally centred in our accounts of global events (Evans, 2019). In this Minority World context young carers can become problematic figures because of a discomfort with children as workers (Becker et al., 2001, Morelli et al., 2003) and concern about the status of people who are occupied with unpaid care work (Barnes, 2001, O'Dell et al., 2010, Heyman and Heyman, 2013). The category of young carers makes reference to a framework of norms located in the Minority World and a particular history of work, citizenship, childhood and care (Cunningham, 1991, Olsen, 2000, James and James, 2001). However, a study of young carers, with methods that accommodate broad categories of interest such as ethnography can allow us to critique these assumptions. The restriction of grounding the concept of young carers in a Minority World understanding of children's care can be challenged, engaging with global and globalised knowledge of care work, childhood and family life (Alber, 2003, Katz, 2004, Evans, 2019, Akkan, 2019a). Also in practice, the biographies of those classed as young carers and their families cross the Minority-Majority world boundary because of migration and globalisation. Therefore, to do justice to their stories we should reflect upon the ways that the young carer concept may inadvertently limit the resources we can draw on to represent their circumstances and their views. Whilst the subject of study addresses the weaknesses in the relatively well-developed field of research on young carers in the UK, it is connected to a critical perspective on the way that the concept of young carers is applied to a wider world of children's care work (Miller, 2005, Leu and Becker, 2016, Leu and Becker, 2017).

1.3.2. Young carers in the UK

The UK, as a country in the Minority World, lays claim to being an influential site of development on policies on young carers (Leu and Becker, 2017). The young carers policies have the potential to be particularly effective at becoming a daily presence in the lives of children classified as young carers. It is important to explore this hypothesised presence, in the little researched spaces of family homes (Miller, 2001, Jupp et al., 2019, Cuthill and Johnston, 2019) to document it and understand its affect and texture (Sedgwick, 2003).

Current policies on young carers in England are based on the framework of the Care Act 2014 and the Children and Families Act 2014. Significant changes represented by this legislation make understanding young carers as part of families a pressing issue. These pieces of legislation create an obligation on local authorities to assess the needs of young carers and to consider offering services to a range of family members in pursuit of better outcomes for the young carer. While the policies formalise a more ambitious stance in terms of changing the lives of young carers, and implicitly making changes to the family arrangement of care, these same families are going to be affected by austerity policies that harden and enforce the boundary between public and private responsibility for care, wellbeing and social reproduction.

Alongside the pieces of legislation, young carers are more established within a range of government initiatives which set out obligations on local authorities to support private family care arrangements, that address children’s educational engagement and mental health and that identifies families in need of specialist local support (Joseph et al., 2019). Carers, including children in the role of young carers, are established as a relevant group for these areas of policy making, in government documents, in advocacy group responses and in political debates (Hammond, 2018, Department of Health and Social Care, 2018b, NHS England, 2019).

Alongside an intensification and consolidation of policy instruments that recognised young carers as a group due government responses to unmet need, there are other patterns in policy-making that will be affecting young carers and their families. Under austerity, the dominant policy direction set by the Coalition Government of 2010-15, and continued by subsequent governments, families faced increasingly harsh conditions in accessing social security payments (Hills et al., 2016, Cuthill and Johnston, 2019, Ryan, 2019) and disabled people continue to experience high levels of discrimination in the labour market (Barnes and Mercer, 2010, Kilkey and Clarke, 2010). Whilst policies claimed to make progress towards better life chances for young carers, the financial conditions and the state of social infrastructure deteriorated.

Family is acknowledged when government policy documents and legislation set out a standard for local authorities to support young carers, however, this become more tenuous at the point of delivering these services. There is a lack of information about how a Whole Family Approach can be created in those interactions, even though there are sets of guidance materials about what a local authority might do (Department of Health and Social Care, 2018a). The approach is, in fact, heavily constrained by limitations on the institutions, resources and knowledge that could support a Whole Family Approach to young carers. Studying family life can contribute to an understanding of what a Whole Family Approach would need to respond to, in the case of young carers. The likely interaction between policies on young carers and austerity in family life has been largely ignored by governments, young carers are seen as requiring a state response that is ‘whole-family’.

In the case of young carers, the idea of incorporating an awareness of family connections in the life of children carrying out care was seen as beneficial because it would provide a better framework if the objective was to reduce children’s involvement in care. Current government policies on young carers, the Care Act 2014 and the Children and Families Act 2014, identify the family as an important target for intervention and advocate working in a way that is informed by an understanding of young carers as being embedded in a family. Nevertheless this was developed in the absence of research on the family life of young carers, showing the importance of addressing the gap in knowledge in anticipation of a more interventionist position of the state for this group.

1.3.3 Policies as a Presence

This thesis is threaded through with an interest in the policies that are referenced in the everyday life of families, explored as a lived presence. Some are explicitly referred to, but there are also those that are implicit in particular concerns or discussions. This leads to an exploration of the ways that policies are implemented and a continued focus on the public policies that directly address young carers, formulated nationally and locally by government departments or national policy-making bodies for the National Health Service.

This is also understood by looking at the policy arrangements in local authorities who hold significant responsibility for this group (Association of Directors of Children's Services et al., 2015, Local Government Association, 2018). The emphasis is on the legislative and documentary framework, as well as sources that aid our interpretation of the intentions set out in these documents or materials. It is beyond the scope of this thesis to explore the experiences or perspective of those who make policies. This means we cannot represent the complexities and ambivalence that lies behind this process (Ferguson, 2016, Newman, 2017, Cuthill and Johnston, 2019). Instead, what we can represent are the nuances that are transmitted through the process to implementation, to be encountered by families and the ways these interact with intersecting inequalities.

Like Shah and Priestley (2011), I wish to set out the relationship between the methods used in this study - ethnography and the use of visual data - and the study of policies. The methods have been chosen for the ability to situate myself, as the researcher, meaningfully amongst families and learn from government policy. This fits with the framework put forward by Spicker (2006), using tools to sketch the ways that policies work. This is modified by the people that represent them and are charged with putting them into practice (Cuthill and Johnston, 2019, Hitchen, 2019). Unlike other methodological approaches to studying young carers, the distinctive contribution of ethnography to the topic of young carers is that families' debates and decisions can be studied in greater depth, incorporate more complexity and span a longer period, which reduces the risk of attributing fixed circumstances to something undergoing change. It contributes to our understanding of how policies on young carers are reaching their intended objects, comparing the findings to the intentions set out.

It is important not to create an idealisation or an unrealistic interpretation of what these policies could be, because by using documentation such as government statements or formalised strategies we encounter ambitious words or aspirations which may have a problematic relationship to most policies that actually follow them. However, I have sought to understand the core intentions in these policies in order to use the research to describe whether these can be traced to the experiences of families who should be reached by these processes.

Understanding the policy intentions also provides the opportunity to use the study as a way of benchmarking the implementation in its current state and open up the possibility of comparing its progress in other areas or at a future point. The study therefore draws on in-depth knowledge of a small group of families to give an insight into how policies are acting on family lives now, and the ways we might measure change.

1.4. The West Midlands context

This thesis presents a research project that developed through the process of refining an answer to the question of how to create a theoretical and methodological response to the problem of missing out families in an understanding of young carers. The study moves from these questions through a process of empirical research, theoretical tool-making and engaging with a group of families in the West Midlands who show how much there is to explore if we want to situate young carers in families as the premise for analysing policies.

There is little research on the impact of current policies nationally or in particular local areas (Joseph et al., 2019), which this study seeks to address by exploring the lived experience of policies in the West Midlands region of England. Basing the study in the West Midlands provides a localised political context for the study with strengths that are based on its diverse social geography and large population of young people. In terms of policies on young carers there are a spectrum of more detailed provisions to limited statements from local authorities, all within the national framework and ethos (Solihull Metropolitan Borough Council, 2014, Worcestershire County Council et al., 2015, Birmingham City Council, 2018). The study drew participants from a population that was diverse in terms of ethnicity, class and backgrounds of migration. There is some representation of young carers’ lives in inner-city, suburban and almost rural neighbourhoods. Another connection to this particular place is a focus on youth and childhood, when the region and the city of Birmingham have a particularly high proportion of young people (Birmingham City Council, 2019). This area is an important place for understanding childhood now and the foundational family and care experiences of forthcoming generations.

Local authorities in England, including those in the West Midlands region, have responsibility for services for young carers and typically have policies in place that echo the principles of national legislations and strategies. These transmit and solidify the national ambitions to identify and assess children who may be young carers. This local response to young carers could potentially reach large numbers of young people. The 2011 census counted 19,000 children in the West Midlands who provide care for a family member. This method of counting children as young carers has been criticised as a likely underestimate (Cheesbrough et al., 2017, Vizard et al., 2018, Joseph et al., 2019), so rather than a rate of 2.2% of the population of children being a young carer other measures would indicate 4-5%. Nevertheless, based on data collected by the Children’s Commissioner for England, 25% of the population of young carers in the West Midlands counted by the census will be receiving support from the local authority (Children’s Commissioner for England, 2016). That policy presence will be reaching a significant minority of children and their families connected to the young carer category.

1.4.1. Young carers in the local economy of care

In the field of young carers it is significant to localise the discussion of young carers' lives. Although, as stated above, the policies reflect a national policy direction, this belies the potential for the importance of local factors. Children's care work is embedded in an economy of care, in which the government (local or national) interacts with the market, the voluntary sector and private/domestic groups to collectively account for a totality of local care work (Miller, 2005, Razavi, 2007). Young carers' involvement in care will be shaped by the way their contribution to care work and their receipt of care interacts with commercial care provision, public services, charitable organisation and other family figures. The care resources are also connected to a wider economic system, for example, the commodification of workers in the labour market (Esping-Andersen, 1990) and the investment or depletion of the resources needed for social reproduction (Federici, 2012, Rai et al., 2014). We can use the detail of local experience at a scale that helps us explore the economy of care perspective as part of the analysis of young carers and family life.

The West Midlands regional economy of care, connected to those of the national and global (McDowell, 2017), provides an important context for studying family life. The shifting social policy terrain of austerity influenced resource availability and necessitated alternative practices in families and in care work (Crossley, 2016, Parr, 2017, Power and Hall, 2018). These social policy measures have been undertaken against a backdrop of ideological associations between care and private spaces, a normative position long-sustained in social policy design. The assumption that care will largely be managed by families in private implicitly involves children, but this is often not considered directly when those policy decisions are made (Barry, 2011). The family is idealised where it contains care needs without recourse to the state and measures within the welfare state that encourage family arrangements can be subtle or sustained without much political scrutiny.

The economy of care in this period is powerfully shaped by austerity policies (Power and Hall, 2018). Parents, children and families are objects of austerity policies, connecting them to historical trends in the social experience of reduced public financing of community services and harsher public decision-making for the welfare state (Jensen and Imogen, 2012, Crossley, 2016). These have intensified across the 2008-2015 period when today's young carers are growing up (Burchardt and Obolenskaya, 2016) with families affected by austerity policies such as the benefit cap, a freeze on inflation-related rises in working-age benefits and more restrictive assessments of disability benefits (Millar and Ridge, 2019). It represents a historically specific point in the relationship between families and poverty (Daly, 2018). Most marked has been the reduction in public expenditure on social care (Burchardt et al., 2016). Meanwhile people officially recognised within the category of disability are being actively reduced and associated state benefits to this group are shrinking (Roulstone, 2015). Public investment in care in the UK context is restrained and is framed as exceptional, based on extrinsic justification, as in the case of childcare as a measure to encourage greater female labour market participation (Sigle-Rushton and Kenney, 2004). The investment in health services is understood to be distinct from care and is encompassed by a very different settlement to that of the social care category. This is painfully experienced at the individual and collective level (Lewis, 2001), redistributing costs from the state to the private individual and from the formal to the informal sector (Razavi, 2007). This disperses and individualises conflicts over resources.

1.5. Writing care

In the case of young carers, 'care' is central to their categorisation. Public services are required to act under the circumstances that care arrangements in families trigger the labelling of child as a young carer. If the child is a young carer or, even, appears that they could be in the future, the local authority now has the powers to take action through the assessment process. An interpretation of care is crucial to this potential action by public services to alter the organisation of care work in the home.

In the most recent legislation in England, the Care Act 2014 and the Children and Families Act 2014, the category of young carers has been broadened to be more inclusive of a wider group of children. Legislative developments have removed criteria that restrict membership to the group by removing the criterion of care work being “a substantial amount of care on a regular basis” as in the 1995 legislation that new laws supersede. Thus the Children and Families Act 2014, which amended the Children Act 1989, defines young carers as “a person under 18 who provides or intends to provide care for another person” with the qualification that this care would be disqualified if it is undertaken within a contractual relationship or as a volunteer.

The concept of ‘care’ is taken to be self-evident or well-established in law. Whilst the legal definition will not necessarily be reflected within research or in the local infrastructure that often defines young carers in practice, it has a profound institutional and rhetorical status within public bodies (Cooper, 1998). This represents an effort to rearrange the relationship between young carers, their families and the state. It is part of a history of these changes (Olsen, 2000, Thomas, 2005) but is significant because it elevates the status of being a young carers into a formal mechanism in a new and distinctive relationship, with implications for families’ control over the boundary between public and private interests in the organisation of care.

The meaning of care is left implicit in many instances described above. This study has proceeded without pinning down ‘care’ as a concept. Its breadth and lack of boundaries facilitated conversations, for example, phrased in the question “how do you and your family care for each other?” It could be interchanged with ‘support’, ‘help’ or ‘look after’; all these phrases have different, though also broad, connotations and resonance (Jupp et al., 2019). I have thought about care, in the deployment of it as a word, as the actions that people take in response to one another’s needs, motivated by knowledge of forms of need that have existed in the past, exist in the present and will exist in the future. It has many forms and constitutes a type of work but crosses the boundaries of paid/unpaid, formal/informal and public/private. It is not easily contained, yet care is characterised by the effort to contain unmet needs. This complexity of care, across childhoods and in the context of inequality, is discussed in relation to the state of knowledge of young carers in the next chapter.

2. Responding to existing knowledge on young carers, family life and policy presence with the theory of the public/private politics of care

2.1. Introduction

This chapter discusses the state of knowledge on the topic of young carers. I focus on the way this group are defined and the extent of knowledge about their experiences in the context of inequalities. The literature review developed iteratively, opening up new lines of thinking as I prepared for and undertook empirical research. This approach has been influenced by reflections on literature reviews from do Mar Pereira (2017), therefore I aim to provide a discussion of how this work connects to that of others, ranging from those who have undertaken related endeavours and those who present different interpretations of the problem at hand. As do Mar Pereira sets out, this exercise can be “a critical discussion of what one might learn from that literature and how it can be used to formulate different or further questions” (Pereira, 2017, p.17) instead of an approach that I might have used previously which constructs a gap but restyles it as a description, reducing the representation of collective contributions to knowledge.

The approach is enhanced by the results of a collaboration that resulted from one of the participants, Kaya, Alia’s mother, who will be introduced in Chapter 4, suggesting a selection of books that could inform my project. This prompted me to put a request to my participants to suggest reading material for me to engage with. The book recommendations informed some of the later discussions about fieldwork findings but also had a bearing on the scope of this literature review, where some suggestions initiated more varied reflections on the written material that informs the project.

2.2. Defining young carers

The study began with an interest in the subject of young carers and therefore an engagement with a broad set of research and scholarship on children who are characterised by their involvement in domestic care work. It focuses on evidence and discussions pertaining to England, however, it is important to acknowledge the highly relevant global literature on young carers, which is indeed drawn on here. Firstly, I consider the definitions and conceptualisation of young carers in the academic literature. The earliest writing on topic of young carers shows an emerging field of study on young carers, with researchers creating schemas and definitions that shape the subject area (Becker and Aldridge, 1993, Jenkins and Wingate, 1994, Frank, 1995). Collectively referring to a group of children as young carers, researchers, activists and policy-makers have increasingly relied on this term to define a crucial characteristic and to explain their relationship to the “policy problem” (Bacchi, 2009) of carers and the ways that informal and unpaid care is carried out in the UK. Different definitions are operationalised into research that estimates the population in the UK (Kelly et al., 2017, Aldridge, 2017). These definitions persist despite concerns that the children being labelled as young carers do not easily associate themselves with this term (Jones et al., 2002, Molyneaux et al., 2011, Hughes and O'Sullivan, 2017, Evans and Becker, 2019). For this study, young carers are defined with reference to the Children and Families Act 2014, that states that this means “a person under 18 who provides or intends to provide care for another person” unless that care is provided as part of a contract of employment or as voluntary work. This definition has been used as a starting point for research and then discussion because it governed the institutional processes that decided which children are young carers and therefore were recruited into this study. This national criterion, very broadly set out, is implemented via local government provision which funds work that connects children who fit that definition to specialist public or voluntary sector services.

The literatures on young carers and adult carers demonstrate growing recognition of the historically and geographically specific construction of the carer (Chattoo and Ahmad, 2008, Evans and Becker, 2019). The consideration of young carers as a socially constructed category (O'Dell et al., 2010), in contrast to those who emphasise its universal application (Leu and Becker, 2017, Stamatopoulos, 2014), has parallels with the case of ‘street children’ discussed by Glauser (1999) in which the concept is created and used by those with more powers to set the terms of interactions. Those with less power may struggle to identify themselves with the label but may reconcile themselves to it. They may show a determination to undertake a process of “refusing recognition”, in the words of Skeggs (1997, p.139) based on the cultural resources that surround the idea of young carers.

One participant, XD, a young carer, recommended the book, ‘Face’ by Benjamin Zephaniah (2018), which had impressed upon him the ways that the identities that young people recognised were sometimes forced to change when circumstances changed around them. The difficulties of children taking on the label of being a young carer has been explored mainly in relation to their interaction with services (Jones et al 2001) but not in the ways these tensions might also be present as part of family lives and the household-based understandings of care. Constructivist approaches to young carers (O'Dell et al., 2010, Day and Evans, 2015, Akkan, 2019a) help us pay attention to the ways that this category is interpreted and used in a particular context and is therefore used in this study in order to consider the ways that it is constructed and embodied in the lives of participants.

2.3. Deconstructing the academic literature on young carers

This section develops two arguments based on a deconstruction of academic knowledge on young carers. Ramazanoglu and Holland (2005) refer to Judith

Butler's description of the act to deconstruct as "not to negate or dismiss, but to call into question and, perhaps more importantly, to open up a term, like the subject, to a reusage or redeployment that previously has not been authorized." (Butler 1992 p.15 quoted in Ramazanoglu and Holland, 2005). They call for the use of deconstruction as a feminist technique that is attentive to the potential for this practice to bring together theory and lived experience. The approach here seeks to consider the techniques of construction and alternative paths for the concept of young carers in order to provide a foundation for understanding lived experiences meaningfully and with an interest in arguments for social justice that recognises and responds to young carers.

The academic literature on young carers shows particular strengths in an in-depth engagement with children's words and ability to represent their experience of providing care and its ramifications across areas of their life, based on the selection of methods and close attention to individual children's accounts of their lives. It succeeds in valuing children's experience as children, rather than in their potential as adults (Lister, 2006). In achieving this the academic literature on young carers is dominated by empirical work that draws on particular methodologies. These frames of research add evidence in support of the thesis that children who undertake care in families with a disabled person as a member are best understood as 'young carers'. Methodologies of research into young carers have framed and sought solutions to concerns about young carers' lack of voice and experience of disadvantage by using methods that individualise the experience and that have prioritised an inequality of care as dominating other forms of inequality (Ward, 2015a). The two problems of individualisation and inattention to intersecting inequalities have consequences for the ways that young carers are understood, particularly in the context of growing policy interest in their family life.

2.3.1. Methods of research on young carers

Research into young carers tend to use a narrow range of methods. The dominant methods are small-scale non-random quantitative cross-sectional surveys (for example, Dearden and Becker, 1998, Warren, 2007, Sempik and Becker, 2014) and semi-structured qualitative interviews (for example, Aldridge and Becker, 2003, Barry, 2011). These have contributed data which has consolidated a set of conclusions about the populations of young carers. Young carers are presented as a distinctive feature of a set of family units, as an aberration of care practices in the context of limited social care provision in the UK (Bibby and Becker, 2005). They are situated in families that contain a person who is disabled (whether through physical or sensory impairment, learning disability, HIV status, mental distress and/or a chronic illness). The reach of how disability is defined may sometimes include or exclude families (e.g. addiction or neurodiversity being included or excluded) (Clarke and O'Dell, 2014). A young carer is a child who takes on care work, which is sometimes explained as the work that adults, individually or collectively, are unable or unwilling to do (Becker et al., 1998, Bibby and Becker, 2005), that is if we accept the premise that care is the rightful domain of adult labour and that it is not something that children, like adults, may wish to do. This sketch of private family care arrangements is connected to descriptions of distress within public environments, such as schools, health services and welfare agencies (Thomas et al., 2003, Eley, 2004, Bibby and Becker, 2005, Butler and Astbury, 2006, Barry, 2011, Crafter et al., 2017). Recent studies have contributed an assessment of the methodological strengths and weaknesses of existing research into young carers (Kelly et al., 2017, Cheesbrough et al., 2017, Aldridge, 2017, Joseph et al., 2019) but this recent development illuminates the lack of methodological critique of the literature until this point. A response to this problem is set out in the next chapter on methodology where I argue for greater methodological innovation, contributing one answer in the form of ethnographic approaches.

2.3.2. Challenging the definitional limits in the literature on young carers

In addition to the point about the methodological limitations of the literature on young carers, this study provides a response to the limitations of the young carer concept by taking a broader approach informed by the feminist literature on care work, intersectionality theory and work from a range of disciplinary perspectives.

A key perspective from cultural anthropology that could introduce another dimension to understandings of young carers is from Alber (2003) who examines the cultural formulation of adults' claims on children, within hierarchies of legitimacy. Children's labour has a different status depending on the adult figure that requires, oversees, disciplines and adjudicates this work. In the case of Alber's work on children, kinship and work in Northern Benin, she conceptualises changes in the claims that are available to a range of adults based on relations of biology, family and geography. Adults compare claims on a child for kinship or fostering relationships, paying attention to the different educational opportunities for children in the arrangements for children's receipt of care and their membership of a household. Biological parents are one part of a network of relationships that care for and train children at different stages. Expressions of shame play a role in signalling people's recognition of a lower place within hierarchies of claims on children. This research introduces a cultural perspective on how children are mobilised across geographic and economic spaces, which could strengthen understandings of how children are part of a culturally-specific economy of care. As Evans (2019) argues we can recognise the Majority World understandings of care and intergenerational obligations in reflecting on the application of the young carer concept in the UK, and it may have a specific relevance in lives informed by migration between the UK and parts of Africa, as represented in one participating family in this study.

An array of other groups of young people are connected to forms of care work but are not included in the young carer definition. It is helpful to recognise the way that the term "young carers" has captured understanding of children's involvement in care work without acknowledging a wider context of this work.

Other areas of research discuss children doing unpaid care work in families not defined by the presence of a disabled or ill family member, for example, in 'post-divorce families' (Haugen, 2007), in families where there is domestic violence (Callaghan et al., 2016, Åkerlund, 2017), as language brokers (Dorner et al., 2008) and when parents are returning to the labour market (Millar and Ridge, 2009). Children are also involved in paid care work (Morelli et al., 2003, Souralová, 2017) and should have greater recognition as part of the economy of care (Qvortrup, 1985, Miller, 2005) because they are unjustifiably overlooked and this is necessary to inform work that improves children's access to their rights (Camilletti et al., 2018). Acknowledging the limitations imposed by over-associating children's care work with the young carer concept, we can begin to bring a wider and more nuanced picture of children in the economy of care into policy discussions.

Influenced by these cross-disciplinary perspectives, I intend to contribute to two conceptual shifts in working with the young carer concept: seeing connections to wider forms of children's care and work and a more nuanced understanding of the position of the person seen as the care recipient.

2.4. Considering inequalities in the lives of young carers

This study addresses the limitations of research on young carers in terms of intersecting inequalities. This section reviews the extent of knowledge in this area and ways of building on it. This section begins by explaining the intersectionality theory-informed framework and reviews current research on inequalities of ethnicity/’race’, gender, age and the lifecourse and disability.

A few studies have discussed this under-explored element of young carers experiences. The study by Jones et al (2002) stands out for providing insight into limitations of the developments of the young carers concept when viewed from the perspective of Black and working class families. They argue that it misrepresents the varied ways in which children participated in the efforts of mutual family support. This provides an example of Ward’s (2015a) argument that intersectionality usefully frames the study of the association between care and identity, particularly considering the relationality of care, as emphasised in the Ethics of care body of work. Jones et al (2002) found that services designed to meet the needs of young carers understood in generic terms were off-putting to these families or were inadequate in their responsiveness; families were also wary of the implications of being labelled using the concept of young carers, a concern that reappears across the literature and has not been reduced despite a quarter of a century in which public and voluntary sector services have ostensibly sought to allay these fears (Smyth et al., 2011, Molyneaux et al., 2011).

2.4.1. Intersectionality as a framework for research on young carers

This study engages with intersectionality theory (Crenshaw, 1989, Mirza, 2015, Hancock, 2016, Hill Collins and Bilge, 2016), therefore, considering a wide range of categories of social difference, which are understood as social structures that conceptually arrange people in hierarchical ways. Categories are explicitly or implicitly referenced in social interactions that create knowledge of an individual's salient relationship to society (Hill Collins and Bilge, 2016). Examples of categories of social difference are class, gender, ethnicity and 'race', age, disability and sexuality. An overarching term, social location, describes the collective effect of these structures on individuals or groups. Categories of social difference are used and understood in varied ways within epistemological and theoretical traditions but in the young carer literature they are often seen as determining people's lives by reducing people to positions of low status or at other times drawing people together around particular forms of a social category as the basis for collective action and celebration. However, there has been little research that explores the operation of multiple categories of social difference in the lives of young carers and their families, with the notable exception of Jones et al (2002), or that delves deeper into the theorisation of difference and inequality amongst young carers.

The development of intersectional approaches has been led by Black feminist theorists Crenshaw, Hill Collins, Bilge, Mirza, mentioned above, and others such as Cohambee River Collective (1983), Lorde (1984). They have called for a reframing of theory and empirical research to strengthen the engagement with the social experience of categories such as gender, ‘race’, class and sexuality. It critiques the limitations of existing scholarship which exclude and undermine knowledge of Black women and their experiences as women, as working class, as queer and their relationship to other categories of social difference (Lorde, 1984, Crenshaw, 1989, Hill Collins and Bilge, 2016, Hancock, 2016). This diminishes understanding of gender relations, racism, class structures, sexuality and other forms of inequality (Spelman, 1988). Tomlinson describes intersectionality as a mid-level theory, which adds nuance to understandings of a global “theory for antisubordination and social change”, (Tomlinson, 2018, p. 2). So whilst intersectionality powerfully supports analytical engagement with categories of social difference, it is connected to a political and theoretical project of debating and securing social justice. Intersectionality challenges writing and political movements that obscure Black working-class women’s lives (Crenshaw, 1989, Hancock, 2016, Hill Collins and Bilge, 2016).

The intersectional approach to categories of social difference introduces distinctive features into an analysis of inequality and social relationships. Firstly, intersectionality seeks to establish how categories of social difference are connected to the operation of power. Hill Collins and Bilge (2016) argue that categories of social difference “gain meaning from power relations of racism, sexism, heterosexism and class exploitation” (p. 7). Power is under-theorised within research into young carers and the family is an interesting site for studying how power shapes familial and care relationships. Incorporating this aspect of intersectional theorisation expands what we can say about how young carers experiences shape and are shaped by family life.

Secondly, intersectionality is distinctive in how it attends to categories of social difference as mutually constitutive. For example, intersectional studies would examine how sexism and racism shape each other and an individual’s experience of those relations of power so they cannot be explained one without the other. Foundational work on intersectionality by Crenshaw (1989) examined how Black women working in industrial jobs had their legal claims of sexism and racism rejected. Their subject positions as both female and Black meant that they were excluded from definitions of sexism and racism. Where the treatment of Black men was not discriminatory in the same way as the treatment of Black women, this was seen to undermine arguments of racism. Likewise, where white women were treated more favourably than Black women this was taken to undermine arguments of sexism in legal cases. Black women were made invisible subjects because the social categories of ‘race’ and gender were understood to exist separately. Indeed, the very language we use recreates these exclusions and produces clunky formulations of social difference (Butler, 1999, Tomlinson, 2018). The reduced availability of claims of sexism or racism for Black working-class women demonstrates the dangers in seeing categories of social difference as separate from one another (Spelman, 1988, Konstantoni and Emejulu, 2017). This is an important third element, which is to work toward visibility, meaning something more than just being seen but also recognition, which “substantively attends to what comes into view” (Hancock, 2016, p.48).

The existing literature on young carers seeks to connect data to an analysis of categories of social difference through a range of research questions and methods. This is done in different ways but has not been explored with serious attention to developing an intersectional framework. Research into what categories of social difference mean for young carers has more recently been added into the debate about how to understand children’s relationships to care. Amongst the most recent studies of young carers, some have introduced intersectionality as a reference point (Hamilton and Cass, 2017, Kelly et al., 2017). However, a more extensive intersectional study of young carers, building on elements of the literature, would seek to add a new perspective using the distinctive features of the approach described above. It is particularly exciting to think about responding to the intersectionality encountered through in-depth qualitative research, rather than to explore limited and pre-determined intersections between set categories (although this is constrained by my positionality in the field).

In summary, I argue that the key features of intersectionality that contribute to understandings of young carers are: attending to the ways that categories of social difference are connected to relations of power, the mutual constitution of categories in particular contexts and reframing the approach to positions of invisibility.

2.4.2. Existing research on young carers and categories of social difference

There are a number of studies on young carers that contribute to an initial understanding of categories of social difference but these are limited in the extent to which they build an intersectional picture. I will, therefore, discuss ethnicity and ‘race’, gender, age and lifecourse and disability as topics of research in the young carer literature. In each discussion I indicate the strengths and limitations of research on these categories of social difference that could contribute towards intersectional knowledge about young carers.

2.4.2.1. Ethnicity and ‘race’

Theory and the lived experience of ethnicity, ‘race’ and citizenship status is brought into the discussion about young carers by Jones et al (2002) as discussed above. A few quantitative studies provide statistical analysis of ethnic diversity amongst children categorised as young carers (Becker et al., 1998, Society, 2013, Wayman et al., 2016) but the discussions of how to interpret these statistics are tentative. There is also a risk of ethnicity being essentialised as a determining or factor in the experience of care, undermining the complexity of people’s social location (Nayak, 2006, Chattoo and Ahmad, 2008). The majority of studies about young carers focus on white children. However, whiteness as a social location is unremarked upon in studies of young carers. ‘Race’ and ethnicity are little researched when it comes to young carers but in order to understand this category, I would argue that intersections between it and other categories will be a helpful starting point, learning from Jones et al’s approach to the study of disability and Black and ethnic minority subjectivities.

2.4.2.2. Gender

The analysis of gender recurs as an element of discussion in a number of studies on young carers, although there is a lack of data on what these categories mean for an understanding of this group. The gendering of care work for children and young people is a theme that is alluded to in the literature but even when it is intended for exploration it appears difficult to grasp within the research frame. For example, an attempt to illicit comment on gender using discussions of a vignette about young carers was unsuccessful as the children interviewed did not offer views on the greater involvement of a female siblings compared to her brother (O'Dell et al., 2010). Likewise, Eley’s (2004) research, which sought to explore young carers’ construction of gender through their educational experiences, offers restricted insights. Dearden and Becker (1998) look at the connections between age and gender in providing context to children’s care roles. Sibling ordering and a lifecourse perspective inform their analysis of how girls in some families explain their greater involvement in care compared to brothers. They record a range of potential explanations such as gendered preference, naturalised skills and gender norms for children's unequal participation in care but it is ultimately inconclusive. Research into young people's gender (Skeggs, 1997, Nayak and Kehily, 2007) or adult women's narratives of gender identity and care work (Oakley, 1974, Lewis and Meredith, 1988, Carrasco and Domínguez, 2011) suggest that extended research encounters and a more expansive understanding of how gender may manifest itself within social interactions, intertwined with other categories of social difference, may support a revisiting of gender within the young carers literature.

The intersection between gender and disability has been the subject of discussion within the young carers literature. Arguments put forward, informed by disability studies and feminism, have been critical of the marginalisation of the views of disabled mothers, despite their prominence in the research on young carers (Keith and Morris, 1995, Prilleltensky, 2004, Clarke, 2017). These arguments contribute to a wider discussion of the historic denial of disabled people's sexuality (Goodley, 2011, Shuttleworth et al., 2012, Shakespeare, 2014), including the role of sexuality and parenthood in the identities and transitions of adulthood (Priestley, 2000). In the case of disabled adults, whose child is defined as a young carer by services, the person in receipt of care from a young person is subject to potential policy intervention, with an impact on their autonomy, social status and private life. Therefore, the policy direction that takes increasingly seriously the need to act when children are in the role of young carers has implications for the rights of disabled parents, particularly mothers. This is at risk of being unchallenged unless the critical arguments from disability studies, for example those developing a social model of disability perspective, can draw attention to the disabling context in which children and their families are presented as symbols of conflicted interests (Olsen, 1996, Parker and Clarke, 2002). The intersection between disability and gender is found to give insight into the social construction of parenthood for mothers of young carers but could also be an important perspective on the experiences of young carers and siblings.

2.4.2.3. Age and Lifecourse

Age as a category of social difference in the lives of young carers has been theorised for its relationship to the lifecourse and identity by Hamilton and Cass (2017). They argue that age and lifecourse affect the relationships through which a young person is likely to be carrying out a care role, the progression and intensity of the caring role and the outcomes that are matters for concern. A lifecourse-informed approach, Hamilton and Cass (2017) argue, should include consideration of the way that past, present and future are features of a carer identity. However, Heyman and Heyman (2013) provide evidence of the way that future, in particular, is brought into the conversations between young carers and the professionals supporting them. They consider the relationship of age to anticipated future employment for young adult carers and find that young adult carers dispute the perspective of adults in their lives who discourage them from care work when it comes at the expense of activities that prepare them for future employment and other conceptions of adulthood. Lifecourse, exemplified in these two studies is applied differently in ways of thinking about young carers. This study draws on the ways that past, present and future are co-existing perspectives in the family life of young carers but also considers the social construction and normative context in which ideas of transition and lifecourse are referred to in the representation of people’s lives. These can be socially problematic for young carers but also for disabled people (Priestley, 2000, Shakespeare, 2014).

Age is found to be related to the allocation of different types and volume of care work undertaken by children in families (Aldridge and Becker, 2003). The category of age is drawn on to explore the distinctiveness of young carers’ experiences but also to analyse the sufficiency of policy strategies as they apply to children (Bibby and Becker, 2005). Some studies in the young carer literature use legal definitions to establish how dominant approaches to the category of age contribute to boundary setting around the group whilst other studies draw on ideas of age and lifecourse as socially constructed and culturally specific (Evans and Becker, 2009, Day and Evans, 2015, Evans, 2019, Akkan, 2019a). This consideration of how social differences operate in the lives of young carers and their families has not yet been extended to a detailed consideration of the people receiving care from children and others in the family who may draw on ideas of age in their accounts of family life; the research undertaken here seeks to address that gap.

From a contrasting perspective age and disability are connected in the literature through some forms of analysis about parents receiving care from their children. The language of parentification is sometimes referenced in the young carer literature, meaning the process by which a child takes on an inappropriate role that echoes cultural expectations of parenthood. It is debated for its relevance and criticised for being a problematic representation (Olsen, 1996, Banks et al., 2001, Clarke and O'Dell, 2014). This debate has drawn attention to contentious assumptions about the incompatibility of, for children, childhood/care role and, for adults, parenthood/care receipt. This has particular resonance in representations of motherhood and gendered understandings of parenting roles amongst men and women (Clarke, 2017). The connections between age, disability and gender that could be explored in order to better understand young carers and their families.

2.4.2.4. Disability

Disability is prominent within the young carer research but the adequacy of its representation is contested. Some studies use impairment or different categories of disability to narrow down the research field (Aldridge and Becker, 2003, Evans and Becker, 2009). The focus is on disability as seen through the eyes of non-disabled children and professional adults involved in the family, motivated by concern for the wellbeing of those children (Clarke and O’Dell, 2014). The experience of disability of children that undertake care is little explored, though some studies suggest it is an important category for research into young carers (Sempik and Becker, 2013). As with disabled parents, within the young carer literature there is more scope to explore the relationality of care and the dual participation in being a carer for someone and receiving care ((Ward, 2015b, Aeyelts et al., 2016, Meltzer, 2017). One of the study participants, Kaya, suggested the relevance of literature on neuro-diversity as an alternative perspective on the construction and experience of disability for those labelled as autistic, for example, the study by journalist Steve Silberman (2016) who stresses the potential for individual and collective identification with an autistic community developed in tandem with a social model perspective on disability. The meaning of disability for disabled people and their family members within the young carer context is relatively underdeveloped, viewed in ways that are dominated by concern for the interactions and associated social stigma tied to the young carer identity.

As has already been argued, research on young carers can produce a problematic representation of disabled people as parents, siblings or family members (Olsen, 1996, Keith and Morris, 1995), missing the voices of disabled adults as parents (Olsen and Clarke, 2003) and disabled children’s family lives (Shah and Priestley, 2011, Watson, 2012). There is an acceptance that this has made its mark on the policy development in this field (Olsen and Clarke, 2003, Clarke and O’Dell, 2014). The disability studies literature offers a range of areas of research and theoretical developments that can continue to suggest ways of strengthening empirical work (Watson, 2012) on young carers and the critical engagement with policy; three key lessons are emphasised here. It is extremely relevant to consider work on the family as a site in which disability is formalised, understood and modified as an identity (Watson, 2002, Scully, 2010, Shah and Priestley, 2011, McArthur, 2012). Secondly, it provides theoretical tools for interpreting the language of disability and impairment that are drawn into everyday conversation (Goodley, 2011, Shakespeare, 2014). Thirdly, it details the ways in which disability is a reference point for disabled people and able-bodied people in understanding the potential for social connections and interpreting those that flourish and those that are troubled (Shakespeare, 2014). The able-bodied and disabling world expects disabled people to navigate and resolve social barriers (Scully, 2010) and the economy of care overlays a system in which these difficult processes play out, with real human cost.

2.4.3. Applying intersectionality theory as a critique of the young carer literature

There are some notable categories of social difference that are overlooked in research into young carers and their families. There is an absence of studies of class as a category of social difference. Some connections between class and poverty are noted but this is not developed within the academic literature. Likewise, sexuality has been little studied in relation to the involvement of children in care work (an exception is from Traynor, 2016), despite its use as a reference point within the heterosexual structuring of care work (Twigg, 2000, Price, 2010, Ward, 2015a).

Insights built upon an intersectionality framework could draw together areas of research that speak to connected categories of social difference; however, these insights will be limited if it stays within the individualised frame. Therefore, this research seeks to contribute to the research-based understanding of young carers by building on existing research to examine the relationality of children's care in the context of intersecting inequalities. A selection of studies have argued for the importance of understanding young carers, at least in part, through knowing more about their relationships and about care as existing through the rationality of family life. Examples of this are Meltzer's work on siblings with and without disabilities, including arguments about the potential for knowing more about young carers as siblings (Meltzer, 2017, Meltzer, 2019). Aeyelts et al (2016) provide a detailed analysis of a young carer, her relationship with her mother and the shifts in care over time. The broader research by Cheesbrough et al. (2017) incorporates some attention to parent-child relationships within a study of support for young carers but this was limited in its ability to recruit and go into detail about what this means for assessing needs and reconciling the conflicts that services might face when seeking to support more than one member of a family. Evans and Becker (2009) used an approach informed by an Ethics of care, which stresses the relationality of care in families with a child caring for a parent with HIV in the UK and Tanzania. Jones et al (2001), in their study of Black families that include a young carer (although they raise concerns about the applicability and acceptability of this term) show the rich potential of studying young carers as part of families. They also make a strong argument for seeing the development of policies in this area and their consequences as unequal when we consider how they are experienced by Black and working-class families. These studies show the potential for understanding young carers as part of relationships.

The literature on young carers has demonstrated the importance of understanding children's involvement in domestic care but methodological and conceptual limitations have obscured the relationality of young carers lives and the ways that care is a varied form of work in the context of intersecting inequalities. Addressing this requires overcoming theoretical and methodological challenges (the collective/relational and adapting to study the 'private' sphere) to promote a way of seeing young carers that makes space for knowledge of families and is open to shifting the definition of young carers as a consequence.

2.5. Literature on family life

Research into children's care work and young carers can be connected to understanding family life and family relationships. Families are central to care provision, with families as the site of the majority of care work (Shelton and

John, 1996). From a cultural perspective, they are also the archetypal site of caring relationships (Barnes, 2015).

The family is the site of personally important and socially formative relationships. It has a particular significance for children and young people, who may spend more time with family members or have more of their time defined by family activities. However, the family has in some ways been overlooked as a site of research interest, being seen as less important, interesting or prestigious in terms of sociological or economic debates (Morgan, 1996). Feminist academic work has established a greater importance of families, households and associated relationships as sites of labour, as part of the picture of inequalities and as interesting in their own right.

Reviews of the literature point to the risk of a functionalist view of family life, which defines families in ways that are evidenced by the world we see now. Such work often refers to the family, as a bounded and coherent institution supporting social structures of control and continuity. This has been criticised for perpetuating oppressive gender norms and it is associated with hierarchies of class, ethnicity and sexuality (James & James, 2001; Smart, 2007).

A move against this static view of the family includes the concept of ‘doing family’ by which Morgan (1996) defines family with reference to practices that are actively engaged in and which build meaning, relationships and ways of living. Smart (2007) extends this to a wider concept of ‘personal life’ that situates people in the social work and relates them to it. It also provides a platform for the exploration of meaning and its creation through the medium of family life (Ribbens McCarthy et al, 2011). An element of this creation of meaning is the construction and commitment to the idea of a private space, despite the challenges that families might face in realising this or the consequences individual family members might face because of threats and isolation entailed by this seclusion (Ribbens McCarthy et al, 2011).

The concept of doing family reduces the potential of the family to be an analytical tool or unit of comparison. Instead we can trace the activities that build meaning and by which people are mutually socially located. Doing family is an active and participatory concept, with conveys the potential for flux and change. It is not necessarily progressive, participated in equally or benevolent. By restating family as an activity, rather than an institution or state of being, it encourages critical reflection on the activities that are continually undertaken to build the feeling of family, those experienced both positively and negatively.

An example of doing family is family photographs. The act of discovering or rediscovering photos is used as a metaphor for the challenge of accessing meaning within family (or constructing it). Smart (2007) and Poulos (2009) are two examples where discussion of the author’s family photographs initiates a new and complex engagement with the contested process of doing family. The concept of doing family asks us not only to consider the image placed on the shelf showing a group of people at certain points in their lives but it asks us to consider instead the process of selecting the image, displaying it and creating family materially and culturally. This is a discursive production of family, as an image, an ideal and a shared form, marking family spaces (Harker, 2010). We can then enrich this further by considering the way the use and reference to photographs as a collective activity that builds shared reference points, which are revisited, drawing on the past and looking forward to the future. This presentation and display of family has particular resonance in the context of care. The material and symbols arranged in someone's home give insight into the individual identity that people may assert when they fear that care interactions may be reducing them from a social to a biological body (Twigg, 2000).

Within the sociological study of family and its performance we can also add nuance to the understanding of particular family roles. An important area in relation to this study is the experience of being a sibling. Children perform sibling roles and their social construction makes reference to complex interplay of gendered relationships, as experienced and participated in by social actors (Edwards and Weller, 2014, Callaghan et al, 2015). The role of siblings in providing care to one another and the way that the sibling identity is inhabited has been studied in a range of contexts, for example, in managing the experience of domestic violence (Callaghan et al, 2015, Akerlund, 2017). This draws on gendered ideas about care but also refers to the importance of sibling age order (Edwards et al, 2006). Greater appreciation of the significance of sibling relationships sociologically has contributed to this area of study, along with the exploration of the creation of sibling identities in the context of disability. Interesting findings about the misrepresentation of disabled childhoods and siblinghoods by non-disabled siblings points to the significance of social construction as empirically experienced by young people living together in families (Meltzer, 2017, Shah and Priestley, 2011). This provides an important background to the discussion of sibling relations, as the basis for the practices of designating social identity through family interactions. Thus, alongside the literature on 'doing' family, the sociological study of siblings lends itself to a rich analysis of the activities, relationships and identities in families containing young carers.

2.6 Public and private politics of care

This study introduces and explores a theory of the public and private politics of care, which has developed in and through ethnographic research. The public and private politics of care is defined as the contestation of care in and across 'public' and 'private' spaces. Politics was not an element that was anticipated at the start of this study. The young carers literature does not sufficiently consider the political context in which policies are formed or the everyday politics in implementation and families encountering it. This incorporates a depoliticisation of young carer research, despite the insightful political arguments put forward by those working within a disability studies framework and taken into account in later work (Aldridge and Becker, 2003). This is connected to a wider representation of carer issues as uncontroversial and relatively apolitical, even in a political sphere (Manthorpe et al., 2019). However, a growing appreciation of the process of negotiation in the home through ethnography, as developed here, urges a reflection on the political. It also suggests the potential to connect an understanding of families' organisation of care to representations of interpersonal and affective micro-level politics that are shaped by inequalities.

2.6.1. Relevant literature for a public and private politics of care theory

This approach builds on a range of work on how politics is brought to bear on people's scope to act, in the context of inequalities in the freedom that individuals and families are afforded (Crossley, 2016, Garthwaite, 2016, Jupp, 2017, Parr, 2017). It has connections to theoretical work on affect and the politics of the body which explores cultural interpretations of people's differences at both the social and individual levels (Butler, 1993, Cooper, 1998, Wolkowitz, 2006, Ahmed, 2014a, Fog Olwig, 2018). The politics of care, therefore, will be explored with reference to the ways that different types of bodies are understood and how this knowledge is acted upon in the organisation or contestation of care work.

The theory also builds on work that defines and accounts for the emergence of ideas of ‘public’ and ‘private’. These are taken as troubled and troublesome terms subject to critique but nevertheless ones that have a legal and normative power in many contexts (Cooper, 1998). Queer theories of public examine the heteronormative assumptions that inform the governance of public space and have implications for the legitimacy of behaviour in ‘private’ spaces. This work supports a creative deconstruction of the separation of public and private. Taking on this challenge of seeing the construction of public and private spaces in opposition to one another, what becomes more visible is a greater range of practices that construct these ideas so that they can be made to feel real. It also makes visible their malleability and potential to change (Berlant, 1997, Hemmings, 2002, Warner, 2005). Work on emotional geographies suggests that policies work with and through the boundaries between public and private space, which are then negotiated in the implementation of policy and in the process of receiving services (Pykett et al., 2017, Jupp et al., 2019). Feminist theorists urge a questioning of the separation of public and private, particularly when different entitlements to public and private roles contribute to gendered inequalities (Phillips, 1995, Young, 2005). The historical figure of the public citizen is premised on a contrasting private world of repose assuming an array of resources available to few people and a larger group who undertake the reproductive work that enables the distinction between private leisure and public liberal right holding (Daly and Lewis, 2000, Siim, 2000, Lister, 2003).

This study takes on the ideas of public and private, as contrasting social constructions of spaces, with cultural significance. However, this is being pursued with a recognition that public and private are continually reformed ideas rather than being neutral timeless labels. The idea of a private life is one that has widespread recognition in the context I am studying and is associated with a range of emotionally significant aspects of life (Smart, 2007), suggesting a framework for studying family but one that is not straightforward. Engaging with ideas of public and private in this study asks us to question the way that spaces, for example the home or specific rooms within the home are put to work as signifying privacy or as an engagement with single or multiple publics (Warner, 2000). The use of space in the home, the arrangement of objects and the matching of places and activities are deployed in ways that engage with ideas of privacy and public engagement (Smart, 2007, Miller, 2001). For example, this is problematised and creatively explored in one of the visual ethnographic methods, informing the analysis in Chapter 8.

The ethnographic methodology sets up an encounter with these contested concepts. It is not undertaken in the expectation that it will give access to essentially private space. Indeed, the use of participant observation disrupts the opposition of public and private and allows for its exploration over time (Hall, 2014). The methodology gives insight into the construction and deconstruction of public and private spaces within the home and in the activities of family life. It is predominantly framed as public/private, recognising the connected construction of these ideas rather than independent meanings. The critical engagement with public/private works alongside the literature on doing, displaying and performing family (see section 2.5). This study hinges upon an engagement with the concept of public/private, as a recreated binary that acquires meaning in the context of family life. It connects the research design, with its exploration of crossing spaces designated as public and private, and theoretical concerns about the politics that socially locates families and individuals within it. Nevertheless, it remains a pairing to be questioned, critiqued and deconstructed.

A few areas of research provide a starting point for empirically exploring the public and private politics of care, although these leave space for exploring children's care work. Some key studies, often informed by feminist theories, have shown the importance of seeing processes of contestation in households. Pahl's work (1995) on couples' financial decision-making encouraged research that opened up the 'black box' of the family to build up greater recognition of the economic processes and a range of inequalities that exist (Henau and Himmelweit, 2013). We are called on to take the family more seriously within research by understanding its real processes rather than limiting its presence to that of the 'black box' or as a romanticised ideal (Gillis, 1996, Papadopoulos and Roumpakis, 2019). For example, Vogler discusses financial decision-making as reflective of micro-political processes within the household (Vogler, 1998). Finch and Mason's study of the negotiation of family responsibility (1993) develops a framework that has informed the close attention to negotiation as a form of contestation that covers public and private spaces in this study.[1] The idea of negotiation is introduced as a useful framework by Aeyelts et al (2016) in a case study of a young carer and her mother, in which they discuss the process of arranging care over time, showing its potential for wider application in the study of young carers. The "politics of home" is a powerful current in our personal lives and one worthy of study (Jupp et al., 2019, Papadopoulos and Roumpakis, 2019, Cuthill and Johnston, 2019).

A linked area of empirical and theoretical work is research on households informed by bargaining models. Bargaining models dispute the unity of household economic behaviour, beginning with a critique of the assumption that 'traditional' ways of organising households such as the male breadwinner model are in the interest of all members (Carrasco and Domínguez, 2011). This is based on economic modelling that test the hypothesis that there is a relationship between the decisions reached when people are in households and people's relative financial position as individuals. This literature suggests that being a person who faces worse economic prospects should the household be dissolved might be in a less favourable position to secure resources in the household because their bargaining position is weaker. This area of work has developed in response to critiques that it does not take into account cultural interpretation of work to have more or less value based on gender (Agarwal,

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[1] Negotiation is a term used in a range of studies about care, particularly those engaged in a constructivist or post-structuralist ontology. In this study I am careful to see negotiation as a deliberative and detailed process, aiming to distinguish this use from its deployment as a metaphor or ontological signal about the way a piece of research defines social processes.

1997, Budig, 2004, Bennett, 2013). It has provided a framework for detailed exploration of decision-making in the household and its connections to economic inequalities. This important area of work encourages us to see the relationship between forms of inequalities and allocation of work in the household but does not consider it in a political dimension.

A series of examples of research in families has shown the potential for recognising children as active within these economic, social and political processes. Miller (2005) points to a tendency to overlook children but we can see studies that emphasise their varied roles in family life in real-time, not just relying on retrospective accounts of adults looking back at their childhood. Children are active in the times when families manage changes imposed by poverty and labour market activation policies (Mayall, 1994, Millar and Ridge, 2013, Daly and Kelly, 2015). Young people are also navigating the inequalities imposed upon them individually and their families, constructing identities over time distinctive from and entangled with family life (Skeggs, 1997, Thomson, 2011).

Lastly, we can draw on historical perspectives to situate this study in the changes and fluctuations shaping households, family life and care as a historically shifting form of work. There are political contours imposed on families (Papadopoulos and Roumpakis, 2019). The physical and social construction of families and households has changed, in conjunction with wider changes of labour, gender relations and currents of globalisation, including colonialization (Davidoff and Hall, 1995, Gillis, 1996, Ehrenreich and Hochschild, 2003, Kilkey et al., 2013). Neither is care an unchanging form of work, subject to pressures, intensifications and regulation (Ungerson, 1997, Federici, 2012).

Taken together, the theory developed here is informed by feminist studies of the household, bargaining models and negotiation literature, children's agentic position and the historical shifts that place people in culturally specific family lives. Within this context there is great potential for understanding a form of politics that shapes care in and across 'public' and 'private' settings.

2.6.2. Literature on the politics of care and young carers

The research on young carers draws on political theories, although without developing a political perspective on the study of family life. Three theoretical perspectives emerge from the field of young carers. Firstly, the Child Rights framework and the Disability Rights framework have been referenced in the debate about the representation and treatment of family members through the formulation of policy (Morris, 1997, Parker and Clarke, 2002, Bibby and Becker, 2005, Wihstutz, 2011). Indeed, there is also an articulation of carers' rights, adding another layer to the consideration of obligations towards children as young carers in families (Knight and Davy, 2019). These have been seen to disrupt the policy making that might see family relationships and shared interests as more central to caring lives (Aldridge and Becker, 2003, Clarke and O'Dell, 2014) in their usage. Nevertheless these remain highly relevant to the legal position of these groups and an important theoretical reference point for the classification of people within a human rights informed world.

A second and third area will be discussed as significant theoretical developments contribute to thinking about the politics of care. For the second, work on young carers has been informed by the Ethics of care literature, which stresses the relationality of care in a specific context, contesting more dominant discourses that undermine its presence and centrality to life (Tronto, 1993, Wihstutz, 2016, Skovdal and Evans, 2017) and its emancipatory or ethical potential in the research relationship with young carers (Evans, 2019, Blazek et al, 2015). This is particularly helpful in formulating a counter framework which may be of interest for the future development of alternative cultural constructions of children’s care, an exercise that has been called for elsewhere (Aldridge, 2008) and is still much needed. However, it is less relevant to understanding why in our current organisation of care some bodies matter less (Butler, 1993) and are due less care and emotion (Ahmed, 2014a).

A similar set of strengths and problems exists in Akkan’s (2019b) theoretical engagement with Fraser’s work on recognition and parity of participation as social justice prerequisites, informed by feminist theory. In applying this to young carers, we can see the insightful argument about the ills of contemporary formulations of care and better interpret the dissatisfaction, suffering and deprivation of young carers and their families. It still leaves untheorized the shortcomings of care that cross between ‘public’ and ‘private’ spheres in the interrelationship between policies and family life in the context of inequalities.

This thesis intends to make a distinctive contribution, not to these wider frameworks for understanding what care is and the political responses we could envisage. Instead it addresses a theoretical gap in analysing how children’s care work happens. This is useful because there is a lack of theoretical proposals that helps us to understand how and why children are involved in care in diverse ways and what relationships this might have to intersecting inequalities.

2.6.3. Alternative politics of care

Interlinked work connects the public and private politics of care to a wider body of work on the political boundaries and qualities of care. Bassel and Emejulu (2018) explore the politics of care by analysing the connections between alternative progressive and radical politics with its foundations in Black women’s practices of care and activism. Their wellbeing and citizenship is threatened by political decision-making but challenged on the basis of their creativity and strength rooted in care for themselves and others. Their work examines a group’s application of care practices to activism, community associations and politics. It draws attention to the resources that marginalised groups use to act in ways that challenge their exclusion and diminishment, based on beliefs about and experiences of care.

An area of work already mentioned above, explores the broad potential for political change directed by a fuller understanding of care comes from the rich Ethics of care literature (Tronto, 1993, Barnes et al., 2015). This approach is applied to a distortion or undermining of Ethics of care in the age of austerity (Power and Hall, 2018, Hall, 2019, Hitchen, 2019). However, core work in the Ethics of care field is the development of a normative stance which gives greater appreciation to the importance of care in collective morality. Gilligan (1986) argued that an Ethics of care is a widely based approach to morality that grows from a feminist critique of psychological research. Held (2006) and Tronto (1993) likewise develop an Ethics of care theory, contrasted with an ethics of justice, which proposes a morality that redefines the self, relationships and forms of responsibility, challenging widespread violence and domination. This literature is heavily shaped by a normative commitment to care, as both a set of practices and values (Held, 2006). The normative framing of this literature and its investigation of values is less relevant to this study than its contribution to the understanding of care as a form of practice. Also excluded from this study are questions about the caring characteristics of those participating in care as part of family life. The interest instead is how are practices undertaken by those who are not in a position to take on or reject care work, instead all are thrown into the family mix of care. Lastly, this study is connected to the Ethics of care literature because of its investigation of relationships and relationality, especially in the design of methods discussed in Chapter 3 and in the analysis of social location in the family and security practices in Chapter 7. However, the overall study is not framed by the Ethics of care approach because of its descriptive rather than normative aims.

These studies take similar terms as those used here in the public and private politics of care theory, but focus on the ways that contact with elements of care, including from people in subordinate positions, show potential for political renewal. In contrast the public and private politics of care formulation asks us to examine the ways that political processes shape care with reference to ideas of action legitimated by the cultural significance of public and private spaces. Despite drawing this distinction between these two approaches it is important to note their similarities because in the words of Gill et al. “both policy and care distribute relations of power and generate categories of difference” (2017, p.3). Whether you focus on the way that care generates politics or politics generate a historically and culturally located form of care there is a shared recognition of their complex interaction. Indeed, this could be asserted to the extent that we find ourselves challenged to explain the construction of their separation (Freeman, 2017). The visibility of care in policy, as in the case of children as carers or more generally, should be put into the context of the way care is being constructed as moving into the realm of the ‘problem’ (Jupp et al., 2019).

We can also recognise the political potential in children’s experiences of care, as is argued by Akkan (2019), Evans and Becker (2019) and others. Therefore, this study, informed by an array of work on the politics of care, can suggest some of the ways that the politics of care in the family life of young carers has the potential to speak back to politics within and beyond family homes.

2.7. Conclusion

The literature on young carers is diverse in its ability to explore the practices of care. It can be situated in relation to wider fields of study about children’s work and the norms of childhood. I have drawn together a range of findings on individual and, to a lesser extent, intersecting categories of social difference in the lives of young carers to show how an intersectionally informed approach to qualitative research can contribute to existing knowledge and provide greater cohesion in the representation of socially constructed difference and inequality. This study also adds to the literature by exploring the use of new methods where other studies have focussed on other forms of research, a subject that will be taken forward in the next chapter. Lastly, this chapter introduces a theory of the public and private politics of care theory, proposed as a framework for interpreting the practices of care in family life in the context of inequalities and interventionist social policies.

3. A methodology for the study of care work

3.1. Introduction

This chapter explains the reasons for choosing ethnography as the research design and as method. This is a crucial part of my response to the research questions that asks me to detail a methodological response to the problem of understanding what has so far been elusive - a way of explaining the impact of policies on the family life of young carers. In this chapter I describe how the choice of ethnography creates a framework that incorporates a set of flexible and complementary data collection methods. I provide an outline of the decisions that set the research on a particular path and describe how the research progressed. By sharing the multiple decisions that added up to the ultimate design and practice of ethnography, this is intended to increase the transparency of the approach (Reyes, 2017). The overall argument in this chapter is that in order to understand care in this context it was necessary to prepare a study that would enable me to tackle three complex aspects. These were: the ability to bring research practices into a quintessentially private space; to be able to understand the nebulous and shifting forms of family life; and to record manifestations of categories of social difference. These three aspects (the private realm, family life, and categories of social difference) are each used as starting points to discuss the methodology, the research methods and the way the study dealt with ideas of population, sample, difference and positionality.

As this chapter is set out thematically, this introduction includes an overview of the research process and the way it was situated in wider theories of knowledge and research methodology. The approach here was informed by constructivist understandings of social worlds and social knowledge, I saw the process of research as creating data with my participants, something that was made particularly vivid through a reflexive approach to ethnography (Aull Davies, 1999). This provided a common basis for engaging with critical theories from across a range of disciplines, for example post-structuralist feminist theory (Butler, 1999, Ahmed, 2014b), queer theories of public (Berlant, 1997, Cooper, 1998, Warner, 2005); disability studies theories connected to work on the social model (Shah and Priestley, 2011, Shakespeare, 2014) and Black Feminist theories of intersectionality and ethnicity/'race' (Mirza, 2015, Hill Collins and Bilge, 2016). I also revisited the idea of relationality through the analysis, so this has informed the ontological position of the work (Chattoo and Ahmad, 2008), seeking to understand participants as embedded within relationships. A strength of ethnography that recommended it to me as the best methodology for this study was its suitability for studying groups, allowing for the observation of change over time rather than a static picture and its ability to accommodate a great complexity of data. The ethnography of family life was selected instead of alternatives such as biographical interviews or the observation of young carers projects.

The study is orientated towards the paradigm of qualitative research. Qualitative data is suited to exploring the connections between ideas and the nuances in the ways that social experiences relate to one another. For example, it was the best approach for understanding the multiple connections between categories of social difference, in order to explore the arrangements of power that distinguish people, creating privileged and subordinated positions in a particular social context (Konstantoni and Emejulu, 2017). In the case of ethnographic research with the emphasis on observation, alongside dialogue, we can supplement the record of verbal expression with notes of the experiences, affect and reflections that a social situation provides. The multiple data points of qualitative research mean that a greater amount of data can be collected but also a different type of data based on an evolving knowledge of the site of study. This provides layers of knowledge, based on social interactions, record keeping and iterative analysis.

The study had five phases, through which the research question evolved in tandem with the development and applications of methods. Firstly, there was a planning phase in which ethnography was selected after consideration of a range of qualitative methods. This phase also included the process of applying for the study to be reviewed by the University of Birmingham Ethical Review Committee. The second phase continued alongside the planning phase, during which I volunteered with three young carers projects. The third phase was recruitment of participants, followed by a fourth phase of fieldwork. The final phase was the end of fieldwork, analysis and writing of the thesis.

In section 3.2. on research in the private realm, I start by arguing for the importance of ethnographic research for the investigation of this topic. Ethnography supported close and sustained attention to the ways that people inhabited private spaces. I make a case for this methodology as a problematisation of public/private, in a way that integrates it as a theoretical, methodological and empirical concern. This particular approach to public/private recognises it as a theoretically generative methodological problem.

The section 3.3. of this chapter explains the approach to researching family life and the centrality of relationality to the selection and development of methods. It contains an explanation of methods, including participant observation, the use of fieldnotes, visual data collection and book recommendations. These are put into context of the requirements for the study of family life. This second section considers the relationality of methods and ethics, by which I mean the ways that the research process was defined collaboratively by the utilisation of the nascent relationships between the researcher and participants. This second section also includes an account of the process of analysis.

Section 3.4. argues that ethnography provided a useful framework for understanding categories of social difference, taking into account their manifestation in the context of family life in a private setting. I describe the approach to conceptualising and observing care, which tackles the intertwining with categories of social difference. This began with the decisions made about recruitment and continued into the affective engagement with participants. I give an account of a set of feelings about the limitations or clumsiness of research tools. This is a way in to exploring reflections that occur during the process of ethnographic research, at times troubled by doubts about the knowledge gained over time and through relationships. I describe these problems in making the methodology real and explain the ways I sought to confront it.

An additional section, 3.5., reviews the ethical consequences of research in private, with families and children and across categories of social difference. I set out the approach to research that attended to my ethical responsibilities as a researcher and as someone who had set out to research a sensitive topic.

Together these four sections provide a description of the methodology, research methods and positionality, through which the reader can put the findings into the context of the wider study and be informed of the unique relationships that built up a collection of data on young carers and family life. I also offer some reflections on the ways that theoretical problems have been worked on through methodology as critical technique.

Table 1 Summarising key participant characteristics

Young carer	**Parents**	**Siblings (age)**	**Housing**	**Carer classification**
Sapphire Age 8	Becky and Chris	Jane (age 12, turning 13) Luke (age 10, turning 11)	House in rural area	Sapphire classified as young carer because of support for father and siblings
XD Age 13	Tizzy		Two rooms in shared council accommodation in urban area and on waiting list for council housing	XD classified as young carer because of support for mother
Aidan Age 13	Marie	Joey (age 4, turning 5)	Council housing in suburban area	Aidan classified as young carer because of support for mother Joey classified as young carer because of his brother's diagnosis of Asperger's
Rosie Age 8	Dominique	Poppy (age 10)	Privately owned house in suburban area	Rosie classified as young carer because of support for sister
Alia Age 14	Kaya and Ben	Amber (age 17, turning 18)	Privately owned house in a suburban area	Alia classified as young carer because of support for sister

As a reference point, a table is provided here summarising the key characteristics of participants. The participants are introduced in more detail in Chapter 4, however, details from fieldnotes are brought into the methodology discussion in this chapter.

3.2. Ethnography in the private realm

To understand care, data needs to be created in private spaces because the majority of care work takes place in households and the space of the home (Miranda, 2011). As a UN Women report observes, the global picture is one in which governments, markets and voluntary organisations make a small contribution to the organisation and delivery of care work, while “families, especially when they are poor, pick up the slack, doing the bulk of the care work. Within families, women bear the disproportionate burden of this care,” (UN Women, 2019, p.144). To begin with, specifying the meaning of private, it is important to state that the idea of private is understood through its contrast with the idea of public. This contrast is discussed in the previous section as a basis for the theory of the public and private politics of care. With care as a form of work with a strong relationship to the private realm, the methodology relies on empirically exploring understandings of public and private through research. Taking account of knowledge of what happens in private spaces and inferring a significance to the collective, to the public, I drew on public discourses to justify an intervention in to the private. In some cases that is using the framing of a subject of academic importance, but also it is making reference to the logics of public policy, which assert the importance of that which is taking place in private for the public interest.

I set out to study action in people’s homes, as private spaces, where people are deciding on what work should be done and who does it. Policies assert that this and other behaviour in private homes matters to ‘us’, to people outside those demarked spaces (James and James, 2001, Crossley, 2016, Parr, 2017). The collective effects of family life are to create patterns such as gender and class inequalities, as well as being subject to and absorbing those inequalities (Marx Ferree, 1990, Shelton and John, 1996). Private spaces are important for understanding the process by which inequalities of gender, ‘race’, class, disability etc are manifested (Oakley, 1974, Yeandle et al., 2017). The back and forth of ideas about who should do care work, which turn into the inequalities of care work, calls for us to establish that there is a complex relationship between public and private spaces, and that public and private are relevant to this system of organising care work. Data need to be able to say something about the nuances of care work and family in public and private but also to integrate them, recognising their interdependence.

3.2.1. The research question

The development of the methodology for this study was animated by an engagement with the problem of understanding the separation of public and private areas of life, marked by a dual interest in family life and the policy context. The research question for this study was:

> **What does an ethnography of family life contribute to understandings of young carers?**
>
> > **What consequences does this have for the conceptualisation of young carers as a social group?**
> >
> > **To what extent does ethnographic research design build an understanding of family life and what methods can be applied and developed to gather observational and visual data?**
> >
> > **Are policies on young carers reaching families and what is the impact?**

A response to this question required a methodology that recognised the ways that public and private realms were separate features of people's lives but it also needed to be a vehicle for investigating the points where this separation breaks down. The idea of the separation of public and private was encountered in the academic literature, with perspectives from a wide range of disciplinary backgrounds (Elshtain, 1981, Phillips, 1998, Lister, 2003, Warner, 2005). It was a problem that connected the study's points of theoretical inquiry and its empirical investigation. My approach was for the critical engagement with theories of public/private to be drawn into the methodological work. I could then work empirically with the ways that I encountered ideas about public/private, whether those were distinct physical spaces, contrasting expressions of culture or as economic systems. The methodology stimulated a way of grappling with theories of public/private because of my sense of social expectations that included the navigation of these two realms and their separation. Progression through public and private encounters with families was underpinned by a set of decisions about how to create data that could say something about the construction of private spaces, in particular.

3.2.2. The choice of ethnography as methodology

The study required a research design that would be suited to detailed and sustained investigation of private spaces and moments. I chose ethnography as the overarching research design because it could encapsulate a range of methods that contributed to a finely grained account, within which areas of theory could be explored empirically. Ethnography is a methodology with claims to be especially useful for understanding groups, their culture and its form over time. The decision to use an ethnographic methodology for studying the private realm and family life was made after consideration of biographical interviews or an ethnography of young carers groups. These were rejected in favour of the current methodology because neither could say as much about the determination of care roles, which I hypothesised was firmly rooted in domestic processes, and about its association with the complex inequalities within and between families.

The methodology has its origins in social anthropology, which seeks data that could speak to questions of culture, specificity and location. Social anthropologists developed and trialled methods of emersion in an unfamiliar culture in the context of understanding the imperial ‘other’ (Marcus, 1998). A wide range of flexible methods were employed so that an outsider, bearing academic knowledge, could create a detailed description of the relationships, structures, beliefs and material culture of a hitherto unfamiliar group (Sluka and Robben, 2007). Another strand of ethnographic methodology was developed in the discipline of Sociology, within the Chicago School (Whyte, 1993, Alexander, 2006, Hammersley and Atkinson, 2007). Bell (2019) points to the broadly different orientations of ethnography in these disciplines, resulting in an analysis that deconstructs the world in the sociological frame, while the anthropological application of the method seeks to resolve an understanding referencing the context it came from. This study is more influenced by the anthropological tradition, seeking to make sense of care practices within the context of the families studied, rather than deconstructing them based on a prioritisation of external knowledge.

These methods persist and represent a vibrant contribution to social science research, although they have been the subject of interrogation and debate for their politics and the extent to which they carry the assumptions of building knowledge from the position of rationality and neutrality. Feminist working-class and anti-colonial theorists have contributed to the methodology, establishing conventions of critique, reflexivity and consideration of positionality to disrupt sexist, racists, classist and colonial traditions of research (Marcus, 1998, Nayak, 2006, Lareau, 2011, McQueeney and Lavelle, 2017). What remains is the status of ethnography as a qualitative research method, centred on the practices of observation and participation, which aims to immerse the researcher within a community to explain the perspectives of insiders, whilst using their outsider perspective and research skills to create new knowledge (Geertz, 1973). The constructivist paradigm of ethnography is the starting point for this project. My approach makes use of the flexibility in this method and the potential for developing ethical, knowledge-rich relationships through which theoretical questions can be explored.

3.2.2.1. Ethnography as the basis for studying public/private

Central to the idea of ethnography is the researcher's journey to join a group and understand it, after which the researcher will often step away in order to reflect and write about the subject of study (Hammersley and Atkinson, 2007).

This process is recorded, largely through fieldnotes and written reflections, to capture different moments through the process (Spradley, 1980, Lareau, 2011), including the development of new understandings and the creation of relationships that enable it to proceed. The researcher is unavoidably a prominent participant in the research landscape, calling for reflexivity as a crucial element in fieldwork and analysis (Aull Davies, 1999, Hammersley and Atkinson, 2007). Through the researcher's presence, ethnography stages interaction with the social boundaries established by groups in a 'natural' setting (Hammersley and Atkinson, 2007). The researcher is tasked with acquiring a kind of membership of a particular group; it is a process of moving from being an outsider to an insider.

In ethnography there is the opportunity to note and analyse the boundaries through the ways that public and private spaces are encountered, negotiated, overcome or those which hold the researcher at bay. In this case, cultural understandings of public and private realms, are relevant social structures that are encountered in the research setting. This is because the research setting is families' homes. They are important sites of privacy, where elements of a private life are expressed, understood typically in opposition to the public world beyond the front door. Research in people's homes offers the chance to understand more about personal experiences that are significant for people's identity and in many cases the aspects of people's lives that matter most to them (Smart, 2007). It can give us insight into families, households, the activities that sustain people materially and emotionally. It could represent an ontological contribution because of the significance of private spaces as sites of knowledge creation about categories of social difference and much else (Widerberg, 2010). This methodology establishes a strong foundation for studying private spaces, despite the technical and ethical challenges of basing a research study within such an environment.

3.2.3. The privacy of the home as a research challenge

Research in people's homes offers the chance to understand more about personal experiences that are significant for people's identity and in many cases the aspects of people's lives that matter most to them (Miller, 2001, Smart, 2007). The literature on the study of people's homes and of life in the home describes multiple challenges of the home as a research site, particularly in terms of access (Miller, 2001, Gabb, 2008, Lareau, 2011). However, the challenges of research in the home can be categorised in similar ways to the challenges of research in "public" or institutional settings. Research in many "public" settings presents parallel challenges of access, of recruitment, of dealing with gatekeepers, of researcher discomfort and sensitive topics. This chapter therefore engaged with similar categories of methodological and ethical challenges, although the nature of them reflects the particularities of ethnographic research in family homes.

Before this study there has not been an exploration of ethnographic methods in the young carers literature, and no application of these methods to study young carers' family life. Outside of the young carer specific literature, children's care activities have been studied ethnographically. Thus, work by Eldén (2013), Katz (2004) and others have informed the design of this study. This study also draws on methodological debates in the disciplines of anthropology, human geography and sociology, which provide a relevant literature to inform ethnographic research in family homes. The context of these debates is a recognition that families have often been under-explored as sites of study in their own right. For example, human geographers have argued that families are overlooked as a research field (Hall, 2014, Valentine, 2008, Harker, 2010). There is also a criticism of anthropological, sociological and feminist research paying greater attention to families as constituents of other communities, rather than as subjects of study in their own right (Harker, 2010).

In the wider literature on ethnographic research with families there is debate about what it means to utilise participant observational methods with families and the ethical repercussions of this approach. There is a questioning of the possibility of using participant observation methods with families, as a fundamental question about the feasibility of studying other people's family lives. Researchers studying families are restricted in the time they can spend with subjects compared to other areas of research. People's homes are not likely to be easy spaces to linger and the researcher, especially to begin with, is highly conspicuous (La Rossa et al, 1981). This may be a problem that can be overcome, through sensitivity of conduct in that space and extended periods of research to increase participants' trust and familiarity. This is considered worthwhile because writing in the sociological literature argues that especially interesting data can emerge because of the informality of the domestic space and a disruption of the hierarchical relationship (Huisman, 2008). This established literature on ethnographies of families from outside the field of work on young carers demonstrates the potential for following this approach, as well as urging us to recognise the distinctive contribution of pursuing these methods for the study of families.

The challenges of access, once overcome, open up family life and provide exciting research opportunities but also call for recognition of specific ethical concerns, recognised across the sociological, human geography and anthropological literatures on ethnographies with families. This literature presents debates about the ethical risks for participants, for researchers and for academia (Huisman, 2008). Ethnographers reflect on the ways that participants are sharing wide-ranging information, without the boundaries usually set by a more focussed data collection process (La Rossa et al, 1981). This is an ethical concern during fieldwork but can also re-emerge in concerns about the sensitivity of information shared when research is written up and disseminated (Lareau, 2011, La Rossa et al, 1981). Despite the ethical principles at stake, researchers may face the limitations of reciprocity and non-exploitation (Huisman, 2008), becoming emotionally and practically involved in family life (Iverson, 2009) and navigating power relations in intimate relationships (Forbat and Henderson, 2003, Eldén, 2013). Cross-disciplinary writing about ethnography calls for the researcher to scrutinise and present the way they navigated engagement with families as a methodological and ethical necessity.

There is a strong case to be made for overcoming the general and specific challenges of access to the home because the limited research sustains the "black box" of the family, leaving empirical questions unanswered (Pahl, 1995, p. 54). The feminist research agenda, described by Pahl and others, makes explicit and challenges a hierarchy of subjects for study that designates domestic, feminine and private experiences as an area of limited interest (Morgan, 1996). Others may argue against research in the home because of its status as private, as a site where the public world, and research interests, are not welcome. In response, I argue that it is justified to pursue relevant topics of research by investigating private spaces but we are obliged to take seriously ethical obligations that emerge from this approach. It is also beholden on us to consider the differences between people's private worlds and how some may call on us to consider additional issues, for example, when some groups have their private lives placed under additional strain or face greater risk of intrusion. In the rest of this section I shall point to some of the challenges of research in people's homes.

3.2.3.1. Challenges of research in family homes as private spaces

From the methodological and theoretical literature on family homes as private spaces there are three main issues to confront in making it the centre of a research project. These are its incoherence, the presence of inequality and violence, which are worth addressing in turn but this brief discussion recognises the ways that they are thoroughly interconnected.

The first challenge is that of struggling to find a coherence of the home as a private space, when it is characterised by extremely diverse or even contradictory experiences. For example, popular historic representations of the home as a place of privacy and repose obscure the labour that sustains this environment (Gillis, 1996). People are socially located in the home with such a diversity of experience that we should challenge assumptions about the shared and unified experience of ‘home’ (Smart, 2007, Widerberg, 2010, James, 2013). Alongside the diversity of experience, there is an intense personalisation of experience, located in fragmented interpretation of space, action and objects, connecting stories of past, present and future (Sedgwick, 2003, Smart, 2007). The literature on practices in the home draws our attention to the density, multiplicity and diversity of experiences there (Davidoff and Hall, 1995, Miller, 2001, Blazek, 2016). An understanding of this contradictory and rich environment as part of the ecology of young carers is critical in order to put their perspective into the context of the empirically explored family environment. So far this has remained a gap in the academic literature and is addressed in this study particularly through the use of ethnographic methods that accommodate the complex data to support exploration of this complexity. Ethnography can serve as a methodological response to the challenge of capturing and working with the contradictions that characterise family life. This approach has the potential to introduce a greater understanding of the dynamics of family life into the discussion of children's care work.

The private space of the home is also central to a wider picture of social inequalities. This has been explored with reference to the bargaining models developed in feminist economics (Agarwal, 1997), mentioned in the previous chapter, which test the consequences of gendered financial inequalities for the decisions made about the distribution of labour and resources within households. The status of the home as a private space often draws on an understanding of the home as free from the pressures of labour and social control. This is contested because in many ways it is not a space free of labour. Unpaid work invariably takes place in the home and it often serves as the location of paid work for those from outside the household (Twigg, 2000, Daly, 2002, Ehrenreich and Hochschild, 2003). Social control and expectations are not left outside the front door and some social groups have less autonomy within the home, for example, because of state policies that target their families for interventions and surveillance (James and James, 2001). Studies of gender and the home illuminate unequal participation in domestic work (Shelton and John, 1996). Gender, age and class-based roles in the household have been defined separately and hierarchically (Steedman, 1986, Davidoff and Hall, 1995). Realms of femininity and masculinity are rhetorically used to set the boundaries of the home and the spaces within it (Hunt, 1995). This is just one example of the intersecting inequalities of gender, age, class and more that impact on people's experience of the family home (Oakley, 1974, Skeggs, 1997, Valentine, 2004, Cieraad, 2013). Disability is also an important factor in understanding different and unequal experiences of the private sphere (Shah and Priestley, 2011) and for researcher positionality (Zarb, 1992). Research needs to proceed informed by knowledge of these inequalities and the literature of their manifestation in the family home as a private realm and in this study it forms a part of the central exploration of the topic of young carers within a framework of intersectionality theory.

Lastly, issues of violence are also relevant to the pursuit of academic knowledge in private spaces. The private sphere is an important space in the wider picture of violence that has often been overlooked in sociology and other disciplines or adversely segmented off into narrow areas of study (Walby, 2013). Although this has been a topic rarely connected to studies of children as young carers (Aldridge, 2017), the wider literature on childhood recognises the widespread experience of violence amongst children (Steedman, 1980, Cieraad, 2013). Popular representations of the home as a space of safety overlook relatively common experiences of violence and abuse within the home (Hunt, 1995, Chapman and Hockey, 1999). Professionals going into family homes are acutely aware of the risk of violence both towards themselves or triggered by their presence (Ferguson, 2016, Cuthill and Johnston, 2019). This study was pursued in awareness of those issues, with plans in place to share knowledge of the researcher’s location as a protocol to mitigate against the risks of the researcher working alone. There was also a system in place to share information about concerns of violence witnessed in family homes. Neither process was triggered in this case but the researcher was made aware of historical issues where violence had been suspected, enacted or accusations made in the context of state services knowing about these incidents. Ethnographers debate the intellectual and ethical practice of representing violence in written ethnographies, although recognising it may be particularly necessary when this methodology is politically allied to the representation of marginalised lives (Jones and Rodgers, 2019).

My response to the challenges of incoherence, inequality and violence is to conceptualise the home as an environment to which we can respond methodologically by gathering a wide range of data and working with multiple perspectives and contradictions rather than seeking to smooth them over. This echoes the way that Geertz (1973) frames the study of culture using ethnographic methods. He argues that this method enables us to build an empirical model of a cultural arena that replicates its contradictions. A written ethnography can form the basis for the development of theory and contribute to knowledge, aiding me in this study to share this complexity and the nuance of young carers’ family life.

3.2.3.2. ‘Particularizing’ the home as a private space

As discussed earlier, this study seeks to connect the experience of participants to the local economy of care. In line with this aim, ethnography also asks us account for location. It asks us to ‘particularize’ (Geertz, 1973); in contrast to a wider social science pursuit of generalisability, ethnography uses “rich description” to inscribe a social world on the page, a unique and particular one so that it can be explored in order to apply and test academic ideas. In this case the study was of particular homes in particular places. The different locations, where the participating families lived, were all in the region of the West Midlands and this was a common reference point. They also shared features of urban or suburban life. Through observation, I was able to identify ways in which their locality features in their accounts of home and the ways that the ideas of the private home were developed in this particular context for example, exploring the context of care, shaped by their neighbourhood.

I could also particularise the home over time, recognising the dynamics of its configuration. I detected a seasonality of public/private, whereby the balance between public and private strands of behaviour in the home changed during the school term or during the holidays. The school terms demanded that families orientated themselves towards managing their relationship to the public world, while the holidays gave them more autonomy, whilst reconnecting them with other kinds of public institutions, such as youth activities and local groups.

Public/private went through waves of organisation and was reconstructed for different seasons. This goes some way towards introducing the ways that I encountered and conceptualised the particularities of public/private through ethnography.

3.2.3.3. Research design in response to children's care work at home

Carefully considered methods were needed to support the investigation of children's care work, so that it could incorporate the connected ideas of family, home and care, all of which are associated with private spaces. Therefore, the focus of the ethnography was on carrying out observations and developing other methods to understand private spaces, including the ways they were defined in practice. For example, it was important to note who used those spaces, who else was talked about as relevant to that environment and the everyday practices of family life.

However, the idea of public was not there just as a foil to the idea of private because it had another more concrete meaning in this study. The aim of the research was partly to consider the relevance of activities in private to public policies that are based on assumptions about what happens in family homes and its significance for social objectives. I was interested in the ways that public institutions such as employers or schools, third sector organisations and the ideas and norms about young carers were brought to bear on the events that played out in people’s private worlds. I could learn about the ways that people carried their sense of self, as cultivated in private spaces, out into public spaces. I wanted to notice how people tried to reconcile their experiences in private and public or whether their efforts went into building up a contrast between the two. The study needed to grapple with the ways that public and private manifested themselves in the lives of the families participating in the study.

Alongside that strand of investigation on how spaces are experienced as public and private, those ideas also fed into the ways I was seeking to understand care. We can trace the ways it is part of what we understand as the ‘public’ and ways it is part of what we understand as the ‘private’. For example, expressions of concern about children as carers, start from the position that the public is motivated to see this change through more active social policies which act on people’s behaviour in their homes (Dearden and Becker, 1997, Dearden and Becker, 1998). Situated in the discipline of social policy, this study justified studying domestic spaces because they are crucial to the ways that policies are intended to be effective. The ethical implications of this are discussed in the final section of this chapter.

3.2.4. Adapting ethnographic methods for studying public/private

Having established that explaining the division of public and private spaces through interactions with families is an important requirement of the methodology, I will explain how the ethnographic methodology was developed in ways that made it well suited to this task. The key areas to be discussed here are gaining access and using flexibility.

3.2.4.1. Flexibility in the research design

The methods that I drew on in the fieldwork process were of a type that provided a platform for flexible and unpredictable interactions. The methods of observation, conversation, participation and holding back created moments of unpredictability whereby I waited and absorbed what happened next. My hesitations meant that my reactions were delayed and instead I took in what was happening. This meant I noticed curious things about the place I was in, the way things happened, who did what. I could see some of the ways that information way shared, gestures were made or when they were withheld. It was as if public/private was materialised through these small moments and could be recorded. The flexibility and, sometimes, prosaic nature of those methods seemed to draw out those daily markings of public/private, rendering them more visible than usual to a researcher presence. The methods led to a process of returning to the family home and taking on an evolving role. I could watch for how people’s roles change over time, observing the fluctuations and changes. Other methodologies, especially those that rely on a snapshot cannot match the depth of understanding available through this method. It directs a particular kind of engagement with private spaces as the backdrop for family interactions. This engagement enabled me to experience the ways that family homes are constructed in relation to non-private spaces and to understand the processes that repeatedly establish feelings of privacy, however imperfectly. The flexibility was used to enable the development of specialised methods, described in the next section.

3.2.4.2. Gaining access

Negotiating and gaining access to families’ homes is a direct encounter with the boundaries established in people’s lives that distinguish between public and private realms. The repeated negotiations, as I visited again and again, gave me insight into the ways those boundaries were reconstructed for each encounter, with slightly different inflections, or the ways that they were dismantled. This provided useful data and the potential for comparison over time as my status changed through familiarity, relationship building and different circumstances. It particularly informs the data analysed in Chapters 6 (Intersectionality at the separation of public and private space) and 7 (Social location in families).

The recruitment methods provided a set of insights into the ways that the separation of public/private are established and re-established. These were started through two institutional processes, firmly located in public spaces. The first of these was drawing on my contact from my previous occupation working in third sector organisations, including those that were focussed on carers. I used these links to contact the local organisations about the project and ask whether I could volunteer with their regular groups run for young carers and young adult carers. This contact was well received and I was able to start volunteering with three young carers groups in the West Midlands. This began in July 2017 and built up to volunteering about six times a month with the young carers groups. I took on the role of being a “volunteer researcher” (Garthwaite, 2016, p.29) in which my researcher identity was inflected with my introduction to people as a volunteer. The organisations that I volunteered with were a mix of local voluntary sector organisations, local organisations linked to national networks and national organisations. All the organisations had contracts with local authorities to provide services to young carers, in some cases delegated powers to carry out statutory young carer’s assessments. The organisations worked across urban, suburban and rural areas, working with young carers from a wide range of backgrounds and supporting children who represented considerable diversity in terms of age, class, ethnicity and care role at home. The organisations are not named here in the interests of protecting participants’ confidentiality.

At the same time as working in the public setting of the young carer projects, I was navigating the University of Birmingham Ethical Review process, sharing information about how I would establish an ethical framework for research and awaiting a response. This has been debated as a fraught process for the realisation for ethnographic research (Hurdley, 2010, de Koning et al., 2019, Bell, 2019). Two institutional engagements continued simultaneously, as a phase in which the research was clarified in relation to the institutions of the university and in relation to the local third sector infrastructure for young carers.

Moving from this phase of scoping the institutional context that structured the ways that children were labelled and responded to as young carers, I worked with those voluntary sector organisations as gatekeepers (Heath et al, 2007). I provided them with information setting out the details of my research project, building on the more informal information that I had shared during my period as a volunteer. For each of the organisations I was set up with a contact person who would be organising the way that the charity supported my research recruitment and I answered questions through a phone call or a meeting. With one of the charities I attended the young carers team meeting to do a short presentation and answer questions from members of staff. The proposals were received positively and I was offered help from the charities to recruit participants. The results of the recruitment process are shown in Table 2.

Table 2 Recruitment of families through young carers services

Organisation reference	Number of families contact details requested (number provided) [number met with]	Number of families who began participation	Full participation in the study
1	6 (6) [4]	3	2
2	6 (5) [3]	3	2
3	5 (3) [1]	1	1
Total	17 (14) [8]	7	5

The greater representation of families from the first two young carers groups is accounted for by the greater number of contact details provided by the charity. The families that were not available for me to contact through the young carers groups were decided by their key workers to be in circumstances that were not appropriate for the additional strain of participating in the research. Where this was explained to me the thinking behind these decisions seemed appropriate. In the case of the third group, it is less clear why the details were not provided. The funding instability faced by that organisation and other challenges made it hard for me to communicate with them in order to clarify decisions about contact details.

I attempted to contact each of the families by phone and in some cases, where I did not get a response, I also sent a message by SMS. This resulted in meeting with eight families of whom seven agreed to proceed as participants in the study. Five of those families continued with me to the end of the fieldwork period, while two fell out of touch, not replying to calls, messages or a postcard so their participation did not continue beyond late Spring of 2018. They had received information at the start of the study about their right to withdraw but the fact of their having withdrawn took a few months for me to clarify and I was unable to gain instructions about what they wanted me to do with their data. I was in the position of making a decision about how to use their data without being able to discuss their preferences. My decision was for the data from two families collected during the initial meeting and several subsequent visits to be excluded from the analysis, although kept securely in case they resumed contact in the later stages of the study.

A number of families declined to take part, stating that it would be too much strain on top of already difficult circumstances. Two families explained that they had made a collective decision that it would be uncomfortable or awkward. The remaining families either did not respond to phone calls or messages, or they responded but then did not confirm a date for a meeting to discuss the project. A number of these families may have decided that the demands of taking part in the study, the burden of being a participant in an ethnographic study, including the emotional labour involved (Feldman and Mandache, 2019), was something they were unable or unwilling to do.

At the outset of the project I had aimed to recruit between three to six families. The ultimate number of seven was manageable although I was able to increase the intensity of fieldwork after two families effectively withdraw from the project in late Spring 2018. The remaining five families were split between charity group 1 (two families), charity group 2 (two families) and charity group 3 (one family) and they provided the data reported here.

3.2.4.3. First meetings with participants in the private realm

This discussion considers the way that ethnography was a changing encounter with the boundaries of public/private, which shifted through the phases of meeting participants, building contact and then leaving the field. The methods used during fieldwork will be discussed in the next section. Instead, here I will focus on the way that this methodology brought out a series of reflections on public/private.

The first meeting with each of the families who had agreed to see me was always an occasion that made me nervous. In the meeting I noted the complex interactions that I was entering, noting in my fieldwork journal that in my first meeting with Sapphire’s family:

> **Fieldwork journal 14/3/18**
>
> I felt like I was straining my ears to catch meaning but wasn't observing so much. At this first meeting my priority was adherence to a planned process. It did play out ok but felt shaky and unwieldy.

I felt the pressure of how important it was to be able to share the right information but also not to stick to a script so that I could be responsive to what the families needed to know from me. I also entered dynamics behind the front door that I could not anticipate, within which I needed to ensure that each individual receive information tailored to their age, interests, and preferences for a way of understanding the study. Indeed, those requirements were very different, varying between families and between individuals within each family. Some of the key ways I did this were to take my time and not rush the process of sharing information about the project and the details of consent. I worked with family members who could take on the role of interlocutor to use their knowledge of their family members to help me share information with them and adapt the approach. I also made a point of checking understanding and revisiting the discussions at subsequent visits. The first visit was therefore an important moment in which I developed a rapid preliminary understanding of my potential participants, their communication styles and their relationships in order to use that encounter to share an understanding of the project and explore their feelings about taking part.

In the later months of the fieldwork, the process evolved into a feeling of something on-going and established. I noted about one visit to Rosie's family:

> **Fieldnotes 25/7/18**
>
> After the visit I feel tired. It was a long one. I had not realised how much the time had passed. It was three hours and a quarter. The time passed so easily, first sitting outside chatting, then inside playing games, then having lunch and then back to games and music videos. I still don't know how it passed so easily. I do feel that I was quite at ease. Dominique and I had a few short, snatched conversations. Mostly I was speaking to Rosie and Poppy.

I had embedded myself in the social world of others and I had an emotional engagement with it (Luvaas, 2019, Bell, 2019, Feldman and Mandache, 2019). Participants expressed their belief that I had built up in-depth knowledge. For instance, Kaya said "she was thinking that I knew them better than other people." (Fieldnotes 3/8/19). Those visits reached a point of feeling like business as usual and more comfortable, but to start with there had been a feeling of everyone working it out as we went along. Over time, I became more confident that the process had altered to reflect the preferences of adults and children in the family, for example, limiting the visits to one hour in Aidan's family and meeting in locations away from the family home for XD's family.

This change came from not imposing a rigid structure on the visits and introducing more structured exercises, such as the visual data collection and the collection of book recommendations, which I describe in the next section. Family members chose the pseudonyms to be used when writing the ethnography, so the names used here were those selected by participants. As the number of visits increased, I re-introduced the idea that I would be finishing the research process and worked with the families to consider the process overall, and whether there were any reflections at this point that I could record. The finishing of the research process felt emotional and poignant. I felt sad to be drawing that period to a close and to disrupt some relationships that felt like they were deepening, going beyond a theoretical exploration into being connected to the families.

3.2.4.4. Leaving the field and next steps

Going from recruitment to closing the fieldwork process charts a movement from public space to establishing a presence in a private world. This was a presence that needed a resolution in order to adhere to the terms of its initiation: the families had agreed to an interaction of up to a year during which the process was continually reviewed. I had to fashion (and re-fashion) my ethnographic research methods so that I could start the process and progress to a deeper understanding of private spaces. This was an emotionally heightened period of fieldwork, following on from the relationships and the amount of care I felt towards my participants (Feldman and Mandache, 2019).

The emotions of this period followed on from a progression of fieldwork because my presence had disrupted that private space initially but over time I could feel there was less formality in the interactions and more confidence in having me as an observer of family life (Lareau, 2011). Later in the process I would notice my possession of ‘insider’ information because I would know what was coming or see new behaviour when there was more trust in me as part of the domestic scene. Through this process I took up different points of view and I became increasingly embedded in the logic of those private worlds. This was critical to the success of my endeavour and was only possible because my participants opened up their worlds to me, an act that always felt incredibly generous. Some participants expressed sadness at the thought of the visits ending, for example, in my notes from the penultimate visit to Rosie’s family:

> **Fieldnotes 16/10/18**
>
> Rosie and I talked about how she could give me a few suggestions of what I should include when I write. She seemed a bit upset and a bit shocked about me not visiting again. She asked if she could text. I said I was not sure but if they wanted maybe we could still meet again, although I would not be doing the work of writing things down. She asked why it was finishing and I explained that I had a set

> amount of time, that this year had been about talking to people and the next bit was about writing it all up.

It was an emotionally significant process for me, but also my participants. I proceeded with winding down the visits to each family, setting a final date and an agreement for future contact and involvement, having a discussion with parents and children about their future interest in hearing about the project and any requests to review material or have some input later.

With the end of the fieldwork the routine of those visits ceased, so they no longer punctuated my weeks with these moments when I strove to understand others intensely. Bringing the visits to a close meant that I was in some ways extracting myself from private worlds. I ended data collection and broke off contact for over a month in order to give myself a chance to analyse my data. My mind felt awash with different reflections and emotions. It was a necessary step but it also felt abrupt. It was a break in my positionality as someone in the field, where I had drawn on certain ways of being as my strategy for drawing out an understanding of people's private worlds (Luvaas, 2019). I reconnected with a different sense of myself as someone combing through information, as a writer and as a researcher, rather than being embedded in other people's lives. This brought to a close the phase of fieldwork as traversing and experiencing the world of my participants. It meant that I also, in some senses, reconnected with my own sense of privacy. I could exert more control on the contact I had with others. I had more time to spend evenings at home and to live in my own mind, rather than apply my mind to the experiences of others. This was a final period of discovery, severing myself from fieldwork in a new phase of the project.

This late phase of the research then introduced another methodological reflection on public/private, when the early research findings were shared with representatives of public organisations and gained an early audience. The emerging themes and discussion points about policy design and implementation were used to discuss the local experience of young carers and their families. This was organised in partnership with the University of Birmingham Social Work Seminar Series leads and Solihull Carers Trust (See Appendix J). Some of the participants responded to requests for sending in their comments that could be shared with those involved with local service provision. The study became reoriented to a series of publics, with the families that participated remaining as contributors to the project but also an audience for dissemination, alongside those involved with local and national service provision affecting this group.

3.3. Fieldwork as the study of family life and the selection of methods

My task was to adapt ethnographic methods so that I could study other people's family life. It is interesting to create a role for yourself as a formal observer of families, when, for me at least, my experience of family life also involved a lot of observation. I associate family occasions with a feeling of amazement at the endless complexity that family life brings. Going from the amateur to the professional role of observation, I was able to draw on the ethnographic literature to think about the ways that observational tactics can be formalised and how they can become more sophisticated and systematic (Hammersley and Atkinson, 2007). I was also informed by other research on the ways that families were becoming a more intensified environment in terms of the surveillance of external agencies, particularly enforced for families with less privilege and more subject to critique, such as working-class families (Brannen et al., 2000). This meant learning about and refining ethnographic methods so that they were suited to the environment of people’s homes and so that I could set out realistic ways that people would participate in my study. Nevertheless, this element of the study in particular, connected me to my personal understanding and experiences of family life. It was also an important reminder that I was carrying out my research in an environment where others were carefully carrying out their observations too, even if they were not writing them down before my eyes.

From the early stages of planning the research I was committed to observational methods and kept an open mind about the level of participation that would be suitable. I also prepared to use methods that would collect visual data. My approach to methods evolved out of the needs of the field. In this section I will describe the methods that I employed in advance of fieldwork and the later, more creative ideas, that came in response to particular problems, or as I built on ideas from my participants about how they could share information with me. This section discusses in detail the methods I used and developed, alongside reflection about the decisions that were informed by the fieldwork in the context of other people's family life.

3.3.1. Observing and participating

At the centre of the ethnography was the use of the method of participant observation. There are different models of participant observation, which tend to define variations in the use of participation and degrees of flexibility in the way that the researcher conducts themselves in the field (Spradley, 1980). My approach started out with the decisions to observe and to use participation to the extent that it would be comfortable for myself and participants, something that had to be interpreted and balanced along the way when, for example, my participants encouraged me to go with them to the park and I felt uncertain. Postponing the decision about participation was important because I was going to be visiting people's homes, which are places with sensitive meaning, so I needed to be able to follow the guidance set by the family. I wanted to judge what was acceptable by learning from the ways that family members treated me. This approach meant that to the best of my ability I inferred expectations and respected the family's rules about how someone like me should behave, knowing that I would be classified and interpreted by participants (Bell, 2019). I was engaging with a set of complex and caring relationships with the family groups, as well as with individuals (Tronto, 1993). That way I intended to avoid offending people who were letting me into their home and making the process sustainable. This was balanced against an outline approach that I had explained to families at the beginning which had set expectations but I revisited participants' thoughts about the process so that it could be changed as they wished.

Participant observation was the primary method of research. I spent extended periods of time observing family life and participating to a limited degree. I would typically visit each family once or twice a month and each visit would last a minimum of one hour to a maximum of three hours. The timing of visits was in the evening after school, during weekends or weekdays during the school holidays. Data was collected over a period of nine months, covering situations that included a variety of family members in different combinations. During that time the central activity was discussion with different combinations of family members but I also spent time playing games with children, reading books, being shown memorabilia, or making trips outside of the house to the park or to get food. The vast majority of the time was spent in people's homes, more specifically in the living room (Ferguson, 2016). Observations were conducted in the family home but also accompanying family members outside the home as they pursued a range of activities. Some observations were recorded in the moment on an electronic tablet but this was supplemented by notes made at the completion of the visit or in the following days as I wrote up fieldnotes.

I reflected on the experience of fieldwork, making analytical notes that were marked out in the fieldnote documents or with reflexive writing in a fieldwork journal. I would revisit questions about how family members cared for each other, however, my observations and ways of thinking about family life went beyond these confines. I also noted ways of using social categories of difference, consensus or divergent perspectives, the actions of care work, relations with public institutions and much else.

3.3.1.1. Intentions for conducting myself in the field

The nature of the fieldwork in families' homes required flexibility in applying participant observation methods to avoid being intrusive. The schedule of observations was flexible and in each case was planned in discussion with each of the families, an approach described in Sluka (2007). I recorded the conversation that took place in my second visit to Rosie's family.

> **Fieldnotes 11/4/18**
>
> I went through the form to get a sense of what would work. They were relaxed about it. Rosie took the questions quite literally, although maybe I wasn't clear about what I wanted. So we talked about days of the week that would be good. Maybe it is strange for an adult to be

> deferring to a child about the way things should be organised. Dominique was patient, letting me talk to Rosie. She intervened more in my conversation with Poppy, maybe feeling that I didn’t have the knowledge to communicate with her very well.

It was intended that all family members, including children, could express their preferences for how the researcher should conduct observations and the degree of participation (Christensen and Prout, 2002). This was achieved to some extent; however, children and teenagers sometimes called on adults to decide or they withdrew from the conversation so that adults were left as the decision-makers. I saw the different ways that young people used the administrative process of a parent counter-signing their form to signal their belief about their status. So while XD half completed his mother’s section by adding the date before promptly passing it over to her, Aidan had to be called on by his mother to hand over the form while she explained that “Aidan didn’t like to accept her role as the parent and adult because he thought he was an adult already.” (Fieldnotes 26/3/18). In all cases I explicitly asked children and young people to give me their thoughts on how the visits should proceed and was asked questions about subjects such as whether photos would be taken of them, the use of audio recordings and the secure storage of data. I respected these requests and was pleased to take the time to discuss their concerns (Mayall, 2000, Eldén, 2013). Sometimes their views were relayed to me or elaborated on by their parent, so that I could learn about their preferences that way.

The intention was to create a balance between a range of observations, reducing formality or discomfort for ethical but also methodological reasons. If the families were comfortable, as far as I could establish this, I would be happy to work more in depth with them and deepen the relationships to an extent. I also felt that families would increase their trust in me if they could see that I was respectful of the ways that things happened in their home and this did seem to be the case because five of the seven families that took part continue to participate and they increasingly shared more personal information. In practice I sought to maintain boundaries that were based on an evolving understanding of what made me a good presence, would support ethical actions and would prepare me to collect good quality data.

The idea of researcher boundaries was a slippery one, which I continually had to grapple with. When I held back in research encounters this often produced unexpected and interesting moments to observe. For example, after a long conversation with a participant, Kaya, Alia's mother, I gave her space to talk further and in my notes I recorded that following a long conversation about the family's health and recreational activities:

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> "Suddenly those threads about disability, ability and generations converged on a series of very moving and quite painful reflections from Kaya. She posed a rhetorical question about what the girls will be capable of and where they will get to? Then she said, "I don't know. It's not easy to judge because they are older. It's very mysterious."

Kaya then went onto explain some of her reflections on her daughters and her thoughts about their future, which helped me understand her view of family life and the threads of care stretching into the future. Other instances confirmed to me the value of holding back and allowing my participants to use the time in ways they wanted to.

Another reflection on the way I developed these boundaries was that I judged I was obliged to be honest and open when this was asked of me by participants. Those disclosures were often quite fraught, and I sometimes felt regret or concern about how the sharing of information put my participants and me in a difficult position. On a visit to Rosie's family, she and her sister, Poppy, asked where I went to school. When I told them their mother joked about it sounding 'posh' but the reaction from Poppy was that she wanted to know who I went to school with, something that I did not feel I could tell her wanting to protect my private world in a symbolic way. This conversation was slightly uncomfortable for me but it then opened up a conversation in which their mother, Dominique told me about her connection to the area they lived in, which stretched back to her childhood, school days and religious background, topics that interested me and had not been shared before.

I would sometimes conclude that despite my discomfort and uncertainty, participants were often relieved by the occasions when I shared information or when I reacted with more emotional openness. At other times participants seemed dissatisfied with what I shared, reminding me that the re-negotiation of boundaries does not necessarily resolve the discomforts of the research process. In these deliberations I particularly drew on Finch's (1993) writing when I reflected on these decisions, which advocated openness as less hierarchical and less contrived. However, this needs to be balanced against the ways that my positionality made me ill-equipped to fully empathise with, for example, working class life or the experience of material deprivation, something that shared gender positions could not completely overcome (Reay, 1996).

My interpretation of my role as a researcher changed over the course of the research. I was frequently called on to make immediate decisions about how to react or to moderate my reaction to questions, statements, requests for particular types of interactions such as playing a game with children, to stay longer or to give a teenager a lift. The children and teenagers were much more forthright in asking me to participate, while parents tended to ask more of me in terms of giving opinions or advice which I would deliberate over before deciding what it would be helpful for me to share with them. Over time, I felt more confident in my decision-making and would agree to participate more freely. This opened up some interesting experiences, such as going on a bike ride with a family, getting into more in-depth conversations about parenting, or helping a teenager return library books.

3.3.1.2. Unintended emotional participation in family life and its aftermath

The emotional side of ethnographic research presented itself most strongly at the end of the fieldwork process. Reflecting on the fieldwork and beginning the analysis, I noticed that my reactions when going back over my fieldnotes varied. The five families that I had got to know brought out memories with different inflections. The emotional reactions to the families divided into two groups. The first group of families were associated with more turbulent and painful set of memories. There was a stronger and more distressing set of emotional reactions to the record of my fieldwork with them. This made intellectual engagement harder and instead I would reminisce. The emotional side of fieldwork and its aftermath had a difficult relationship with my progression towards an analytic account (Pahl, 2002, Feldman and Mandache, 2019). I stewed over my experiences with them and felt upset at some of the recollections. In my mind those families carried a greater burden of unhappiness and I had been affected by that. I was troubled by memories of the ethnographic collision with the “brutality of the present” (Mirza, 2015, p.2) as I experienced other people’s family lives and the pressure they were under.

A prominent factor in this was my reflections on data about some of the children who were categorised as disabled who were also pained by social rejection and loneliness. This echoes disability studies research, which identifies the ways that disabled people are socially marginalised at multiple points in the (Shakespeare, 2014) but also the way that this can be interpreted inaccurately by those who are not disabled (Shah and Priestley, 2011, Meltzer, 2019). It shaped the possibilities and experience of sibling relationships (Edwards et al, 2006, Edwards and Weller, 2014). This was understood by their family members and they felt powerless to overcome it. It was a collective sadness and fear, although at its epicentre was the particular suffering of a disabled child, who felt shunned by their peers. It was expressed through stories of hating school and having no friends. I was let into the understanding of the ways that they were pushed out of the social interactions and excluded from relationships with peers that had the potential to offer them companionship, support and acceptance. During fieldwork I learned which children felt lonely and were shunned and bullied by their peers. This was sometimes alluded to, delicately, by a parent or was sometimes spoken angrily by the child themselves. Later on, parents disclosed more about their fears and distress at the loneliness of their child. It was as if cohorts of children were edged out of peer groups, marked painfully as different. It was not all bleak and not experienced by all the children labelled as disabled.

This is likely to be informed by my own childhood experience in which I had similar knowledge and fears about my sibling’s isolation. This was mostly understood at the time through the social model of disability perspective but that did not change the painful feelings about the consequences of exclusion, discrimination and injustice. This analysis of positionality was formalised later in the process. It was difficult to confront at the time. Later on, I was also able to build up a picture of other ways I was identified and the elements about myself that communicated a set of labels through which my participants could build up a picture of where I fitted into the world. This is addressed later in the chapter.

3.3.2. Visual ethnography

The research design also included the use of visual ethnography. Visual ethnographic methods (Pink, 2008) were intended to create visual representations of the family organisation of care. There is scope to develop the use of visual methods for research with young carers in the Minority world, notable exceptions are visual research by Evans and Becker (2009) and Blazek et al (2015). Visual methods have been beneficial in wider childhood studies (Christensen and James, 2000a, Eldén, 2013) suggesting their relevance to methodologies applied to young carers. At the outset I surveyed literature on visual research methods to undertake research with children and families, particularly the family care portrait devised by Doucet (1996) and the representation of time and activities by Christensen and James (2000). In

Doucet’s method the researcher worked collaboratively with children and adults in the family to create a family care portrait using words, collage and drawn images. This method gathered data from children in particular, but adults can also be involved in the creation of the visual data. The family care portrait can elicit discussion but also provide data in its own right (Doucet, 1996). This method supported the involvement of children in the creation of data, recognising that for some children conveying information through creative and visual methods is more comfortable, empowering and meaningful (Christensen and James, 2000b), although it is important not to overclaim about the unfiltered voice accessed by visual methods (Pauwels, 2015). Children may well be drawing on experiences of being instructed in drawing in an educational context, or in relation to developmental assessments (Anning, 1999, Gabb, 2008). Visual methods introduce different forms of interaction, thus increasing the breadth of information and encouraging the deployment of different modes of information sharing from participants, without resolving ethical uncertainty and methodological limitations, which are addressed in the final section on ethics in this chapter.

Although the exact approach to visual data creation and collection was to be decided once the parameters of the research setting became clearer, the intention was to use the methods to provide more focussed perspectives on the realities of family life and the desires for how family life could be (Gillis, 1996, Morgan, 1996). Specifically, the choice of drawing offered flexibility and easily procured materials. It bypassed concerns about the implications of photography or video for anonymity (Pink, 2001, Pink, 2008) and suggested the potential to connect the research with existing informative activities in the domestic world. Despite its appeal in this context drawing has received only limited attention in writing on visual methods in qualitative research or ethnography (Hurdley et al., 2017).

The approach to visual ethnography was to be governed by principles of working in ways that encouraged creativity and valued different kinds of contribution regardless of age, educational level or aptitude for creating visual images. I was encouraged that visual creations were often already a part of the family environment, with children and adults involved in creating aesthetic effects in the home and this seemed a recognition of the importance of the visual quality of the information captured in texts (Steedman, 1980, Pahl, 2002). I was also alerted to the presence of the visual through TV screens and photos on people's mobile phones (Banks, 2001) and the ways that visual image creation was framed within family life (Pahl, 2002). The walls of the house also frequently displayed images created by family members or serving as a visual representation of their activities with trophies and certificates present in rooms of the house.

To implement the method, halfway through the research process, at a point where I felt familiar with the outline of family life, I revisited my early ideas about visual ethnography. I developed ideas of using visual methods in response to two questions that still hovered over the research. The first was about how each member of the family understood the way the family care fitted together, their orientation within it and whether there was a sense of how things could be different. The second question was about how family members build an understanding of how things were, when each held and expressed views that often clashed. An exercise was devised by me in response to each of these areas.

For the first area of exploration, about how family members' care fitted together, an idea was sparked by a moment in my writing about care. A recurring idea in my writing was the idea of family life as embodied, so writing on care as the management of bodies. The second motif was the way that bodies were arranged in the space of the home, so particular rooms contained a space that was patterned by certain arrangements of bodies. This exaggerated abstraction of family life, prompted some amused thoughts about bodies in space, as an image of astronauts. I thought that this metaphor, without the stream of consciousness thinking behind it, could provide a fantasy world which could be drawn and used to express an idea of alternative family arrangements. I planned to use simple materials, cartridge paper, pencils and felt tip pens in a rainbow of colours. I asked family members to 'imagine that their family moved to space' and to draw 'how they might live there and care for each other'. This idea, as well as reflecting some particular thinking about care, also recommended itself to me because it did not seem to represent anyone's experience, did not align with one age group and suggested experimentation beyond the existing themes used to interest children in this topic. It had the potential to disrupt more ‘common sense’ or practical conversations (Jagodzinski and Walling, 2013) about care. Family members seemed fairly comfortable to participate in this exercise, although some declined, two of whom were the oldest boys in the study. Fathers were also not represented because both of the fathers were not involved on the occasion when I undertook the activity.

The second visual method was designed to engage with the complex creation of knowledge about care, which accommodated conflicting views whilst sustaining ways of thinking together about care. I wanted to find a way to give each family member the task of representing their perspective and contribute it to a picture of a whole. I thought of using tracing paper, which could allow for information from one person to re-emerge as part of the drawing of another. I asked each family member to draw their perspective on a particular subject. After trying this out with one family, I found that they needed me to prompt them on a particular subject matter. For each family I prepared a selection of pieces of A4 paper, each with an image that represented a topic that had come up in their discussions of care work. I asked the group to agree which topic to focus on and then to draw their contribution which could be layered up. This made use of a key strength of visual methods for research: expression (Barone and Eisner, 2012)

The visual methods, introduced later into the fieldwork phase, seemed to stimulate new kinds of interaction. They produced a different kind of data that encouraged me to think differently about care. Also, the engagement with the visual side of life, jolted me into recognising the visual data that was there in other ways, for example in the display of images in family homes (Pahl, 2002) and the interlocution with the TV that often played in the background of conversations in the living room (Banks, 2001). For my participants and I, it introduced another technique of making the familiar strange, so that we could look at it afresh (Jagodzinski and Walling, 2013).

Through ethnography I gained knowledge but my participants were also learning too. In the case of the visual ethnography these activities were a way of posing my research questions differently so that the participants could engage with me as a researcher to reflect on the ways that they shared information with one another and include me in those developing ideas. I also felt it was important to draw attention to myself as a researcher periodically. Even though my instinct was to blend into everyday interactions I wanted to be sure that my participants had the chance to notice the boundaries and ethics of my approach so that they could tell me if I had gone wrong. Visual ethnography was another element that contributed to the opening up of the research process to my participants as a form of transparency (Reyes, 2017). This summary of visual research describes the process but it also explores the ways that my ethical framework was increasingly tied up with the relational and the longitudinal character of the research process. Family was approached as a site of knowledge creation, one in which I was only playing a small and time-limited part.

3.3.3. Book recommendations

An additional method was introduced by one of my participants, Kaya, and was one that I also encouraged others to think about. This was the offering of book recommendations for me to read for a greater understanding of a particular facet of family life. The initial case came from Kaya, a mother, who suggested that I read two books that had helped her think about neurodiversity and autism which were issues that affected her daughter. I looked up the books and got them out of the library, dipping into them. I was interested in the information they contained but I also found it a way to think with that participant, without having to be physically there with them. It was a way to learn more but without leaning on my participants to tell me themselves. The use of a remote tool for deepening my knowledge of the family's intellectual or literary life appealed to me. It tapped into the ideal of gaining knowledge without straining the time available through visits (Pink, 2005).

This approach was then offered to other participants. I created a simple form, a copy of which is shown in Appendix H. which asked for participants to name a book and encouraged them to choose examples because it was "your favourite, about young carers, about families or about something else". Many participants did offer me suggestions and these were wide ranging, the full list is included in Chapter 8 (Layers of knowledge in family care). They provided an interesting afterlife for the fieldwork because I had the time to read them after the research visits finished.

I engaged with the books in the same way I did other texts that I gathered in the process of academic literature review. This meant that I read the book and reflected on its content, messages and arguments. I also thought about its provenance and its relationship to other writing. This provided some ideas for interpreting the people who participated, of gaining another perspective on key subjects in the study. Some of the books I was not able to read because of problems accessing copies but the titles and background knowledge still gave me additional insight into my participants interests and views. In some cases the books were incorporated into a discussion of relevant literature and others were draw into the analysis of the family environment and the public/private politics of care.

3.3.4. Not interviewing

Before starting the research, I expected that interviews would be used as a complementary method in the ethnography but in effect this was left out. I thought that interviews would allow for more focused and researcher-directed conversations on themes that emerge through the researcher (Spradley, 1979, Hammersley and Atkinson, 2007) whether semi-structured or open. However, as the research went on, I felt wedded to the idea that I wanted to defer to my participants in the way I structured our interactions. I felt that I learned most from the material that they chose to share. Of course, this was not something I pursued in a pure way because I asked questions, probed about interesting issues or I asked them to try out drawing activities and other ways of sharing information. However, I came to the decision that interviews were too disconnected from the ways that I felt the ethnography was developing and its strengths.

As I developed my techniques as an ethnographer I felt that interviewing would be inappropriate, despite the potential benefits of extended focussed discussion of selected topics. There were two main reasons for this. Firstly, interviews would lend themselves to atomised representations of family if carried out individually as I had planned, while observation of group conversations allowed me to see how agreement and disagreement were negotiated in practice. Secondly, interviews would be poorly suited to conversations with the younger children who favoured a blended style of interaction in which conversation, games and movement tussled with one another and offered them the chance to direct things in their favoured direction. Interviews felt too static, too individualised and too hierarchical because of they are structured by the researcher, which I was trying to minimise in my methods.

The only exception in my choice not to use interviews was that one parent suggested a private conversation at her workplace, which took place and was then repeated, so that I could be given information that she did not want her children hear discussed. During other family visits individual family members, both children and adults, took the chance to share information with me more privately but this was at their discretion.

The research was also shaped by my decision not to interview policy-makers or the staff in services for young carers. This group have their voice heard more frequently, and feature to some extent in the literature on young carers (Butler and Astbury, 2006, Cheesbrough et al, 2017). For the purpose of this study the focus was to address the exclusion of data that addressed young carers alongside their families. There was in some ways a commitment to studying the families exclusively, rather than to counter-balance their perspective with the views of those outside the family. This is justified in terms of the orientation of the methodology, which focusses on insider knowledge. It also draws justification from the context in which the study took place. Understandings of family life are needed in the context of policy changes that centre young carers' families as sites of intervention in relation to policies on young carers specifically and as a wider set of welfare policies intensify attention on families (Papadopoulos and Roumpakis, 2019, Jensen and Tyler, 2012). The focus selected here was on the relationships within families and their views on interactions with the representatives of policy implementation, accepting that this is limited by the exclusion of the views of those working with families. The design of this study, therefore, also represents a decision to not interview professionals.

Instead of incorporating this group into the data collection the research involved the views of those designing and implementing policies and delivering services at several points. Firstly, it drew on my background of working in an organisation that engaged policy-makers and aimed to represent the interests of young carers and young adult carers within that process. Secondly, the process of recruitment was connected to my volunteering with three young carers organisations, which established gatekeeping relationships for involving young carers and their families. It also provided background information on the local landscape of service provision aimed at young carers. Thirdly, at the completion of the fieldwork phase, the early findings were shared with practitioners, particularly social workers, and representatives of specialist organisations at an event at the University of Birmingham. This event is described in Chapter 9, in section 9.3.1.

3.3.5. Emotions and ethnography

The process of analysis catalysed a period of reflection about the emotional experience of ethnographic research. This is documented here and connected to a wider discussion about the place of emotions in this ethnographic study.

Beginning the process of analysis, I had to confront some assumptions about the emotional part of the process and the PhD as a whole. I was troubled by the overwhelming nature of the emotions after fieldwork and was reluctant at this point to see them as representing a form of analytic engagement (McQueeney and Lavelle, 2017, Feldman and Mandache, 2019) and a reflection of the depth of understanding achieved through the process, although I did move towards situating them in this way (Harding, 1992). At this point early on in the analysis I found it upsetting to re-examine my fieldnotes. The basic task of tidying the formatting of my fieldnotes, printing them and ordering them brought up painful memories and I kept finding myself pushing the whole lot away, unwilling to engage in recollections about the fieldwork process. Feelings of panic started to creep in. How was I going to do analysis if I couldn't bear to look at my fieldnotes? I noted in my reflective journal that "engaging with the product of my fieldwork upset me. It was often horrible - distressing, unrelenting, confusing. I am still caught up with these feelings, particularly for certain families." (fieldnotes journal 30/1/19). Taken together, I felt that those records added up to an account of emotional difficulty that I still did not know how to deal with. I gradually realised that some emotions were blocking me from creating a more analytical relationship with my data that would form the basis of a written ethnography and a thesis. I had to try to work with those emotions, but I found I was reluctant to, wanting to avoid them and leave them behind with the end of fieldwork. I wanted to disown those feelings, afraid that they were an illegitimate part of my study.

The process of fieldwork and its aftermath brought strong emotions to the fore rather than the intellectual stimuli that I was hoping for. The sense of emotional connection encouraged me to both protect my participants by avoiding the scrutiny that analysis entailed (Gabb, 2010, La Rossa et al, 1981) but also to protect myself from that gaze. Going over my notes I was particularly unsettled by the amount of reflexive writing contained in my fieldnotes. These records of my thoughts and feelings were like “a cacophony of my own voice” (fieldwork journal 4/1/19). This kept emphasising the emotional component of my experiences and through them I was reliving those experiences (Smart, 2014). I dwelt upon the most difficult parts of the fieldwork process and I reflected that “I absorbed a lot, in order to understand (in pursuit of knowledge, to do a good job of the research) but also so that I was able to decide how to react and be a good presence” (Fieldwork journal 4/1/19). These notes contained accounts of guilt and a self-questioning about the ethics of my conduct in the field (Huisman, 2008, Hall, 2014).

I was battling with this problem, resisting the emotional quality of the data and confronting reflexivity as a controversial practice and a potentially problematic stance to take in your methodological work, particularly as someone starting out in academia (Etherington, 2004). I was concerned about what this meant for my ability to represent an analytical account of the data (Reyes, 2018). Yet in reality I came to realise that I had already done analysis throughout fieldwork, including the emotional work involved (McQueeney and Lavelle, 2019, Feldman and Mendache, 2019, Smart, 2014), processing my ideas, exploring them with my participants, drawing connections to theory and building theoretical reference points to unpack some of the features of the lives I was documenting. Alongside these there had been creative moments where ideas had bubbled up, almost as a kind of effervescence, bringing a lightness and excitement to the intellectual project.

This impasse, the inability to move on from a painful set of emotions, produced a necessary confrontation. I was forced to reckon with my self-doubts, the excessive pressure I was putting on this ‘moment’ of analysis (Aull Davies, 1999, Etherington, 2004, Hammersley and Atkinson, 2007, Finlay, 2011). I took some time to revisit the sense of purpose, motivation and my aims, to see afresh how this part connected to other elements of the project. Writing about this difficult point in the process helped a great deal, but was not without its discomforts. Although I had long admired those who had incorporated reflexive approaches, particularly those inspired by feminist methodologies, I realised how difficult it could be. The methods I had used had deepened the potential for some kinds of understanding but imbricating extensive parts of myself in the process, so that I could not neatly draw a line to divide off the parts of myself that were relevant and the parts that were not. This may reflect the particular nature of ethnography of family life, requiring a compelling and challenging absorption into people intimate lives (Hall, 2014). By doing ethnography I had become absorbed into different people’s worlds, calling on me to be present, be nimble, be available and give a lot of myself.

The ethnography is shaped by the emotional connections and relationships with my participants that underpinned the process of data collection and its analysis. The emotional repercussions of this intense engagement produced difficult effects, as I struggled with maintaining energy for the fieldwork process. Nevertheless, the determination to manage those feelings meant that fieldwork continued and the impact of those emotions was felt strongly when I had exited the field, having to deal with the sensitivity of disengaging from my participants (Iverson, 2009). The struggle to move into a process of analysis and to present an account of my research was a reckoning with the emotional impact of ethnography, which remained relatively contained during fieldwork.

3.3.6. Analysis

Building on the reflection of the emotional nature of ethnography, particularly at the point of moving on from fieldwork, this section addresses the process of analysis. Alongside the emotional insight gained from the process of moving away from fieldwork, I embarked upon a process of exploring, grouping and interpreting the data. The steps described below represented a progression through increasingly complex empirical questions that together contributed to a theoretically informed picture of young carers’ family life, tied into the ethnographic research methodology.

The initial phase of analysis was collating a description of each family, clarifying how each family was socially situated and clarifying the care practices that had been explored through fieldwork. This is presented in Chapter 4, serving as both an introduction to the participating families and providing a summary of the practices of care that were incorporated into later discussions.

The second analytic process was to explore the processes of negotiation that fixed or altered care. This made use of the strengths of the ethnographic methodology which allowed for observation over time and the consideration of how family relationships created interactions that shaped care and reshaped it. Negotiation of care served as a theme to explore the practices of care delineation and its allocation within the family over time. This supported a discussion of the ways that children classified as young carers participate in complex exchanges of care. This area of analysis is presented in Chapter 5.

A third form of analysis was to explore the intersectionality of family life. This was considered both as the practices that related the family to others, such as representatives of public or third sector services, by which families built a sense of collective identity and boundaried themselves. This is presented in Chapter 6 and is complemented by an exploration of the way that individuals are socially located within the family, building on the theme of security and protection. The exploration of social location in the family is presented in Chapter 7.

A final area of analysis was largely driven by reflections on the visual ethnographic data. Thus Chapter 8 addresses the way that visual data collection introduced new forms of discussion and is a form of participant-created observations about family life and care. This chapter reviews the development of visual ethnographic methods and explores the potential to use this as a basis for understanding family knowledge about care as layered.

The method of analysis of visual data is informed by the visual methodological literature, but is also driven by the choice of particular visual methods in this study. The majority of discussion about visual methods in ethnography and sociology focus on photography and video (Pink, 2001, Rose, 2014). This study pairs drawing methods (Garner, 2008, Hurdley et al, 2017) with an approach to analysis that examines the construction of images in the context of visual culture and intimate relationships. The approach to analysis is informed by Banks (2001), exploring the content of the image but also the process of its creation and construction. This is referred to as the internal and external narrative (Banks, 2001). Both narrative elements were analysed for each separate image, using the image itself and fieldnotes. The results of this analysis are presented thematically in Chapter 8. This gives recognition to the construction of unstable visual products (Rose, 2014) and invokes a process of reflection on the creation of images in the context of a wider visual culture, family relationships and the structure of the research encounter (Pink, 2001). The use of drawing as a visual method draws attention to cultures of dreaming and creativity that inform participants engagement with the process of creating visual data and the analytic interpretation that followed (Edgar, 2004).

Chapter 8 also presents the results of the analysis of the participants' book recommendations. These were analysed as a secondary source of data for the thematic discussions based on the visual data. For this data the analysis briefly examined the narrative of the specific text being recommended and put that particular book in context of the wider discussions associated with that research participant. The analysis methods developed and applied to the book recommendations also used the Banks (2001) framework, adapting the ideas of internal and external narratives.

3.3.7. Writing an ethnography of family life

The data from fieldnotes, book recommendations, drawing activities and form filling were gathered together as the heart of my ethnography. The methodological and methods decisions that I had made shaped the possibilities for the written product of my research (Jones and Rodgers, 2019). The data were stored securely, as had been agreed with the University of Birmingham and with my participants. On the other hand, my thoughts were not securely locked away. For analysis I prepared to sort my fieldnotes and build an analytic account of what I had learned, which could do justice to the story of each individual, each family and the ways they were connected through the process of my ethnography. I had set a research question, which had been a useful guiding line of inquiry, but I felt that the data was best served initially by analysing it inductively and sorting it in ways that hinted at connections across the family groups. I took some instruction from the methods of grounded theory (Glaser and Strauss, 2009), as an approach to let the data speak back to me. I also drew on the writing of Banks (2001) on using internal and external frames of reference to analyse visual data, the details of which are discussed in Chapter 8 (Layers of knowledge about family care). For the book recommendations, as a method I had developed myself without reference to methodological writing, I decided to connect it to the other two methods as a form of triangulation or additional insight.

I worked outwards from summaries of each of the participating families, presented in the next chapter, Chapter 4 (Introducing the Five Families). These formed a foundation for an understanding of how care was defined in relation to each family's boundaries of their private world and the publics that circled them. I worked outwards to build analytic threads that crossed the data. These ideas, senses of connections and arguments combined into chapters that each explored an element of the public and private politics of care. The written ethnography was both a report of an existing research process and also had a distinctive process of creation, aiming to be a written representation of family lives and recreate the lived encounters at which point the knowledge was formed (Geertz, 1973). By committing these experiences to a page, it provided a framework within which ideas could be sketched, explored, probed, and built.

Together these methods made up a research design that employed flexibility for methodological reasons (in-keeping with the ethnographic approach that seeks the refinement of methods in response to the encounters in the field) but also for ethical reasons to give greater voice to families and young people on the unfolding of research in their own home. The mix of methods assisted with the creation of rich data from participants across the age range (Horgan, 2017). The research design developed alongside an evolving concern with how to operate ethically as a researcher of family life, shaped by my interpretation of that environment and my personal experience of how to conduct oneself in encounters with families (Widerberg, 2010). As a researcher, I drew on codes and biographically-based practices of ethics to direct my decisions in the field, to support ethical conduct, reduce risk of harm and maintain boundaries (Macfarlane, 2010, Eldén, 2013). The experience reinforced my feeling that families bring out the lay ethnographer in many of us. They are at the sharp end of emotions, collective knowledge creation and, ultimately, participant observation.

3.4. Fieldwork as studying categories of social difference

This section documents the challenges of ethnographic research into social categories of difference, particularly in the context of studies of care. It focusses on the application of intersectionality theory during fieldwork and discusses the challenge of using observational methods for this subject. This raised questions about the nature of those subjects and their readability for an ethnographer. I will explain how the research process sheds light on the relationship in this case between theorisation, ontology and methodology (Nayak, 2006, Alexander, 2006), so the observations that are possible depend on how you conceptualise categories of social difference, thereby providing different types of data.

The research process repeatedly raised questions of how I categorise participants, or, even before that stage, potential participants. For the recruitment process I had to work with my ideas of who I wanted to be part of my research participant group and why. I was motivated by a concern to be able to say something relevant to the geographical area that I was studying and the people who typically populated the service-user lists of young carers groups. I was not intending to make my group of participants a miniscule representative sample but I did want to capture the diverse experiences of categories of social difference that people brought to the community associated with young carers services, which had hitherto been under-explored in the literature, particularly from an intersectionality perspective.

3.4.1. Applying knowledge about categories of social difference in recruitment of participants

As one strand of the exploration of categories of social difference and their intersections, I reflected on the process of recruitment as a way in which I applied and learnt about the ways that categories are used, including in research and the administration of supportive services. For recruiting participants, my starting point was an acquaintance with the young carer in the family. I was informed by Finch and Mason (1993) who explained that operationalising the idea of families requires the imposition of one person's family form in a symbolic way, so the inclusion in a family was determined by one key participant. In the case of this study, seventeen participants were grouped as Aidan's family, Sapphire's family, XD's family, Rosie's family and Alia's family, based on the member who was the young carer that connected them to the local service where I had volunteered. The volunteering was a planned phase of the recruitment process but it also was intended to be a way of contributing to the services that were valued locally, rather than just engaging with them in pursuit of research objectives.

I approached young carers' families based on learning from interactions in the voluntary organisations. Where I had been able to interact with the young carer as a volunteer, learn about them and received an indication from them that they welcomed conversation with me, I considered them as potential participants.

With an awareness of the power imbalance between myself as an adult and children as participants, I felt that this interaction was nevertheless an ethical pre-requisite because it showed that they had chosen some kind of interaction before I have asked them about being part of the research project. In this very early stage the research was marked by my thinking about categories, in this case child/adult or age, and the meaning in the context of power differentials. It also draws attention to the way that my biography, my positionality and, harder to specify, my personality, shaped the types of people that I was able to build relationships with. Some children may have been happier to engage with me than others for all those reasons and for other reasons that I did not know. That went onto shape the participants and fundamentally build the study itself.

To build on the observations about how age and working with adults and children shaped the findings I will offer some further reflections on this category of social difference as shaping the process of research. I attempted to establish a position within families that placed me so that I could access meaning from multiple perspectives. In practice I wanted to signal that I was not aligned with one family member or another, one generation or another, although in practice some family members drew me closer to them, while others kept me at more of a distance. Age and gender seemed to work quite strongly in this regard (Christensen and James, 2000a, Eldén, 2013, Blazek et al., 2015). I was conscious of a generational positionality, where my perceived age placed me in a particular relationship with parents and children (Mayall, 2000). I was not a good fit with either age position within the families and I encouraged this idea. It was challenged by questions from children or parents about my age, which I was happy to answer but I was uncertain about how the information was interpreted, whether my closeness in age to some of the parents contributed to my status as someone with adult knowledge or that my markers of youthfulness, such as being a student or childless, kept me at a distance. For the children I was obviously seen as an adult, possibly in that ageless way that adults appear. So it was less of a relevant question for how the children perceived me, although I wanted to signal to them that I was available for their requests, not someone who held authority over them. This indicates the ways that my thinking about the social categories of age emerged at different points in my reflections, evolved and informed my actions in the field.

Decision-making about recruitment happened through the use of multiple social categories of difference. As a starting point I listed the young carers who I felt had built an acquaintance with me, using an understanding of them largely separate from those categories, but then I brought in my consideration of those categories and noted their positions within different categories. I thought about their age, their participation in the young carers group alone or with siblings, which family member had a disability or health problem, their gender, their ethnicity, and by working across the three young carers projects I could identify that they lived in different areas with different socio-economic characteristics. Balancing these categories, I listed a group of young carers who represented different positions within those categories. The selection was made through those categories. I asked for information about the project to be shared with their families. From that diverse group listed by me, the participant group represented different class positions, gender, ages, ethnicities and different types of disability or impairment.

This idea of diversity in my participant group was appealing but it also went against some useful ways of thinking about categories. Diversity draws attention to particular incarnations of those categories, so for example, for gender we tend to think of representing women and for ethnicity/race, we tend to think of people of colour (Spelman, 1988). More privileged positions tend to be invisible, thus there is the phenomenon of the invisibility of whiteness (Clark Mane, 2012, Hill Collins and Bilge, 2016, Tomlinson, 2018) or heterosexual social locations (Berlant, 1997, Butler, 1999, Hemmings, 2011). The use of categories in this case also separated participants from each other, so that I used them to position people without an appreciation of the way that race inflected the lived experience of gender and so on. In this application of social categories of difference I suspended consideration of the way that each category mutually constituted the other (Hancock, 2016). This set up a diversity that offered me examples of a range of social locations within and between each family but also one that risked reduced attention to “embodied intersectionality” (Mirza, 2013).

3.4.2. Embodied and non-embodied knowledge about categories of social difference

The challenge of conceptualising and observing categories of social difference persisted through the study. In discussions about care I noted the associations made with particular categories or groupings of them. However, I identified these through my knowledge which gathered two ways of understanding categories of social difference, each with its limitations. The two groups of knowledge were embodied and non-embodied forms. The first, embodied knowledge, relates to my lived experience of being socially positioned, which has been established at different points in my biography with some small changes as I have aged and taken on different roles in life. Some of these positions were less visible, such as ethnicity, disability and class because of the privileged social location that I have embodied (Zarb, 1992, Harding, 1993, Clark Mane, 2012). Other people will also have their embodied knowledge, founded in different circumstances to me, although some people will take on a wider diversity of positions in life than others, depending on what they do and what is done to them. Whilst recognising the limitations of those living in privileged positions to have the intellectual and biographic resources to study the social position of those who are subordinated, at the intersection of many inequalities (Harding, 1993, Spelman, 1988, Mirza, 2015), I drew on a range of resources to avoid the reproduction of othering and acknowledge a debt to Black feminist, queer and anti-racist theorists whose work illuminates the potential for new understandings of young carers and family life.

Drawing on the theory of intersectionality, without the personal experience of key subordinate positions, I can only make a limited contribution in the empirical work. I am also exhorted to recognise the political implications of this work (Hancock, 2016, Hill Collins and Bilge, 2016, Konstantoni and Emejulu, 2017) and to ensure its dissemination in ways that make it a resource for those for whom “power is not diffuse, localised and particular- power is as centralised, secure and authoritative as it always has been- excluding, defining and self-legitimating.” (Mirza, 2015, p.7). This provides context to the uncertainty with which I pursued discussions about ethnicity, ‘race’ and class, in contrast with the greater confidence in my prompts to family members when they made reference to gender or disability. The implications of my middle class status and my appearance of ‘whiteness’ and the ways it places me in terms of ethnicity (Nayak, 2006, Clark Mane, 2012) are explored particularly in Chapters 6 (Intersectionality at the separation of public and private space) and 7 (Social location in families).

This embodied knowledge is supplemented by other ways of knowing about categories of social difference, beyond that which has been gathered from my biography. So, firstly, I drew on a kind of tacit knowledge, where I had systematically gathered ideas from the behaviour of others around me. This relied on noticing other people and the more diverse the type of people I met the greater my chance would be of acquiring this tacit knowledge. A second kind of knowledge was incidental knowledge, where chance encounters, such as happenings in the street, would show me something outside of my habitual world that added to my understanding of how categories of social difference operate. A third form was academic knowledge, which, by consuming scholarly work, political texts and journalism I gained an understanding by taking into consideration the analytical accounts of others. A final form was empathetic knowledge, which used an emotional interpretation of another person's experience to shed a different light on the ways that social categories of difference were operating from multiple perspectives. Each of these forms of non-embodied knowledge added to my ideas about the categories of social differences, so that I could reach beyond my own standpoint. The imaginative work of combining knowledge (James, 2014) of categories of social difference, both embodied and non-embodied, was a persistent challenge but one that fed into ways of thinking about what those categories are and how they can be part of the project of describing care practices in families through ethnography.

These forms of knowledge, embodied and non-embodied, were carried by me into the ethnography, including the fieldwork, analysis and writing process. In the fieldwork I puzzled over the ways that this knowledge felt limited and I struggled with the fallibility of social interaction to furnish me with understanding. Part of the process was the pressure on me to respond to unpredictable actions and questions and the impossibility of knowing whether my response had helped or hindered the research. I was often stumbling over words, searching and offering the best I could and hoping that it did some good. This stumbling over words was a state of uncertainty, heightened awareness, discovery and frustration in the research process. I reflected on the feeling of stumbling over words as the way that I registered the imperfections of my knowledge of the environment I was in. I felt the extent to which I was outside of the family's social location but I also strove to adapt to it so that I could understand them better. By the end of the research process I felt more certainty, I seemed to stumble less or I could see the humour for me and my participants when it became obvious that I stood out. Rather than failures of conduct, this effect was a way of noticing the difficulty of both learning about social locations and incorporating that knowledge into the practices of participation required by ethnography.

3.4.3. Knowledge of categories of social difference in participant observation

The use of observational methods crystallised the ambiguity and subtlety of social categories of difference. Without a focus on words, questions and answers and transcripts, I was forced to confront what I was looking for and how I would know it when I saw it. I also drew on this problem to reflect on what this said about care work. Care is an activity that people do but also it is something that people 'are'. It is an expression of self in relationship to others. The basis of care through relationships is often premised on an understanding of the type of person being cared for and doing the caring. Through asymmetrical relationships, we often build up this element of care i.e. children-parent, older-younger sibling, wife-husband. Age and gender are well established as the axes along which care is directed and these intersections are acknowledged as important when we refer to categories of social difference i.e. father-daughter, grandmother-granddaughter. Other categories of social difference are more contentious in people's understanding of care work, for example, in the reliance on migrant care workers (Twigg, 2000, Fog Olwig, 2018) and the global care chains (Ehrenreich and Hochschild, 2003, Kilkey et al., 2013) in a post-colonial and racialised economy of care.

Where does this leave my statement of how I understood categories of social difference? Firstly, at a basic level, it means that I understand them to be patterns that can be observed, discussed, disclosed and recorded through the research process. It means that I question the potential to understand these categories sufficiently through more constrained interactions because they are difficult to distil into conversation, going beyond the trivial or the conventional. A commentary that identifies manifestations of a category of social difference, as highlighted through the analytic process, has helped to indicate some of the potential questions we can ask through studying young carers and family life. To avoid reiterating the simplistic point that categories of social difference exist, we require different data and different analytic processes that can tell us more about how these categories are cited, the patterns that explain the ways they manifest in social interactions and the ways that they regulate people's family life, care, childhood and public/private realms. The focus of the analysis was to use the data on categories of social difference so that I could provide insight into how they were connected to the practices of care, what this relationship between social location and care did for the people that lived with it and how this helped us understand difference in families' experiences of the instruments of social policy.

3.5. Ethics and ethnographic research

As introduced through a series of discussions above, there were multiple points of ethical consideration, both in terms of procedural ethics and the more expansive practice of ethical research for ethnography (Hurdley, 2010, de Koning et al., 2019). This section draws together central ethical issues and accounts for the decisions made in pursuit of ethical research conduct. It addresses the rights of research participants in the context of power imbalances, confidentiality and managing data, researcher safety and collective knowledge.

3.5.1. Power imbalances

As a researcher I considered the way that my study placed certain expectations on participants and impinged on their life (Agee, 2009). It was also framed as seeking to inform services in the context of uncertainty about whether this would be successful. Some participants made clear their hope that by taking part in the research this might be realised. For example, I recorded in my fieldnotes:

> **Fieldnotes 19/3/18**
>
> Luke was decisive that he wanted to do the research and wanted his siblings to agree. Becky [his mother] agreed and said her reason was that she supported my aim to tell people where services are missing, causing distress to them and families like them. I welcomed their motivation but was conscious that this may have ultimately disappointed them. Her eldest daughter's time in hospital was mentioned several times. Jane [her eldest daughter] also agreed to take part. Sapphire was hesitant and took herself away from the conversation to play video games. I said that she could decide later but once her siblings had agreed she wanted to too. I reminded her that she could withdraw if she changed her mind.

My role as a researcher and the power I may have held because of that label interacted with family dynamics to produce a complex set of relationships, including with children and young people (Valentine, 1999, Christensen, 2004), through which the study was introduced, information was shared and consent was sought.

There were ethical implications of building a relationship in an ethnographic study. I approached potential participants as someone who had been vouched for by services that they had an important relationship with so it was important to clarify that their decision in relation to the research would not have an impact on this relationship. This message was something that I alerted gatekeepers to, so that they could contribute to making this clear. Participants did not express concern about this issue particularly, nevertheless it was important to clarify that the relationship with the research project did not have a bearing on their access to services.

I also embodied other forms of power, maybe given the trappings of institutional importance as someone linked to a university. As discussed above, my whiteness, middle-class trappings and other facets of positionality may have signalled to my participants that I someone with status and power. It also might have marked me out as someone who would not necessarily understand their lives (Harding, 1993) or should be protected from difficult knowledge (Konstantoni and Emejulu, 2017). The complexities of researcher-participant relationships and power made me aware that this would be an unstable position and would change over the course of the research (Hammersley and Atkinson, 2007, Sluka, 2007, Feldman and Mandache, 2019).

I intended to moderate the influence of my status, by communicating the ways in which participants could have a say, or exert power within the research process. This was a tangible issue, as I noted in my fieldwork journal:

Fieldwork journal 14/3/19

> I felt able to be quite clear about the amount of choice they had over the process. I didn't try to impose things on them. Yet despite all that I felt discomfort. I felt I had power over them and they have limited scope to reject me and the research process. For example, I suspected that much of that [rejection] would be classed as 'rude' towards me as a guest, so would be censored, although I don't know that for sure.

I addressed these concerns in the first and subsequent meetings, discussing their rights as participants, for example, to withdraw fully or adjust their level of participation. It was important to keep checking about people's preferences explicitly to show my interest in their views and my openness to being guided by them. Nevertheless, I maintained significant control over the research process, setting broadly the terms of interaction and asking them to work with me on specific activities such as the visual data collection or book recommendations. Although I invited their involvement in reviewing the production of the thesis this was something that few wanted to be involved in.

3.5.2. Informed consent

I designed the study alongside consideration of my prospective participants' rights. These needed to be recognised and respected in the context of power imbalances between researcher-participant and different positions within families that had consequences for people's ability to voice concerns. I recognised that my potential participants included children whose ages ranged from four to seventeen years old and their parents. It included children with learning disabilities, although it could have included those from different backgrounds, for example, Deaf adults or children.

I made a series of decisions about how to communicate during this process, aiming to make the approach clear, informative, empowering and engaging. To recruit participants, I sent a list of potential names, chosen to provide a varied sample of families, and asked for them to contact each of those families to outline the suggestion of their participation and, if they wanted to know more, send them an introductory letter and a leaflet (Appendix D and E). If families responded to the young carers service by expressing interest in finding out more, I was then given contact details for the families that agreed for me to follow up and contact them by phone. The information sheet and consent form was written in order to be easy to read, suitable for children and their parents (see Appendix F). I drew on previous experience of writing accessible and Easy Read formatted documents in writing the recruitment material.

I adapted the information to be shared so that it fitted with what I anticipated the charity staff and the families would be interested in. I was often surprised by the extent to which staff and parents wanted to know my motivation or the value of the research or where the information would go afterwards. I assumed they would be focussed on their own motivations and interests, forgetting the likelihood that they wanted to know more about me as part of their deliberation and how important trust would be in their openness to building a relationship (de Koning et al., 2019). I tried to be clear about my hopes for what the research might do, informing people deciding on and running services, but also the uncertainty of whether this would happen. That communication became more refined and confident as the recruitment process went on, so I was able to learn from gatekeepers and potential participants about how I could prepare myself to answer their questions and help them decide whether to be involved.

The communication process was only partly under my control. I was also reliant on the ways that I could build relationships with staff in the young carers charities because they would be representing my project to parents first of all. Sustained contact with them and several opportunities to clarify my objectives and approach may have contributed to better quality of communication to the families from those organisations. The positive response I received from many of the families approached indicates that they received an impression of the project that encouraged them to find out more.

Another layer to the communication was the role of children. This is connected to the issue of power imbalance discussed above (Valentine, 1999). I sought to emulate the approach of Annette Lareau (2011) by utilising an existing relationship with children that I knew through an earlier phase (volunteering with the young carer groups) so that they might be able to use privileged knowledge to involve themselves in the family decision about whether to participate. As happened in the case of Lareau's project on family educational strategies, I was surprised by the number of families that agreed to participate. It was not my intention to persuade families to participate when they were reluctant. I wanted them to agree freely, however, I hoped that children holding information about my conduct as a volunteer might give them a particular status within any family discussions and encourage them to express an opinion about participation whether for or against. Children showed a range of behaviours in the process, for example, some, like Rosie, carefully and authoritatively engaged with the information and choices set out on the consent form, encouraged by her mother. Others, sought direction from their parents, for example, in the first meeting with XD and his mother, Tizzy:

> **Fieldnotes 20/6/18**
>
> XD looked to his mum to decide whether they should take part. They both declined to delay the decisions and they carefully filled in the

> consent form and duplicates. XD dated the section where his mum would add her consent because he is under 18.

These two examples of children’s stance in early discussions about informed consent show some of the ways that children claimed space to express their views, decisions and preferences but that this took place in the context of a power imbalance between adults and children.

At the end of each meeting I was satisfied that each person had received information to the extent that they wanted; however, I was not always clear that they knew or had taken in all the information I would ideally want them to (Gabb, 2008, Eldén, 2013). I did not believe that people were consenting without being informed but I had to defer to the limits imposed by individuals on the extent to which they think through the implications of participating or the constraints they felt in expressing their views.

One participant, Alia discussed with me her memory of the early visits and the complexity that lay behind indications of informed consent.

Fieldnotes 3/8/18

> We started talking casually in a friendly way. I said I had a question for her and asked what she thought about how the research was going. She was interested in the question and took it up in a particular way. She said that at first she had thought it would be weird. She had been reluctant to participate but felt that her mum said yes before she had a chance to object. That was not how I remember it but I do remember that Kaya [her mother] did steer things and that Alia seemed fairly uncomfortable. She said that the project was of such a nature that it would be impossible know what it would be like until it started. Actually it was "not as awkward as she thought it would be,"…. She implied that there was a way to go until I really understood them. I asked, "what would help, would it be spending more time with them that would help?" She said "no, it was about them being more comfortable."

Alia was one of the older participants but with the youngest children, for example those aged four or eight years old, I was particularly dependent on their parents thinking this through on their behalf and would therefore have to continue to check through the process that they were comfortable with the contact they had with me and my work. This approach was informed by Christensen and Prout (2002) on ethical parity, recognising the parallel rights of children as participants alongside adults putting an obligation on the researcher to adapt their engagement in order to realise the possibilities for children to speak and express their perspective on the research.

During the first visit I would meet the whole family and talk to them about the research process. I structured this by going through the information sheet and the consent form, with a copy given to each family member to look at as I went through it. All potential participants had a copy of the same form, which was written to be accessible to as many people as possible, using a careful choice of language and format. This was intended to demonstrate the equal way that I was engaging with children and adults, also considering the varied literacy levels of adults. However, the process was adapted rather than imposing the same approach on all. I encouraged them to ask questions and this particularly came up during the discussion of the consent form (see Appendix F). We went through the process of discussing each item of the consent form and including their written permission where they gave it. All the families that I met, except one, gave their consent to participate at the end of the meeting. At the end of the visit, if agreed to, I set a date for the second visit and this started with a discussion of how I should arrange to learn about their lives, including frequency of visits, length of time, weekends or weekdays and whether I should see them all together in smaller groups. As the relationship developed it was important to revisit issues of consent and access, reflecting the way that the process changed and acquired new forms over time (de Koning et al., 2019). I had put in place an ongoing process of consent, which included the discussion and the reintroduction of consent-related questions throughout the research.

The process of checking consent used a number of channels. Especially in the earlier stages of the research, I reassured families that it was fine if they wanted to withdraw or revisit the ways that we had agreed to proceed. This was explained through discussions when I visited but was also worked on through SMS communication or phone calls with families when I checked in about the plans, sent reminders, or rescheduled visits. To discuss this with family members I posed questions to them when I noticed that someone might be hesitating or seem uncomfortable. We did sometimes agree to change the process, for example shortening visits or setting up ways that I could separately speak to children or young adults away from their parents where they might be more comfortable to speak about some subject matters.

3.5.3. Participants’ expenses

This approach sought to incorporate ideas about ethical processes for working with children and their parents and working with disabled people. I used my role as the researcher to spend time sharing information about the project and adapting it so that I strengthened the approach to gaining informed consent. I also drew on ideas about ethical research practice in recognition of the rights of my participants. I ensured that they were reimbursed for any expenses, such as travel, in the small number of occasions when meetings took place outside of the family home. I did not offer payment for their time, feeling this would put pressure on families to become involved or continue despite reluctance, however, this is not a straightforward decision because it resulted in a significant demand on their time without compensation. As a small token recognising this contribution each family was given a thank you gift and card at the end of the process.

3.5.4. Privacy

I have argued for the relevance of private spaces for new research on young carers, as a theoretical justification for the study of the home, despite its association with the concept of a private realm and the significance of this for moving cautiously, on ethical grounds, in designing studies based within it. This makes it unusual within the academic literature on young carers and has the potential to offer new insights on the topic of young carers. Although I understand the ways in which we should question the status of people's homes as private spaces, this did not remove the ethical obligation to consider the importance of those spaces as private for my participants.

An ethical understanding of privacy remained, despite a questioning of the totality of the home as a private space (Young, 2005). Establishing the boundaries of research and respecting the privacy of participants remained a concern to be addressed throughout the research. I regularly questioned myself about the appropriateness of the amount of time spent with participants, the timings of my visits and the type of observations that were recorded and analysed. There were times when I decided that I was seeing an interaction take place that I was not meant to be seeing and that I would exclude these instances from data collection. I did not want my understanding to depend on taking information that my participants had not intended to share with me. This evolved from the understanding of my participants' preferences, those they expressed and those that I inferred from their body language or messages conveyed by other family members, for example, from child to parent to me (Eldén, 2013). This limited some of my data however it did not feel ethical to take advantage of the generosity of people allowing me into spaces that were really important for them as private. I also had to balance different ideas about what was private within the same space, so one family member would frequently introduce subject matters that others who were present were more reluctant to discuss because they felt embarrassed or maybe because they thought that the subject was uninteresting or trivial. I would take my cue from the way that the conversation developed to decide whether to record it in my fieldnotes. On some occasions it was helpful to ask directly whether people were happy for me to record something or to check the way that I had made my notes about it.

3.5.5. Confidentiality, managing data, visual data

People's involvement in research without being identified is of fundamental importance for ethical research (de Koning et al., 2019). Participants may, however, have a range of views, for example, some people are quite relaxed about being identified while others are concerned about the possibility of their data being associated with them (Duclos, 2019). In the case of this study most participants responded to discussions about my plans to withhold identifying details with approval and they collaborated on choosing pseudonyms to be used in the written thesis.

As the study worked with groups of people whose information was highly interconnected, the whole family identity needed to be made confidential. However, there was less scope in protecting people's identity when family member's information was reported. The strong associations between people and the fluid nature of the data collection site meant that information shared by one person could be overheard in the moment (Eldén, 2013) or connected to them in written material by their relative (Saunders et al., 2014). This was discussed with participants at the outset and was taken into consideration when it came to utilising data in the presentation of analysis. Some material was excluded because it seemed to cross a boundary into being sensitive information that a participant may not ultimately feel comfortable having circulated amongst their family members.

Participants were made aware that a limited form of confidentiality was being offered. It was explained that some published information about them may be attributable to them by family members or by professionals that they work with.

Measures were taken to de-identify data to reduce this risk however it did not remove the risk completely. In circumstances where data was considered sensitive, I checked whether they were happy for something to be recorded. I allowed participants to look at my notes as they were written on a tablet. They also had the option of checking the draft thesis, which two of the mothers did. No requests were made to delete specific or general data however, I took decisions to exclude or summarise information that I had surmised was highly sensitive or was delivered in ways that signalled an ‘off record’ moment (Duclos, 2019).

Another constraint on confidentiality was a legal obligation to report concerns about people’s safety. This appeared problematic in the context of limited availability of services to support families but I recognised the ethical basis of raising concerns about a child or adult’s safety (Eldén, 2013). Confidentiality would therefore be broken under the circumstances of a concern about a child’s safety. The breaking of confidentiality to report safeguarding concerns was discussed with participants at the outset and families often signalled their familiarity with this framework from previous encounters with professionals working in a similar way. For example, it was likely that this approach to confidentiality would have been discussed in their contact with young carers services. Clear information was included in the project information sheet on the circumstances under which confidentiality would be broken (See Appendix F). Under the circumstances that a disclosure had been made about a child being in danger I would have followed the University of Birmingham safeguarding policies, making a record of the disclosure. Concerns about adult safeguarding would also have be addressed by applying similar principles as those set out for children in the relevant policies.

3.5.5.1. Managing data

Data was created by typing up fieldnotes in the process of my discussions and observations. These recorded key observations, topics and quotations from participants. Accompanying this process of recording details of the fieldwork was the use of mental notes, paying attention to key moments that I will remind myself to reflect on and write up later (O'Reilly, 2009). Immediately after the visits I would skim over the notes to add further clarification or details. I would then return home and carry out further work to elaborate and extend the fieldnotes, usually done the same day or the subsequent day. Those notes were checked over later on as I developed my ideas during fieldwork and all of them were reviewed at the point of starting analysis.

I followed a data management plan to keep the fieldnotes secure, keeping physical copies of data such as consent forms locked away. Fieldnotes were saved as password protected documents and duplicates were saved on an encrypted hard drive and a secure cloud-based storage system administered by the University of Birmingham and complying with data protection requirements.

Participants were provided with information about these processes and I was available to answer questions when they wanted clarification.

3.5.5.2. Visual Research

Visual research raises particular ethical questions (Howell et al., 2013), for example, ownership of material, however these issues were considered within the existing research framework, for example, reflecting on power imbalances, consent and access to adequate information to evaluate decisions about participation (Pink, 2001). A series of actions addressed specific issues when using visual methods. The choice of drawing methods was made in order to remove concerns about protecting participants' identities if photography was used. A separate consent form was created to address the ownership of visual data and its use within the thesis or dissemination activities (see Appendix I). In line with the use of other methods, participants were advised that joining in visual data creation exercises was optional and could be withdrawn from at any time. This added another moment in which I could draw attention to the decision-making shaping the research process, mine and theirs, encouraging them to reflect on what felt comfortable with.

3.5.6. Researcher safety

In advance of the research I anticipated two key issues for researcher safety. The first of these was a procedure for locating me when I was doing fieldwork. I set up a lone working check system so that family members knew about my location and expected to hear back from me by an estimated time in order to know I was safe. If no contact had been made the person doing the check was instructed to request a police welfare check if the set time period has elapsed. This process continued for the first few months of the fieldwork but once the relationships were more established it became more flexible. There were no concerns during the process about my safety.

The second researcher safety issue was managing the demands of fieldwork. It was expected to be, and developed into, a process that did put me under strain. I felt a heavy weight of emotions and there were periods when visits were several times a week, proved tiring. I maintained conversations about this with my supervisors and sought informal support from friends and family. The fieldwork period was restricted to twelve months for several reasons: feasibility within the PhD timeframe, reducing time expectations on participants but also limiting the strain on the researcher. By the end of this period I had developed closer relationships with participants producing rich observations, so it was an adequate amount of time for data collection but the limit on fieldwork also helped with managing researcher stress. The fieldnotes that formed a substantial amount of my data stored rich information but were only a jumping off point for the fuller and emotionally-informed understanding that I drew on in the analysis (de Koning et al., 2019, Bell, 2019).

3.6. Collective knowledge and ownership

The process of ethnography is a reflection of collective knowledge, which I grew to share with each family. I brought distinctive and specialised knowledge to the process but so did each of my participants. Despite the shared labour involved in the fieldwork the study was heavily determined by the phases in which I worked independently - the early design and the later process of analysis and writing. There is a problematic result of a thesis that capitalises on collective processes of knowledge creation and claims ownership of this work. It aspires to contain due recognition of this debt but works within a format that limits a fuller realisation of its shared knowledge base.

4. Introducing the five families

4.1. Introduction

This chapter provides an introduction to the circumstances and the personalities of five families that participated in the study. In a section introducing each of them in turn, I point to where their home was situated and their connections to the area where they lived, the main pursuits of each family member and the arrangements of care. I also reflect on the degree of change that was encountered over the course of fieldwork.

4.2. Sapphire's family

During a period of eight months I got to know Sapphire's family, meeting them in March 2018 and drawing the research process to a close in October of the same year. During that time I met the family seven times, in March, April, May, twice in June, in July and October. I also had some contact with Sapphire's mother, Becky, in August and September during the gap in my visits to their home.

Sapphire is eight years old and she has a sister, Jane and a brother, Luke, who turned thirteen and eleven respectively in Spring that year. She lives with them, her mother and father and their dog. Together they live in a village attached to a town, which is near to Birmingham. There are large open fields just a few streets away, but also busy roads that rumble away in the background. Their house is on the end of the street, and as their road finishes and the pavement curves around to the left there is a small park with a play area, almost an extension of their home. Luke and Sapphire play there and run around doing gymnastics and parkour with other children who live in the streets around. They do not have family that they see nearby and Becky, the mother, worries that the children lack other adults to befriend them. They have cousins who live in Scandinavia.

Their house is small, with a little front garden with their car parked outside. The back garden has stacks of bikes, a swing seat, a shed and pots full of fruit, vegetables and flowers. Inside the house there are displays of objects like certificates, posters, photos, trophies and trinkets that remind them of happy memories and achievements.

Sapphire has been identified as a young carer. She behaves like the family ambassador, putting their best foot forward and championing their achievements. Her mother is really proud of her intelligence, her confidence and her strength to run around playing and cartwheeling for hours. She likes to challenge people if they are wrong but also to make them laugh with jokes, songs, and witty comments. One of her favourite subjects to joke about is when other girls act outside the way you would expect a girl to behave, or for a boy to act unlike you would expect of a boy. Sapphire helps her father a lot. One way that she helps him is by working with him to build up his skills so that he can be part of a local amateur dramatic project. Her dad had a stroke a few years ago and since then he has struggled with his memory and his ability to learn. Another way she helps him is by engaging him in conversation or diverting his attention when tension is building because he is telling a story which is stopping other people talking for a long time. Sapphire is doing well at school and gets a lot of pleasure from creative and energetic activities, although her mother worries that she does not eat enough food and she also has to sit out of physical education classes at school because of trouble with her bones.

Sapphire’s father, Chris, is often busy repairing the car, or doing small building projects to improve things about the house. He also cooks the dinner. He and his wife take the children on outings to the countryside where the children can ride their bikes on cycle paths. He and his wife, Becky, have an allotment that they work at in the summer months to supply fruit and vegetables for the family. He became disabled after having the stroke, which makes it hard for him to concentrate and to learn, and causes him a lot of fatigue, and he does not do paid work. He receives disability benefits that are a crucial part of the family’s income, although he and Becky were distressed when the amount was drastically reduced because of a new regime of administration of the benefit, implemented by the government. He works for long hours tending the allotment, doing repair work and household tasks, but he also needs to rest. He has drawn a lot of confidence from getting involved in the youth drama group, which his children attend. He helps them build sets, organise the productions and takes on small parts himself. Chris is very proud of his family, for their creativity and their adventures in the countryside. He also takes pride from his marriage, which has survived a great deal of difficulties and hard times.

Becky does paid work part time and has also undertaken periods of studying. When she is at home she moves around the house quickly, responding to the children's needs and labouring at the tasks of domestic work. At the same time, she has half an ear on conversations going on, encourages her children to say more on a particular topic or praises them. She says that her priority is to look after the kids, so cleaning the house does not matter so much in comparison. She is often checking on the dog, a big Alsatian, and picking up objects that he has knocked over. At times this was made harder because of back pain. She also has problems with her hearing, so group conversations can be a struggle. Her son Luke gets irritated with her when she can't hear, but he gets even more annoyed when her English is incorrect or she speaks in her native language, which is not English. Becky used to work as a scientist but has not be able to get a job in that field in the UK. She occasionally did informal paid childcare jobs and she was trying to acquire new skills, like operating industrial sewing machines, so that she can find new types of paid work. She wants to make sure that they can continue to pay for the children to participate in activities and clubs after school, otherwise she worries that life is boring for the kids. Another commitment of Becky's is to improve the facilities in the neighbourhood. She secured a grant from the council to create a play area in the small corner park next to their house and to surround it with herbs and fruit bushes. She is passionate about growing plants, producing food, and protecting the environment. She is often thinking about making sure her children have a good childhood and that they have happy memories of it when they are grown up.

Jane, the eldest, is conscientious and creative. She turned thirteen during the time the family were part of the research and it was significant to her to officially become a teenager. She would often be found pursuing her own interests and leaving the rest of the family to get on with their own things. She helps around the house, preparing salads for the family’s dinner or helping to keep conversations ticking along. She hates school and has been bullied there. She says that she used to be disabled, after having a stroke and then struggling with movements and school work. Her parents are proud of the way that she was so brave and determined in recovering from the stroke and the related operations. Rather than going outside, she prefers to stay in the house and write stories or create illustrations, so if there is a family trip to the park or a cycle ride she is reluctant to go along. When she is at home she organises her time. For the Easter holidays she made a ‘to do’ list of ‘homework, fun, Luke and Sapphire, helping around (the house)’. She takes part in organised activities, like the youth drama group with her brother, sister and father. She also is part of a dance club. She wants to be seen for her maturity, being in older age groups in the clubs they go to, having adult tastes in food, denying herself activities because they are too costly and staying calm when her siblings try to provoke her with criticism or jokes at her expense.

Luke is the child in the middle, with an older and younger sister. He loves being outside and being active. He is proud of his ability to cycle fast and far. His younger sister looks up to him, trying to imitate his athletic tricks and his attitudes, like his hatred of school. He really dislikes school because it keeps him inside and because he does not get on with the other pupils. That makes him angry. Sometimes he needs to take himself off on his own, but he likes people to see, or at least hear about, his clever tricks or exploits. He plays with other children in the neighbourhood, although his mother worries that he is associating himself with older boys who are a bad influence or that sometimes he gets into arguments that turn the neighbours against him. Luke does not consider himself to be disabled but he knows that others do. He has autism and he is learning about it, reading a book with his mother. He sometimes gets angry with his mother and his older sister but he is loyal to his father. He expresses caring behaviour towards his younger sister and also the dog. He is conscientious, wanting to be considerate of people’s feelings and to do the right thing.

The family take on different roles in caring for each other. Some of the ways they do this are cleaning the house, washing clothes, contributing to activities that they can all be part of, instigating fun, building relationships within the neighbourhood, allowing each other's moods to play out without becoming angry, sticking together, entertaining and playing with each other, going on trips out of the house, preparing food, growing food in the allotment, maintaining the bikes and the car and looking after the dog. Sapphire goes to the monthly young carers club, which the family value. Sapphire's brother, Luke, thinks that it is important that it continues for his sister. Other than that, the family have little support. Chris, the father, received Personalised Independence Payment, a disability benefit, and Jane, the oldest daughter, has been seen by child development services but by and large they have tried to manage on their own and not received much help.

The family often seem to be thinking and talking about health and disability, particularly focussing on Sapphire's brother, Luke, and sister, Jane. All of them are caught up in the ongoing conversation about exercise, healthy body size and health. This seems to be even more important when the family are under strain, so the distribution and monitoring of food intake is a priority for Becky and Chris. This is connected to their decisions about spending money because as finances got more restricted decisions about the purchasing of food became more difficult.

During the seven months of getting to know the family as part of the research, there were changes which appeared to be connected as a series of pressures on the family. Firstly, in May 2018 Becky and Chris were struggling with the aftermath of a significant cut in their income when Chris's Personalised Independence Payment benefit payments were reduced after a reassessment of his eligibility. The two older children were getting into difficulties with school and seemed to be picking up on the growing tensions in their home life. Luke was often angry and Jane seemed very down. In August 2018 Becky had decided to separate from Chris, although in October they decided to stay together for the benefit of the children. A better financial situation would make things a lot easier for them and Becky was doing unpaid work for a local company so that she could learn skills and find a job. Becky was also trying to improve her knowledge of autism and help Luke understand it so that he had that perspective on some of the ways he struggled day to day. By October their circumstances had settled a bit and they were looking forward to being part of the youth drama group pantomime at Christmas.

4.3. XD's family

I learned about XD and his family during a condensed period of fieldwork. I met with him and his mother, Tizzy, eight times between June and October 2018. We met at their house twice but the other visits took place outside of their house, where XD felt more comfortable because of problems with their housing. The other locations were a café, a museum and a restaurant. Tizzy and XD picked places which they were familiar with and had happy associations for them, working as alternative locations for understanding their family life.

The focus of XD's family life is his mother. They live together, are building a life for themselves and overcoming the problems of the past. XD is thirteen years old and is quite a serious boy but he has a mischievous side. He is determined to get to do the things he wants to do, whether that is being part of a winning football team, gaming with his friends or being allowed to have a girlfriend. He is focussed on doing well at school but he worries that he may not do well enough to meet his mother's standards. He is close with his mother and works hard to support her. Together they make up a tight-knit family. XD looks to his mum to decide what they should do, although sometimes he thinks they should be doing something different. He pays close attention to conversation and the environment he is in, staying alert and watchful.

Tizzy is the focus of XD's family life but they also have other important people who are far away from them for different reasons. They recently have made contact with some family in the East Midlands that they did not know about. These are Tizzy's half-sister, her husband and child, so XD's aunt, uncle and cousin. They also have friends that they stay with in Worcester. Tizzy's boyfriend spends time with them, for example, taking them out for dinner. They did live with XD's father when they first moved to the UK from Southern Africa but he abandoned them, leaving them distressed and in a precarious position. They had to rebuild their lives after that and it is still something that causes them sadness. Tizzy misses family, some of whom are too far away to see. Other members of her family died during the AIDS epidemic. Tizzy feels quite alone and she discourages XD from spending time with other children, to protect him from racism and bad influences. School is an important time for XD to see his friends and be less bored than when he is at home.

They live in a pair of rooms in a shared terrace house in an inner-city neighbourhood in Birmingham. They share the bathroom, kitchen and utility rooms with the other people living there. They moved there temporarily, but the council still have not found them a house of their own. It has been hard living there because they have had to deal with conflicts with the other people in the house and there is a lack of space for them. There have been burglaries and the problems with damp are causing them allergies and illness. Tizzy has learned to tolerate some of it but sometimes it is too much so she confines herself to her room. It limits the activities they can do at home but they still enjoy activities like cooking together occasionally, watching TV in Tizzy's room and XD plays video games.

Tizzy has had problems with her mental health; she had depression. She had physical health problems too, experiencing tiredness, vertigo, and pain. When this was bad, she did not care about her appearance. She and XD were not interacting, they were just at home and at school, not going out. XD would come home from school and find that Tizzy had not cooked anything. He had to fend for himself by going out to buy chips and washing his school uniform. As it was just Tizzy there to care for XD and she was not ok, it was a bad time for XD. They both talk about the work that XD does as a young carer. Tizzy recognises its importance for her because it helped her keep things going when she struggled with her mental health. She also compares it with the hard work she undertook as a child, doing domestic work for her cousin's family, alongside schoolwork as a child.

Another problem they have faced was uncertainty about legal residence and citizenship status. After Tizzy separated from her partner, her right to reside in the UK was at risk. With the residence status uncertain and legal restrictions on Tizzy's right to work, Tizzy could not look for a job. This worsened her mental health because she felt her independence was taken away. She was back to square one and they had lost everything, since moving from a country in southern Africa, where she had a job as an accountant and could afford to send XD to a private school.

The housing problems have continued for a long period but other things have changed and improved. Social services looked into them as a family because they needed to find out if Tizzy was neglecting XD. Social services said that Tizzy could lose custody of XD unless they saw that she was caring for him. When they looked into it they found that Tizzy was doing her best but needed support. The family received good support from mental health services, primary health care, a young carers service and a housing charity, which helped both of them a lot. They got the help they needed and learned other ways of doing things, for example being part of local groups so they could take up affordable activities and get out of the house.

During the time I spent with XD and Tizzy, things stayed quite stable. Tizzy attended an academic course for four weeks during the summer, which she enjoyed. It took her mind off things and she learned a lot. It made her think about other courses that she could take. Meanwhile XD was limited in the activities he did. The school holidays were often quite boring except when he was allowed to do his gaming. When back at school he regularly played for the school football team and throughout the year he was connected to a young carers project, which gave him the opportunity to have fun and took his mind off more difficult issues. He was not able to be involved with their activities as much as he would like as money is tight.

4.4. Aidan's family

Aidan is a thirteen year-old boy. His family is made up of his mother, Marie, and his little brother, Joey, who at the start of the research was aged four. Aidan and his family contributed lots of time to taking part in the research, although Aidan did not always find it easy. There were fifteen research visits to the family home through 2018, starting with two in March, two in April, one in May, two in June, one in July, three in August, one in September, two in October and a final visit in November. Aidan was there for all but one of those visits and for three of them we went on trips to MacDonald’s.

Aidan, Marie and Joey live in North Solihull and Aidan goes to school nearby. Their house has two bedrooms, so he shares a room with his brother, but he is often staying at the house of his best friend, especially during the school holidays. Aidan does not like sharing a room with Joey and wishes that he could have his own bedroom. At home he often watches videos on his phone or listens to music on his headphones. The rest of the time he likes to be outside, exploring the neighbourhood on his bike, persuading bus drivers to let him travel for free and running errands. He likes cycling, swimming and being active. He wants to be independent, so to make his own decisions about what he does and where he goes. He is proud of the fact that he is tall, so looks grown up. He wants to be seen as an adult and to earn money so that he can have a car and more freedom. He is particularly attentive to the different ways that people earn a living. He respects that kind of work and considers his options for future jobs seriously. Aidan wants to take a parental position in his relationship with his younger brother, Joey, enforcing his mother’s instructions on his younger brother or imposing his own authority. He also wants to protect his brother because he is so young and can get scared.

Aidan looks for what is possible and seldom acknowledges any things that might stand in his way. Aidan likes provoking people a little bit, challenging them to express disapproval when he is going about his business. He is proud of appearing fearless and audacious. He likes how adult acquaintances can help him get things like free bus rides or lifts in a car. He has got in trouble for stealing from a supermarket when money was really tight at home. He does not talk about it much, but he has pain in his knees that makes it hard to walk upstairs. He focusses on when we can use stairs rather than when he can't. Aidan hates the idea of getting ill and is scared of germs that might infect him. School is not easy for Aidan and he gets special assistance because he is autistic and because he is a young carer, but he finds it tiresome. He has got bad results from school and his mother does not expect him to get higher grades for his GCSEs, although she hopes that he will pass them, offering him a financial reward for every pass or high grade.

Aidan's mother, Marie, is a very clear-thinking woman. She is open to talking about her life. She likes to find the funny side of things. Marie's best friend lives around the corner. They keep in touch by phone and they see each other almost daily. They help each other with childcare and domestic work. Marie's focus is on being a good mother and making sure her children have everything they need. She is alert to enforcing the rules that will keep the children safe, healthy and within the bounds of good behaviour. She spares them deprivation wherever she can, making sure the house is always well heated in winter and saving up for a holiday 12 months in advance. Whilst working hard to look after Aidan and Joey she has her frustrations. Marie finds Aidan's behaviour difficult, because he does not always show much emotional engagement and he challenges her authority. She finds his autism difficult. She enjoys Joey's games and enjoys stimulating his learning, but she gets tired of him waking up so early and looking after him when he is ill can be exhausting. Marie is trying to improve her health, attending a diet club, referred by her GP, cooking different kinds of food and restricting the sugary foods that Aidan eats. Aidan shows some awareness of this too, trying to contribute to Joey's health by adding fruit into his food when making a takeaway order.

Marie has had to deal with health problems that have made her life difficult. She has very bad migraines and experiences vertigo, which affects her mobility. She has had mental health problems, with Post Traumatic Stress Disorder after a very bad experience during Aidan's birth. She still has some problems with her mental health, but good support from mental health services has helped her recover. She also had support from the housing association where they lived before. As a result of Marie's mental health problems, Aidan, was classified as a young carer.

Aidan regularly goes to the young carers club, which is held once a month, and during the school holidays he goes on their trips. In the past he had one to one support and also counselling. Marie chose the school for Aidan because they impressed her with their recognition of young carers and attitude towards supporting them. He was the focus of meetings at his school to review his support because of his autism and because of incidents that highlighted problems, including a teacher bullying him. He was also voluntarily working with the youth offending team after he had got in trouble for stealing.

Sometimes Marie thinks that Aidan does not do enough to be a young carer. At other times she feels that Aidan is a big help, caring for her when she is ill or helping with the daily tasks in the house. Marie says that Aidan used to do a lot and was very helpful to her, really involved in medication and housework but as a teenager he has become less involved. They had not got much help as a family in the past. Aidan is asked to do washing up, tidy, take out the bins, clean, pick up food, help Marie when she is unwell and he makes teas and coffees. Aidan had to deal with a lot of difficult periods when he was younger and his mother's health was much worse. Joey, who turned five during the research period, helps with tasks such as making the bed and laundry. He helps his mum with tasks and by cheering her up but he also helps his brother, although Aidan rejects the idea that Joey helps him.

The youngest in the family, Joey, loves to play games, wanting to get people involved so he can interact with them. He is often excited about new little toys that his mother adds to the collection. He is showing a lot of ability in his school work, doing particularly well at maths. His mother is proud of his ability to learn quickly, takes pleasure from his energy for making up games and suggesting new ways he can challenge himself and learn. Joey likes playing with his mother and he wants to play with Aidan but does not often get his offer taken up. He looks up to Aidan and wants to be like him although he teases his brother and wants to wind him up sometimes. Sometimes he starts fighting with Aidan and makes his mother cross. Generally, Joey wants to avoid getting in to trouble and is ashamed when he is seen to have done something bad but sometimes he does not care and sees it as a joke. Joey has been assessed as being a young carer because of his relationship to his brother with autism, so once he is five he would be eligible to access the young carers service. He has also had an assessment for potential hearing problems. His mother does not think he does have a hearing problem and she also does not think that accessing young carers services is necessary for Joey.

Aidan is the only one in the family who does paid work, mowing lawns and doing odd jobs for neighbours. His use of the money he earns sometimes gets approval from his mother because he wanted to treat his mother and brother, easing the financial pressure, but other times she is angered by him wasting the money. Marie relies on government benefits to support her family. During the year she went through an assessment for her eligibility for Employment and Support Allowance (a government unemployment benefit for people who are ill or disabled) and was scared by the result of this assessment which concluded she was ineligible. As a consequence, she faced being moved onto a less generous benefit with additional work requirements. She reported that this outcome did not reflect her circumstances and was concerned that it meant there was the possibility of a serious reduction in income. She was appealing the decision, seeking to get it overturned.

4.5. Rosie's family

Rosie's closest family are her mother, Dominique, and her older sister, Poppy, who she lives with, and she is also close to her grandfather. I got to know eight-year-old Rosie and her family during seven research visits. Two visits were arranged to meet just Dominique, Rosie and Poppy's mother, after work and there was one visit to the family house when Rosie was away, so with just Dominique and Poppy present. They live in an affluent suburban area in South Solihull.

Rosie spends time every week with her father but she does not like seeing him. She is courageous and stands up to her father when he is behaving in ways she cannot accept. She is proud of her achievements and keen to build relationships with people. She has made a lot of progress with learning karate. She loves watching TV after school, finding videos on YouTube and reading books. Rosie is doing well at school and she sometimes also attends an after school club in the evening, or the summer activity club. She attends a Catholic school, similar to the school that her mother went to and at one time her older sister went to. Rosie likes spending time with her family and with friends, being outside and going to the seaside. Together with her mother and sister she does lots of dancing and plays games. The sisters play together, with Rosie often taking the lead about what they do. Rosie thinks that she can get the better of her sister, getting her to go along with what she wants or getting her to give her extra food.

Her older sister, Poppy, who is ten years old, is at a different school that is for children with special educational needs. She asks lots of questions, sometimes to find out something but other times she wants to have information reiterated so she can check that things are as she expects. She keeps a careful eye on things in the house, so if a light bulb has broken she is very aware of it and prefers things to follow a routine. She watches what her mother is doing in the house and she wants to join in with the housework or the preparations for a meal. She loves stories and reading books. Her favourite place is the library. She has a good memory, is very observant and is a very generous person. She is interested in whether people have been good or bad, so she checks with her mother about whether her own behaviour has been acceptable and sometimes she points out when her sister, Rosie, has not obeyed the rules. Poppy is skilled at connecting with people, smiling at them, learning their names and talking to them. People are drawn to her and show her affection in response to her behaviour. This is a quality that her mother really admires in her and she encourages her other daughter to emulate it.

Poppy has autism and learning difficulties. She is often is unsettled and anxious, which makes her angry and scared. The pattern of visits to her father has a destabilising effect on Poppy and makes her very upset. Dominique describes the effect of Poppy’s time with her father as if she is a can of pop that is shaken and shaken. Rosie says her sister has moments of distress and anger most days. Sometimes that turns into violent behaviour which has caused her mother injuries. The family receive three hours per week of respite time from the local authority, during which time Poppy is looked after by a learning disability service. At the same time, Rosie and Dominique spend some time together. Dominique also accesses support for the family, like a blue badge for the car and funding for families with disabled children.

Rosie is another pair of eyes for Dominique to make sure Poppy is ok. She helps her mum and repeats things that Poppy needs to pay attention to. Rosie sometimes tries to keep Poppy calm by engaging her in conversation. She finds it upsetting that Poppy gets angry. Dominique watches Poppy carefully, always checking that she is safe. If Poppy is agitated Rosie stays very calm and uses techniques that soothe Poppy so that she is less likely to become distressed or angry. Dominique works hard maintaining the house, caring for the girls and planning activities for them. Dominique’s father provides childcare, supports Dominique and does work around the house, like fixing a gate. Dominique has to be extremely organised to balance her job and her responsibilities towards her daughters.

The three of them like being at home and prefer the days when they have nothing to do with the girls’ father. When they go out on a walk in the neighbourhood they take a photo of themselves standing next to the street sign at the entrance to the cul-de-sac. Both the girls like to stay close to their mother, talking and playing with her. Dominique instructs the girls in speaking correctly and sticking to the rules while they chat and play.

Dominique is confident and always seems sure of what she is doing. She pays careful attention to what people are saying. She has lived in different countries and speaks several languages. She has a job in the public sector and she can make the hours work with the timings for looking after the girls. She keeps a careful eye on money but also feels that she is secure financially. This was made more precarious with the impact of paying for legal services to contest her ex-partner's ownership of the house and custody of their daughters. During that period her job carried on, but it was difficult at times.

4.6. Alia's family

I got to know Alia and her family through a steady set of visits. There were nine visits in 2018 taking place in March, April, May, June, July, August, twice in September and in November. They live in an affluent town in the Black Country. I always spent time during those visits with Kaya, Alia's mother, but I also would spend time with Alia herself, her sister Amber, and occasionally her father, Ben. During those visits I was able to take part in long conversations about the family's way of life, hear their stories, and see how they negotiated the routine of family life. Alia gradually joined in longer conversations and shared more of her thoughts. I found out more about her concerns about friends, the identity she wanted to establish and her politics, resisting the oppression of people based on labels or differences. She gets angry when people are racists or homophobic and notices that people express ignorant views about disability. She became less cautious and reserved through the research process but she is quite a private, self-contained, person with a strong sense of what she wants. She keeps an eye out so that she knows what is going on.

When Alia is at home she listens out for signs of her sister’s mood, so if she hears her dancing and jumping around she relaxes but if she goes quiet she is worried. She likes how their new house gives them all more space. She worries about her family and her mother wants to encourage her to be more focussed on herself and enjoy her teenage years. Alia thinks a lot about the future. She plans for a career, independence and living in her own place. She does not want to get married or have a family. She wants to go travelling. She worries about how her sister will be looked after when they are all older and what she will need to do as part of that.

The dominant part of Alia’s routine is school and homework. She is fourteen years old and spends a lot of time every evening and at the weekend doing her homework. On top of school, Alia goes to extra maths and English classes every week and this adds extra homework. Kaya and Ben tell Alia that she needs to work harder, take more responsibility for her work and hold herself to a higher standard. She resents their intrusion but is conflicted because she does not want to disappoint them.

Alia attends a young carers group, switching to one in the new area when her family moved house. She likes how she can leave thoughts of home behind although she also wishes that the previous group had been a place where she could talk about the experiences with her family, rather than just take time away from it.

Alia’s older sister Amber had her eighteenth birthday during the course of the research and likes being seen as an adult. Amber’s favourite hobby is watching TV programmes. When she gets up in the morning she will dance and sing. She draws and fills notebooks with written thoughts and sketches. She loves parties and gatherings of families and friends, as well as fashion and shopping for clothes with her mum.

Amber attends a college for young people with special needs. She is learning about independent travel, getting travel training through the college. Amber helps the other students at her college and is kind towards them. She can give wise advice to her friends and sister. She is sometimes lonely and wishes that she had more friends or more satisfying friendships. She finds it hard when she sees her mother and her sister enjoying their social life. She turns to her mother to help her with her feelings and is asking for her practical help so that she can build friendships.

Amber’s focus is not on homework but on preparing herself for the adult life she wants. She wants to live with her family and stay close to her parents. She imagines earning her own money, getting married and having children. She loves her parents and her sister but she says that she does take things to heart at home and gets into squabbles with them. Amber, like her sister and parents, spends a lot of time with her extended family. She has spent an extended holiday with her grandparents in Pakistan when she was taken out of school because she was so unhappy and the school was unable to support her. Since changing schools and as she got older she has started regular hours of work experience at a beauty salon. She really enjoys her work, is proud of her role there and has learned a lot. She is trying to get a paid part time job.

Alia’s mother, Kaya, works at a university. She is sociable and knows lots of people. She is very close with her sisters and parents, counting on their support and valuing their involvement in her life. She is confident and commanding. She maintains a connection to her childhood ambitions to be successful and independent, not to follow a traditional path but her career has receded into the background as her focus has been on adapting her routine so that she can help her older daughter. She has done extensive research on autism and her daughter’s genetic condition so that she can understand her daughter better and learn how to help her. She has needed to take time off work regularly so that she can put it into caring for her eldest daughter and making sure that she had the right school and healthcare. Kaya has recently had time off work because of back pain. Both of her daughters are worried about the pain she has been in.

Alia’s father, Ben, works hard for a private company, which requires long hours, including at weekends and in the evenings. His work has given him more flexibility, which has helped him to contribute more to caring for his family, particularly his eldest daughter Amber. Before that there was far more pressure on Kaya to balance her work hours against the time spent pursuing support and medical services for Amber. Ben has growing concerns about his job security so he is trying to get extra qualifications that would help him if he needed another job. He is very close with Amber and they have a relatively easy relationship, including going out for treats to eat or getting out the house to run errands. Ben is conscious that he does not do as much housework as Kaya and Alia. Ben enjoys relaxing with his daughters and he is very committed to being a good father to them, giving them lifts, monitoring their progress at education and being able to enjoy their childhoods. He used to have a hobby playing squash, although that had to stop because of an injury. He backs up Kaya’s decisions about parenting the children and working to look after the house but he is more easy-going by nature. They do not always see it the same way.

Alia and Amber spend time together watching TV in the living room or upstairs in Amber's bedroom sitting on the fluffy rug on the floor. They go to visit and stay with their grandparents, who live a few streets away. The family socialise a lot with their wider family, particularly Kaya's parents and the aunts and uncles that live nearby. Sometimes Amber and Alia help their grandparents doing housework and keeping them company. Most years, Kaya's parents are in Pakistan for several months so that changes their routine. The parents pay for the girls to go on trips, on holiday with them or attending a summer camp. These holidays were not always a success because some resulted in painful arguments, but the girls came back from the summer camp really happy.

As a family, they care for each other by sticking together and not arguing. Amber's particular role is that she helps with housework and supports her aunt by being her friend. She asks her mother to give her affection when she feels uncertain or sad. Her parents and sister coordinate their efforts to reduce Amber's distress or anger and to protect her from being in danger without supervision when outside the house. The message that Ben and Kaya give their daughters is that the house is their environment too and they need to look after it. Alia goes along with what is expected of her in terms of housework but Amber sometimes disagrees and does not help. Ben works on the house, along with Kaya, painting rooms that need redecorating or working in the garden. All of the family members are involved in cleaning the house and being part of bigger tasks such as batch cooking meals for freezing and eating during the week.

The family have had contact with a range of public services. Social workers, psychiatrists and educational support services have assessed Amber and respond to requests from Kaya for support. Amber is autistic, has been diagnosed with a genetic condition, has had mental health problems and experienced difficulties at school. They have periods of engaging with a family support group for families with disabled children and they are also part of a network for those with an interest in a particular genetic condition. Amber has been assessed because she is becoming an adult and is moving from being under the remit of children's services to adult services. The family are trying to improve the healthiness of their diet and increase the amount of exercise that they do. This is driven particularly by Kaya who has committed them to a healthier lifestyle.

The family are Muslim, although they have an ambivalent relationship with the local British Pakistani community. They do not want to be closely involved because they feel that they are judged harshly for the way that they practice their faith. They feel that the community put pressure on them and others to conform but they resist it, making their own decisions about what is right.

4.7. Conclusion

These introductions to the families show the differences in their circumstances that provide varied contexts to arrangements of care and the role of children as young carers. A number of the families had in common fraught incomes and problems with housing, crucial elements of family life which will be examined in following chapters. They also had difficult relationships with public services that will be considered as well. The children, who the families are named after, were all part of young carers projects and were labelled straightforwardly in those institutions as ‘young carers’. This research demonstrates they were part of a complex network of care within their family lives. By delving into the detail of family life, working with the examples of these five families, this thesis explores the ways that the patterns of family and the ways it is shaped by inequality can offer new ways of thinking about young carers.

5. The negotiation of care work

5.1. Introduction

This chapter argues that negotiation is an important feature of the organisation of care and family life, which should be recognised by those who undertake study on young carers in order to increase understanding and improve insight into the everyday politics of family life. In this study I found that young carers' experience of care is shaped by the process of negotiation and its outcomes. Negotiation features in the study of families (Finch and Mason, 1993) and has gained some attention in one study of young carers that used a single case study of a young woman and her mother (Aeyelts et al., 2016). This study explores negotiation and offers insight into the politics of young carers' family life. This chapter uses ethnographic data to show the potential in understanding negotiation as a political process, both in private spaces and at the boundary between public and private. As part of this undertaking we need to situate young carers in their specific family circumstances.

The chapter is informed by the observations and the conversations over nine months of fieldwork, but it also looks back to earlier phases of those families' experiences, as well as anticipating future changes. This timescale reflects the way that care processes were understood within families, with its own relationship to a past and a future (Hall and Sikes, 2018). For each of these families, their daily activities involved a complicated array of activities, some required and some chosen. All family members contributed to care, carrying out tasks that sustained themselves and others, but also by communicating in ways that affirmed an emotional connection, creating a feeling of being cared for.

This chapter begins with focussing on Aidan's family because they provide a detailed and challenging account of how children are involved in care and its negotiation as work. They are particularly crucial for understanding the potential for developing ideas about negotiation in the family life of young carers. The experiences of other families will also be drawn on as they provide different perspectives that complement Aidan's family's story. Aidan's family were an example of the complexity and change brought about through this process of negotiation, as will be explained in the following analysis. In particular, their experiences support a strong argument for the importance of interdependence rather than the binary of carer/disabled that can obscure many features of young carers' family life (Chattoo and Ahmad, 2008, Ward, 2015b, Clough, 2017, Engster, 2019). This is followed by putting Aidan's family into the context of families as organising institutions. I consider the way that families are conceptualised as organising institutions in policy-making on young carers. Finally, I look at three themes on negotiation from data on families, categorisation of carer/disabled, the emotions of negotiation and policy presence in negotiation.

5.2. The example of Aidan's family

5.2.1. Patterns of care organisation in Aidan's family

Aidan and his family were introduced in Chapter 4 (Introducing the Five Families) along with the other families that took part in this study. I now return to consider how they are embedded in an economy of care, managing needs within their own family and interacting with paid and unpaid networks of care. To understand how care was organised in the family I map the rules that govern care roles of each family member and recognise the process of negotiation that is shaping these roles.

In Aidan's family, the organisation of care work is led by Marie, Aidan's mother, but she and her son revisited and contested care organisation repeatedly, enacting a process of negotiation. Aidan is heavily involved and, in some cases, takes ownership of parts of the care work, rather than being directed by his mother at all times. Fieldnotes from the research visits record the ways that Aidan would step in when he saw a need for him to take a role in care:

Fieldnotes 11/4/18

> While I was there Joey wanted to play a lot. He was refusing to eat his toasted sandwich. Marie was asking Joey to eat it and later on Aidan backed her up and enforced the idea that he should eat it.

Aidan was more involved in care when Marie was ill, for example, when she has a migraine which can last for a couple of days. However, he also rejected responsibility for some forms of work, refusing to tidy his room or carry out other tasks requested by his mother. On some occasions Marie reported that she was pleased with Aidan for having done the washing up, emptying the bin or looking after her when she was ill. Both Marie and Aidan had significant roles in care but the division of work between them was often negotiated over.

Joey, Aidan’s younger brother, has a role that was small but important, contributing greatly to the atmosphere of fun, play and affection which motivated Marie and Aidan. He also helped with practical tasks such as making the beds and sorting socks. The Early Intervention Team had indicated that Aidan’s difficult behaviour, explained by his autism, meant that Joey would be entitled to receive a break through the young carers service. This implied that Joey was adversely impacted by his interactions with Aidan, his brother, and would benefit from time away from him. It appeared that Marie’s health was sufficiently improved that Joey was not seen to be a young carer in relation to his mother. There was a dispute between Marie and the assessors about how to see Joey’s role in care. Part of this dispute was a disagreement about whether the discussion should be located in the private space of the home or whether outside actors such as social workers would become involved.

Other than Marie's episodes of ill-health, there are different factors that were seen to change the dynamics of the organisational process as the months of fieldwork added up. Here, I briefly describe three factors that had a significant impact on the organisation of care. The first factor is whether Aidan and his brother were at school during term time or whether it was the school holidays when they are at home much more. During school holidays there is a much greater demand on Marie to provide them with meals, manage the extra cost of the food provided, and organise activities and trips for them in line with their restricted budget. Her receipt of Employment and Support Allowance only provided a limited income to meet the family's needs. A second factor is the changes in the amount of care that Aidan's younger brother, Joey, needs and the timing of that care. There were several times when Joey was ill with a cold or had chickenpox. His symptoms kept him awake at night with pain and he was distressed. During those times Marie stayed awake with him, comforting him and trying to relieve his symptoms. This tired her out and she struggled with other tasks that she usually managed in the day. As a result, Aidan became more involved, temporarily, to cover other tasks while Marie focussed on looking after Joey or resting. These provided a seasonal pattern to care work, with the fluctuations of the school year or the brief illnesses picked up along the way.

A third and longer-term change has been Aidan’s reduced care role when Marie’s health improved, as the extract from my fieldnotes shows:

> **Fieldnotes 11/4/18**
>
> I asked Marie how things had changed in terms of Aidan being a young carer. She said that Aidan “used to do lots as a young carer” and was very helpful to her. He was “really involved” in medication and housework but as he got older, as a teenager, he had been less involved. She said he is “in adolescence and has emotions and hormones swirling around in his head”, so that means he had changed. It does seem like he had rejected activities that contributed to his being viewed as a young carer. Marie questioned his knowledge of her medication and raised complaints about his failure to wash up in the morning. He said he “didn’t know” what medication she has been taking, implying maybe she wasn’t on any. She emphatically said that she has “a full cupboard of pills” and that he “never asks”. She seems hurt to not have his help.

The research process enabled us to observe a change in Aidan’s status within the family as a young carer, as his mother questioned it and he distanced himself from association with those tasks. Their interpretations of these changes were informed by interactions with public services which provided them with a particular framework for classifying their positions as people in need of care and giving care. It helps us draw together findings by others on normative ideas about who should care (O'Dell et al., 2010) how someone should be a parent (Jensen and Imogen, 2012) and the pressures to medicalise an understanding of disability within the family (McLaughlin, 2006). This put pressure on people to incorporate or resist dominant ideas, potentially using the family environment as a place to test out their responses.

Marie had received support from mental health services in previous years, while Aidan, identified as a young carer, still received support from the local young carer service. The family’s relationship with services had changed and sometimes served as markers for the ways they should participate in care within the family. Marie, no longer in receipt of mental health services, was seen as officially ‘better’, while Aidan was receiving young carers services and was expected by Marie to fulfil that role within the family. Aidan distanced himself from this by refusing tasks or asserting the end of that obligation. Their care relationships had been understood partly through the definition and label bequeathed by services, but these were repurposed in the exchanges about responsibility for care work, adapted for deployment in the private world.

In the family, Marie manages the provision of care, although Aidan makes a regular and important contribution to the work that makes this possible. Joey is implicated in these systems, adding to the positive emotions of the home and drawing on the care work of his mother and brother to meet his needs. Aidan’s role is noted as an area of deliberate but contested change.

5.2.2. Negotiation as a mechanism of organisation

These patterns of care were animated by the process of negotiation, which utilised representations and counter-representations of care organisation. This care talk is an important part of how negotiation took place. During the nine months of fieldwork with Aidan’s family I was given a range of different accounts from Marie about the extent and value of Aidan’s contribution to care and housework. At times she greatly valued his contribution, at other times she felt let down by his refusals to carry out tasks. Listening to and being part of these conversations is not just the collection of data about care but is also a form of participation, being the audience to the negotiation.

In Aidan’s family there were ongoing negotiations about how to provide care, how to classify need and who could make decisions about what caring tasks to carry out and when.

> **Fieldnotes 28/3/18**
>
> Later Marie spoke about her anxiety and migraines and vertigo, how it was difficult to go out sometimes and how her mobility was impacted so that people thought that she was drunk. She said that that affected Aidan. He agreed and said people thought that she was drunk.

Aidan and Marie shared memories about setting up care in response to episodes of ill health, but also showed an awareness of the way that needs were publicly misinterpreted, causing discomfort and distress. The moments of responsiveness were sometimes represented as taking place without prominent negotiation, more of a shared understanding. However, at other times being responsive triggered emphatic negotiation, as illustrated by the following record of the family's interaction.

> **Fieldnotes 29/10/18**
>
> At one point during the games, Marie stopped suddenly. She was in pain and said that she had felt dizzy. Joey continued talking loudly but Aidan looked over to his mum. She seemed to recover but it worried me.
>
> At one point Aidan was saying that Joey should not be allowed to carry on playing because he was disobeying instructions. Marie snapped at him that she was Joey's mother, not him, so it did not matter what he thought. I wonder if this reaction from Aidan was connected to irritation about his mum feeling ill and Joey adding to the noise.

There were shifting feelings in the family as care needs emerged but throughout Marie asserted her status as both a parent and as a disabled person in the family interactions. These concerns formed a subtext for negotiations about the nature of care work and the appropriate responses to it.

This description of Aidan’s family indicates a series of questions to be explored to build an understanding of negotiation in family relationships. Firstly, in seeing negotiation in family life, as a factor in the creation of care roles, it can indicate a line of questioning about the way that negotiation is connected to the distribution of power in families to speak and decide about care. In particular I am interested in the power implications of identifying one person as a ‘carer’ and another as ‘disabled’, interacting with other signifiers such as ‘parent’ and ‘child’. Secondly, attending to negotiation asks us to say more about the skills that parents and children draw on to negotiate care. Lastly, it suggests a way of explaining changes in care roles or looking at negotiation as an expression of change already taking place. Answering these questions can simultaneously contribute to a new understanding of young carers’ family life but also to a better empirical basis for assessing social policies targeting this group with interventions designed to potentially shift the organisation of care work.

5.3. Families as organising institutions

The framework of negotiation is explored, based on an understanding of a relevant aspect of families being organising institutions. Families are groupings that organise care work, recognised as crucial institutions in managing a large proportion of that work and connected their efforts to those taking place in other institutions (Razavi, 2007, UN Women, 2019). The processes by which families organise resources are highly gendered, both in terms of care work and other economic processes, such as allocation of financial resources (Oakley, 1974, Vogler, 1998, Featherstone, 2004). Despite the common nature of these processes, they cross diverse family forms and the ways that these in fact operate can remain surprisingly obscure.

The ethnographic methods are an attempt to intervene in the ‘black box’ effect we see in the academic representation of families (Pahl, 1995). It is an attempt to go beyond the way that the term family can operate so broadly as to obscure more precise questions about the operation of this institution. Borrowing a term from the study of materials to interrogate the way this is perpetuated, the concept of family has “drapeability ” (for example, Maki et al., 2005, Ghosh et al., 2015), adapting itself to multiple forms, covering the lumps and bumps of messy social relations established with reference to kinship, relatedness, emotional ties and cohabitation. Rather than accept the way that such a term accommodates diversity and encourages a view of unremarkable commonalities, I examine families as groupings of people that are actively organising care in complex and precise ways. Therefore, I am seeking to uncover the lived experience of family and the way that care is organised. The case of Aidan’s family shows how much there is to document about the way patterns of care are set up and changed. The device of focussing on negotiation helpfully focuses the research onto the empirical detail rather than missing out the mechanisms within family life and the power relations that underpin them.

Care work is distributed across multiple settings with an array of actors involved in the labour and benefitting from it. It is organised in each of the areas where it takes place, but there is also a necessity for it to be coordinated across those sites so that the ultimate objective of care, sustaining a person and meeting their needs, is achieved. The study of care and carers often illuminates the considerable work involved both in carrying out care but also in aligning the care work of multiple people, acting under different circumstances, such as the person with care needs, a paid care worker and a family members coordinating their work to meet agreed standards of care (McArthur, 2012, Shakespeare, 2014, Miller and Bowd, 2014).

As illustrated by the case of Aidan, his mother and brother, families in this study were active in organising care, both as a need within the family but also in concert with other actors beyond its boundaries, calling on external organisations and coordinating their actions. Marie and Aidan joined in with the care activities of the neighbouring family that they were close to, where Aidan often stayed overnight and the two mothers supported each other. This was a valued source of friendship and support for Marie, as a mother without close relationships to an extended family and impacted by the impoverishing impetus of austerity policies (McLaughlin, 2006, Millar and Ridge, 2009). Likewise, Aidan incorporated his friendship with this family into his sphere of care (Mason and Tipper, 2008, Eldén, 2016, Hall, 2018, Pimlott-Wilson and Hall, 2017).

We can also locate families in a network of places and relationships through which care takes place, shaped by a context of “everyday austerity” (Hall, 2018, p.769). Aidan consistently paid attention to the cost of items and consequences of spending for worsening poverty. Other children in the study signalled their awareness and concern about dwindling resources and tried to take decisions that reduced the pressure on their parents.

> **Fieldnotes 24/10/18**
>
> Jane was expecting to go on a school trip that week although she insisted that it was too expensive so her mother should not pay it. Her mother reassured her and directed comments to me that she was able to pay it. I felt concern about Jane’s intense and selfless concern about money. Clearly those worries about affordability are very important to her and influence the ways that she interacts with her family.

We might consider the way that negotiations were intensified by scarcity and awareness of an impossibility of making ends meet.

5.4. Negotiation and the families of young carers

This aspect of organisation that manages, coordinates and evaluates the collaborative work of care, is an element of family life with ramifications for the role of young carers. Paying attention to negotiation as part of organisation encourages us to see the active roles and disputed processes that mean care is in flux and remains unresolved, despite that fact it continues. Children's involvement in domestic care work is paralleled by their involvement in its negotiation. Their active presence in care (Miller, 2005) and family life (Millar and Ridge, 2009, Daly and Kelly, 2015) can be seen through attention to negotiation. This approach also offers a way of going beyond the restrictive representation of care work as centred on an asymmetric relationship between two people, sometimes referred to as a dyadic portrayal of care (Barnes, 2015). We need to proceed in the study of care in recognition of the ways that need for care and provision of care are embodied in people.

Care is not necessarily a form of work that is easily subject to management, because of its expansive and cyclical nature, however, it is controlled through an array of processes, some formalised and some less so (Razavi, 2007, Kilkey et al., 2013, Burchardt et al., 2018). Organisation is typically associated with the power of management but in the case of the family home the managerial element is undervalued and enmeshes the person in the low status connotations of housework and care work. The feminisation of care management within the home is part of the explanation of its high demands and slim material rewards (Oakley, 1974, Ungerson, 1997, Folbre and Nelson, 2000, Federici, 2012). The organisational tasks were undertaken as a necessary element of continuing to care and looking for ways for those objectives to be achieved in the context of their devaluing and under-resourcing.

The framing of the young carer ‘problem’ (Bacchi, 2009) draws attention to a problematic position of parents (Keith and Morris, 1995, Olsen and Clarke, 2003). In the context of these questions about the discomfort of a child being a young carer, the families participating in the study show the centrality of parenthood to formal care organisation. Mothers in particular demonstrated their commitment to organising care and had taken this on as part of their responsibilities towards the family. The two fathers that participated in the study were more removed from the daily activities of organisation but were references in the processes of long-term decision-making that structured the family’s care activities. The adults took on parental roles, informed by gendered contrasts in the roles of mothers and fathers (Marx Ferree, 1990, Pearse and Connell, 2016) but in these families the ideas of disability and class were also reference points for the ways that the identities of motherhood, fatherhood or parenthood were understood (Olsvold et al., 2019). Parents indicated some of the ways that disabled adults experience, communicate and contest ideas of themselves as parents (Olsen and Clarke, 2003, Shuttleworth et al., 2012). Despite the way that parental voices might have been marginalised from discussions about young carers, an ethnography that took in a view of the whole family opened up conversations about the parental role in the organisation of care.

5.4.1. Children negotiating a role in care

Children were involved in care, as exemplified by Aidan and Joey, but also in other families. However, it was often the case that children were actively excluded from the organisation of care. Space was made for them to participate in smaller moments of decision-making. They were not always expected to be abreast of housework and care work but criticisms were levelled at them for their failure to anticipate a necessary task, thus creating unexpected additional work for other family members, particularly mothers.

> **Fieldnotes 4/6/18**
>
> Ben said that “the girls sometime enjoy labouring but they do whinge about it.” So they try to “convince them it is their environment and they need to look after it.”

Ben and his family deliberated about the work of care and showed a lot of interest in the ways that work was being organised. Ben and his wife, Kaya, applied ideals of willingness to work to their daughters and chastised them when they persisted in showing reluctance. Care work organisation was located with parents as an ideal; however, in practice children were involved in the process of anticipating care needs and the recurring labour of domestic work. Despite this important role I found that they were given little formal space within the families' organisation of care work.

Negotiation and bargaining were important processes in clarifying the role of individual family members in the organisation of care work. Research on family bargaining and negotiations within families has been informed by people's knowledge of theirs and others' position in hierarchies and their power within and outside of the family (Agarwal, 1997). Other work has explored the moral, rather than economic, framework for decision making in families (Finch and Mason, 1993, Chattoo and Ahmad, 2008). Children's fixed position within the family and reliance on adults to protect and provide for them limits their ability to negotiate (Cieraad, 2013). This might be seen to be compensated for somewhat by their cultural status as protected, and due freedom from the burdens that adults bear (Schapiro, 1999, Morelli et al., 2003). Nevertheless, in this study we find that children partake in disputes about who is allowed to decide and how those decisions should be implemented. They explicitly confronted parental decisions about care, rejecting instructions to undertake work. At other times they contested and then submitted to parental injunctions. In some families or in particular circumstances, children were freed from work, actively excluded from care work or its organisation in order to pursue children's leisure.

We could reflect that policies on young carers subvert this process somewhat by involving children in public discussions about how policies are set. These policies aim to influence the negotiation of care and are attempting to restructure the hierarchies of decision-making in the context of disabled parenthood (Keith and Morris, 1995, Prilleltensky, 2004). Disabled parents are already in conflict with family members about their authority (as is the case for non-disabled parents) but the state is making a particular case for overriding their decisions in a public setting with consequences for their autonomy in private spaces.

Children and their parents engaged themselves in the lively disputes about the allocation of care work. However, they also acknowledged that some features of their relationships limited the scope of these negotiations or bargains. This was also informed by shared understandings of how families should work, or the way that their family in fact did work. There were conventions about people's responsibility for particular tasks. For example, Jane, Sapphire's sister, said that she was always the one who made the salad for the family's evening meal. There were examples of deference to particular family member's authority over certain tasks. This might be derived from their status as mother or father, with gendered connotations. It was sometimes asserted as derived from being the eldest child. Family negotiations were also stymied by deference to the non-negotiability of need. Agreed standards of care needs undermined the potential for dispute.

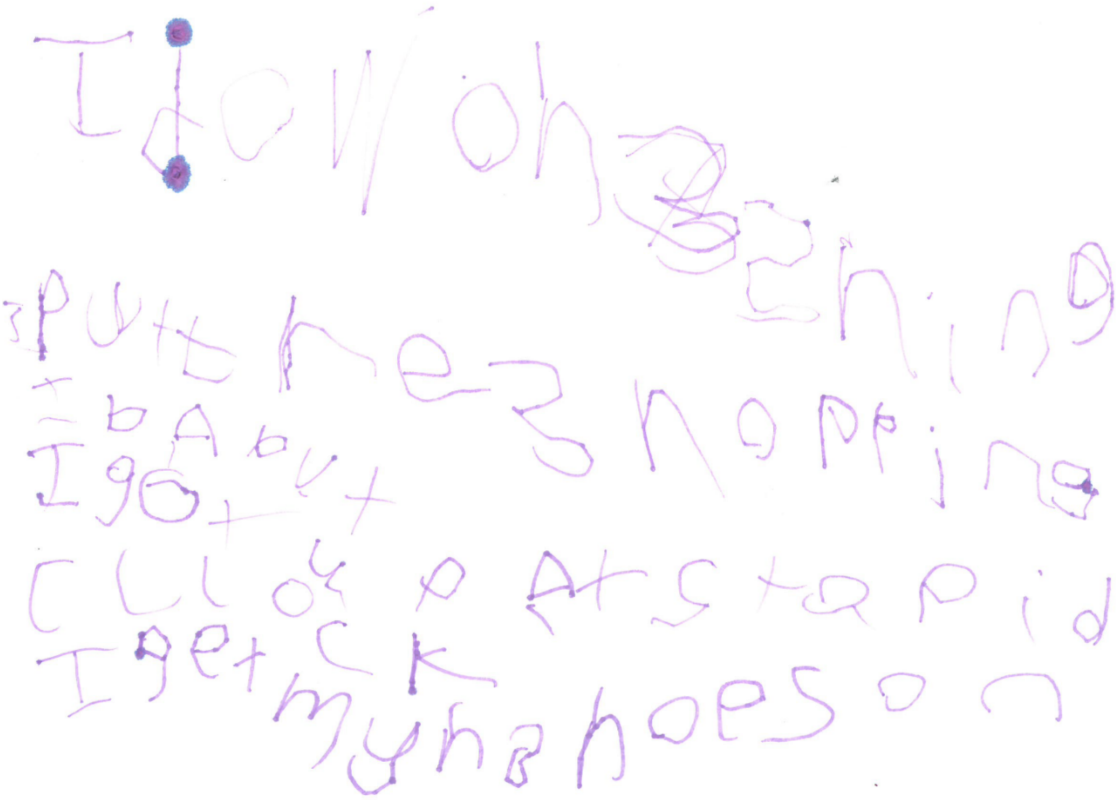


Figure 1 Joey writing about care in response to questions about his role in the family's care for one another: I do washing. I put the shopping. I [unknown]. I got up at stupid [o']clock. I get my shoes on. 30/8/18

Like other research on young carers, this study documented a varied set of tasks that showed how children were important contributors to family care work. This included housework such as washing clothes, tidying rooms, preparing food and cleaning rooms. These activities are closely related to care work, creating the environment in which care is possible or even constituting care itself by providing an environment in which someone feels safe and able to express themselves. The more direct forms of care were also an area in which children worked, putting their sick parents to bed, fetching medication, caring for siblings when their parents were unwell, and calming siblings who were agitated and distressed. They also moderated their demands for care from family members, for example, holding back on conversation or requests for food, when other care needs were elevated and taking precedent. A pursuit of knowledge about negotiation should not lose sight of the work and emotions that followed on from these decisions.

The children who were young carers took their place amongst the cacophony of organisational voices within the family. They contributed alongside their parents and siblings. They found a role in the process that was understood as theirs as a family member. However, they also took on an organisational stance that was more specific to their particular status as young carers. It drew on their classification and alignment with categories that were in part defined within the family, but they also made reference to categories that went beyond the bounds of the family. The young carers were making their contribution from the position of being a child, informed by the specific language and claims codified through the idea of childhood and children within families. They were also to be found making reference to their age or sibling order status, for example, Sapphire said that in a reflection on key messages on family life that, “just because you are the oldest it does not mean you are in charge. Daddy, he thinks he is in charge.” (Fieldnotes 24/10/18). The consequences of a child’s status for their responsibilities and authority over certain areas were disputed and not always fixed.

5.4.2. The category of ‘young carer’

Family members understood and calibrated the contribution of children with reference to the idea of them being a young carer. This provided a shared idea that informed the acceptance of or resistance to children’s contribution. It was referenced in utterances of praise or criticism of a child’s involvement in care work. The idea of being a young carer was informed by knowledge of their role as a gendered family member at a particular point in the lifecourse and marked by their status in other social categories such as disability, which will be explored in subsequent chapters. This is a theme in Aidan’s family, expectations based on his young carers label took on importance in negotiations, but it was also a feature in other families.

Families sought to understand the differences between each other through the opposition between, on one hand, being a carer and, on the other hand, being disabled and cared for. An example of this process in action comes from Sapphire’s family. The family understood Sapphire to be a young carer, assisting her father who was dealing with a disability, and she also played a part in the support for her siblings who each struggled with school. Her sister, Jane was categorised as having special needs in school. She had had a period of severe ill health a few years before, which affected her mobility and made learning in the school environment difficult. Sapphire’s brother, Luke, who was autistic, felt ostracised at school and longed to be able to head out on his bike.

He suffered through school terms and celebrated exuberantly when the holidays arrived. Sapphire sought to make sense of the world with frequent reference to the labels and categories that differentiated between people, for example, she frequently commented on whether a peer's behaviour was typical of a girl or was like that expected of a boy. With her siblings she understood them as gendered but also as explicable through their disabilities, which her older sister, Jane, contested. Both Jane and Luke expressed the idea of themselves as being disabled at some points within family conversations, but Jane was troubled when her siblings referred to her in those terms.

> **Fieldnotes 4/6/18**
>
> Jane said that she "used to be disabled." Luke said that she "still" is disabled. Sapphire said that the wheelchair is still in the garage but she does not use it.

The contestation over these categories, centred on a question of disability status, which needed pinning down by some family members in order to make sense of their own role. The children were cautious about taking on the label of being disabled.

5.5. Emotions in negotiation

Parents and children spoke of and demonstrated the emotional power of the negotiation process and the resulting settlements. An example comes from Aidan's family.

> **Fieldnotes 26/4/18**
>
> Marie spoke a bit more about an argument that she had had with Aidan before I arrived, about the cleaning. It upset Marie and she had a bad headache already. She was upset by it and seemed weary of those interactions. She told me that she had had to have a sleep to recover as she had felt so bad.

The negotiation process had an emotional impact on family members but it also functioned as an expression of emotions such as dissatisfaction, frustration or longing.

The forceful disagreements between siblings, such as Sapphire, Luke and Jane about the label of being disabled showed that something important was at stake. They accepted the idea of their sister as a young carer but Jane and Luke were uncertain about, or resistant to, the implication that they were the disabled relatives that caused Jane to be identified in this way. In school and at home their status as being disabled or having special needs were associated with feelings of isolation, rejection and frustration. Disability carried affective consequences and in the negotiations of domestic identity they tested out the potential to reject it (Butler, 1993, McLaughlin and Coleman-Fountain, 2014, Ahmed, 2014a). The labels came from the education system, from the support services for young carers, from health professionals and social workers suggesting labels for family members. These siblings had a sense that to label someone as disabled or as a carer had different emotional consequences and were reluctant to take on that label of disability because of its connotations, whilst being a young carer was for them seen as more favourable. They perceived a hierarchy in these two categories, carried into the family conversations partly via the mechanisms of services shaped by social policies.

Sapphire’s status as a young carer was acknowledged and a consensus was established, unlike with the family’s debates about disability. In policies on young carers, disability is a category used to explain the need for care in contexts such as these and seen to disrupt expected patterns of care to the extent that this establishes the need for the young carer role. Disability has been understood in these discussions often through a frame of dependence (Keith and Morris, 1995, Olsen, 1996). This is given particular force by the association with young carers that “shoulder” the needs of family members (Frank et al., 1999).

These topics had different emotional qualities, so the disability conversation prompted antagonism and resentment (Goodley, 2011, McArthur, 2012, Shakespeare, 2014) while discussions about young carers were more harmonious. Outside of the families' conversations, public sector workers or organisations commissioned by government had encouraged Sapphire to see herself and be seen by her family as a young carer. This associated her with a specialist service which the family valued. Sapphire, her brother Luke, and her parents, praised the young carers services and spoke of the ways it benefitted her and them. Sapphire herself was celebrated within and outside her family for her contribution to their collective project of care and support. However, within the family the affective consequences of having a young carer, explained by the care needs emanating from disability, were unresolved even if in practice nothing was expected to change. Sapphire's sister, Jane, particularly wanted to reject this association and its consequences for the ways she was seen, but her siblings called on her to reconcile herself to it. The family needed to understand some members as disabled, despite the discomfort this caused.

The categorisation of family members as carers or as disabled are not the only categories that families are drawing on. Other studies on young carers have explored, for example, the gendered understanding of being a young carer (Eley, 2004), the voice of disabled mothers as recipients of care (Keith and Morris, 1995) and the experience of Black working class families with children who do care work (Jones et al, 2002). However, these categories are not echoed in political or popular efforts to build an understanding of young carers.

Meanwhile, the categories of disabled person and carer are embedded in legislative and policy instruments, giving them institutional and rhetorical status (Cooper, 1998). They may take on exaggerated forms when non-disabled siblings overestimate feelings of difference between them and their siblings (Meltzer, 2019) and there is a reliance on binaries of carer/disabled (Chattoo and Ahmad, 2008). In the selection of categories that contribute to understanding, classification and responding to young carers through policy, we can observe the development of a system that organises care work. In Sapphire’s family there was a different reception to the idea of being labelled the young carer and being labelled as the disabled sibling who received care. People are interpreted through categories of social difference and as a result are not afforded the same emotional resonance (Ahmed, 2014a). The specific categories of people under consideration shape the way we understand the possibilities for a project of social change (Steedman, 1990). Children showed recognition of the significance, not just of being allocated work, but the terms under which this was done. Therefore, negotiation had both practical and emotional consequences.

5.5. Policy presence and the negotiation of care work

Families are working with resources distributed through the deliberate mechanisms of policies on social security, disability benefits, the health funding that determines the availability of primary health care, council housing provision, free school meals, talking therapies and respite breaks for parents of disabled children. These policies form the background to decisions about resources and drive forward the motion of family care. Policies galvanise families into action, for instance, through the need to respond to a GP appointment or following the advice of the representative from a public agency. However, these services rarely reach into families in the form of a professional person representing the state branch of formalised care work in the economy of care. Professionals are scarce within the family home or in the domestic processes of care, instead they are acting in settings such as schools, hospitals or remotely through correspondence. The reach of policies, or their presence within the domestic decision-making domain about care is relatively remote, creating an awareness of requirements, norms or decisive moments that will allocate the family resources. However, the processes of care are reinforced as taking place privately, within the family home and what is left undone will not be picked up by public agencies, except usually with the threat of punishment or disempowerment (Prilleltensky, 2004). Policies, both as a presence and an absence, had an impact on the possibilities for negotiating care.

Families reported three ways that services impacted on domestic decisions about the negotiation of care. Firstly, there are examples of services that have encouraged mothers to take on greater responsibility and, thus, remove elements from a child's obligation. XD's mother, Tizzy, had been warned that she needed to take on more responsibility and was offered support to achieve this whilst facing the possibility that her son could be taken into care unless change was seen by the social workers. This is an example of how families reported ways that services applied pressure to reorganise care between family members in order to reduce an arrangement that caused concern.

Secondly, families were given support that enabled them to reduce the care needs within the family. For example, Marie had received support after giving birth to Aidan when she had had Post Traumatic Stress Disorder and Post-Natal Depression. Then in preparation for giving birth to Joey she received really good support that helped her a lot. Joey had not had the same experience as Aidan in the first few years of his life because his mother had much better help and was much more able to care for him.

Thirdly, services were provided that are seen to compensate families for the additional obligations of care even if those remain. So young carers groups provide ‘a break’, in contrast with the rest of the time which is recognised to be constricted by care responsibilities. This is significant as none of the families were influenced to exclude children from care work by the instruments set in motion by policies on young carers. The young carer role would persist.

It is worth reiterating that children’s care work roles did change and were re-negotiated. This was not driven by the impact of policies on young carers. Policies are not contributing to the possibility of a change in young carers’ roles in these families, particularly not the significant reductions in their roles that are the stated interest of policies. Instead the changes come about through families establishing new understandings of children's relative status and therefore a renegotiation of their involvement in care. Within the secluded and private domain of the family home, children and their parents were making recourse to different understanding of status, categories of people and relative positions to revisit the arrangements of care.

When caring arrangements were looked into by external agencies, this could result in decisions in favour of children removing themselves from care work. Alia had conveyed to her parents that she did not want to have her own children in the future and her mother worried that this was because she wanted to reject the obligations of care because they appeared so burdensome. Kaya reported a conversation where her daughter had said "I've seen what you've gone through" to her mother and she understood this comment as a reflection that hardship that Alia had seen arise from Amber's needs. On another occasion Kaya spoke to Alia about the responsibilities towards her sister that lay ahead of her and their limits. She discussed how she might care for her sister if her parents were not there. She reiterated something that she has told Alia before, the belief that "your brother or sister can be someone that you care for but they should not harm your life". She did not want Alia to limit her opportunities because of care, seeing potential risk for her daughter (Heyman and Heyman, 2013) and fitting with knowledge of care, that it can shape a lifetime (Cavaye and Watts, 2018).

Families showed the processes by which they organise care, involve children and the potential to rearrange care work. Policies in their current form are ill-designed to engaged with this process. There is a failure to recognise the political nature of this negotiation, both as the object of a public politics that seeks to arrange care in particular forms (Federici, 2012, Jupp et al., 2019) but also as a manifestation of a politics located in the spaces understood to be representational of private and family life. When public agencies asserted a presence in family life, wading into these politics, these interactions were observed to be moments at which autonomy about organising care would be asserted by parents. They might challenge the authority of public organisations to direct them or threaten them.

> **Fieldnotes 30/5/18**
>
> Marie said that Joey's membership of young carers is because Aidan's autism means that Joey will be accepted. Marie said to Joey that he should look forward to getting a break from Aidan.

Marie questioned the applicability of this service, reluctant to see Joey as a young carer, which would indicate that he, like his older brother, was seen to be supporting his mother beyond what would normally be expected. This contestation of authority of private spaces and its boundaries with publics will be the starting point for the next chapter, Chapter 6 (Intersectionality at the separation of public and private space).

5.6. Conclusion

This chapter has argued that families are continuously involved in a process of negotiating care work. The outcomes of this process structures each family member’s role in care. It does not fully determine it because these outcomes can be ambiguous or without the ultimate coherence that would make them enforceable. However, they have a powerful effect upon the discussions that family members have and the scope for either freedom from or participation in care. Family members have shown that they would revisit these decisions in order to redistribute care either to decrease or increase the level of responsibility children felt for this work. Children, alongside adult family members, were active in this negotiation process. They were aware of the idea of themselves as young carers, or in some cases as the disabled figure who are part of their sibling’s identification as a young carer. This informed the way they approached these negotiations. Policies are already part of this picture (albeit in a remote fashion), present in the family organisation of care work but falling short of the ambition to bring to bear normative pressure for families to reduce or curtail children’s care work. The idea of negotiation is therefore helpful in drawing attention to an under-explored element of family life for young carers and a potential object of policy in future.

6. Intersectionality at the separation of public and private space

6.1. Introduction

This chapter draws on ethnographic data to explore how the participating families constructed a separation of public and private spaces. These processes were informed by, and should be explained with reference to, an intersectional analysis of categories of social difference. Alia's family, introduced earlier on, were a frequent reference point in the development of this chapter. The central place of Alia's family in this chapter was the result of many hours of contact with her family, discussing and debating ways of categorising each of the family members. Alia's family had been enthusiastic about explaining and exemplifying their experiences of these categories. Their account of family life was imbued with references to gender, to disability, to ethnicity, to sexuality, to age and to class. They drew connections between those categories and continually sparked reflections in the fieldnotes about how these terms were used and made meaningful. Their crucial role can firstly be explained by the subject matter they introduced, establishing a pathway towards ethnographic knowledge of intersectionality.

A second element reflected in the material is that this family and Alia's mother, Kaya, in particular, took the opportunity during fieldwork to open up her stories of family life and use this medium of conversation to take time to reflect. She seemed to enjoy the space it created for her to think and to put words to complex layers of feeling about family life. She used her authority within the family to call on her daughters, Alia and Amber, and her husband, Ben, almost as witnesses who were invited to provide their evidence. As they withdrew from the conversation she then reclaimed the time as an extended exploration of her family, before another person was told it was their time to give their perspective. The research was seized upon as a mechanism for Kaya to reflect and to test out her ideas, to air discomforts and uncertainties. It became purposeful for her, in a way that also provided a wide range of developed and insightful reflections on family life from the inside. The fieldnotes do not account as much for the views of Alia, Amber and Ben, although their approach to engaging with the research visits was interesting in different ways.

A third element of the observations, activities and conversations that has a particularly important place in this chapter is that this family took a position within different categories that was very interesting. They asserted a British Pakistani, middle class identity foremost, but also saw Amber's disability as something they all shared as an experience. The management of Amber's needs was very absorbing (McLaughlin, 2006) and family life was vocalised through the lively and absorbing activities of motherhood, fatherhood, daughterhood and sisterhood. A cast of wider family members were recalled in conversation, invited in or visited. Family life was going at full pace and with many references to the categories that placed the family as a whole in their social world and that differentiated between Alia, Amber, Kaya and Ben.

Working with this material and contributions from the other participating families, this chapter argues that the families conveyed the significance of the ongoing project of separating public and private spheres. To understand its varied iterations across a diverse group of families we need to embed the analysis of separating public/private within an intersectional understanding of how categories of social difference shaped the meaning of such endeavours.

6.2. Alia's family

Alia's family impressed upon me a set of reasons for wariness about the boundary between public and private sphere, alongside an impulse to defend it because it could be overridden in ways that threatened the family. They presented three interconnected themes in the separation of public and private: firstly, ethnicity/'race' and religion; secondly, migration, generation and legacy; and, lastly, class.

Initially, Alia's family provided an example of how 'race' and ethnicity are important explanatory frameworks for families' encounters with the public politics of care. Alia and her mother, Kaya, articulated the ways that they were stereotyped and their frustration with the ways that other people pursued lifestyles that contributed to a stereotype of behaviour based on religion and ‘race’ (Mirza, 2013). Kaya explained how social workers accused her of not properly providing for her eldest daughter, Amber, and that there was a suspicion that she was a possible victim of forced marriage. Kaya perceived that these accusations were based on stereotyping the family because of their Islamic faith and she was determined to show that they were false and ridiculous.

> **Fieldnotes 25/3/18**
>
> Kaya was hurt, offended and angered by a suspicion that Amber was at risk of forced marriage during a period when she was taken out of school because bullying meant that she refused to go. She stayed in Pakistan for several months with her grandparents. Kaya said that this showed her “how racist the social workers and schools could be.” She contrasted that forceful interaction with the disengagement when she raised concerns about Amber’s poor education. She spoke very evocatively about insisting that the social worker went around to see the house and that she needed to see the food supplies to refute that idea that the children were not fed enough.

This interaction with social workers was significant for the ways that it made Kaya feel that she and her family were racialised subjects, reduced to the performance of acts in line with a stereotype of Muslim citizens. They were scrutinised because, in my interpretation, they represented the dangerous ‘other’. Yet the engagement with the state on the family’s terms, seeking support for Amber’s education and mental health services were denied. Kaya felt disempowered by the ways that the family’s attempts to manage the pressures of disability and care were undermined by racialised terms for their interactions with state services. She felt that there were “so many levels of prejudice there.” (Fieldnotes 4/6/18). Ethnicity and religion were intersecting social structures that had impressed themselves upon the public/private boundary, intensifying its importance.

Alia’s family and their extended family of grandparents, aunts, uncles and cousins were a repository of cultural resources, which motivated careful attention to how to separate public and private identities. Kaya also referenced ‘race’, ethnicity, religion and migration, explaining some of the differences in generational formulations of the relationships between those categories. She would revisit the subject, using it to interpret her daughters’ behaviour and the gap between their values. Talking about the differences between her parents’ generation, her own and her daughters’, she presented the following explanations:

Fieldnotes 3/8/18

When they were new immigrants to the country they came from “genuine poverty”. They came for five years “to earn enough money to build a house at home and go back. There was no idea of cultural change. The only attitude they had was to keep on moving, move forward. They were very stoical in that way. Now they are not in poverty, not in war time but the complexities and grey areas of life don’t reach [her mum]. The next generation will be even different again. You can’t take the economic benefits and not take the social degradation. There is so much heartache. We have gone backwards.” Kaya tries to educate her children “not to move into those traps. The grandparents might be happier in Pakistan but the children and grandchildren are in the UK. Also the younger generation would not survive there. Very hard to live. You have to be thick skinned and streetwise.”

Fieldnotes 30/9/18

[Kaya] said that “these kids have a lot of choices. They know that they can say no. There are more distractions. There is less of a hunger to succeed and it’s a bit worrying. Apart from a few privileged classes they will have to work a lot harder.” She implied that she had more chance of succeeding and at the same time

> worked harder, while the younger generation have less chance and work less hard.

She recognised that a legacy, gathering meaning through generations, established a range of relationships to migrations, ancestry and racialised, post-colonial subjectivities. These patterns defined a private world of interconnected households within the extended family. Their legacy across generations induced them to think carefully about how to connect themselves to or distance themselves from those outside this private world, to have a critical engagement with a range of publics.

Encounters with stereotypes and racism marked the point at which public authorities imposed themselves in racialised ways but it interacted with the family's class position rather than being a standalone explanatory axis. Kaya showed that she had had to consider the way that her position in the world was determined by other people's perception of her but also by her own inheritance of values, skills and purpose. This interpretation of 'race', ethnicity and migration, as a generational phenomenon was moderated by differences in class position, access to familial economic resources and an economy that changed around them, altering the likely outcome of their conduct. Kaya was attentive to her class position, her high level of education and the professional jobs that gave her and her husband considerable resources and financial security.

> **Fieldnotes 25/3/18**
>
> Kaya implied that because the family are affluent and highly educated (implicitly middle class, I suppose), that they were dismissed as not needing the input of services.

Kaya felt that her class position complicated her relationship with services, made it difficult for her to navigate and also meant that she did not have the position of power that she was used to holding. She could not express middle class behaviours, instead having to fight for resources that she should have been entitled to. She also noted the different background of those whose circumstances meant they were brought together by their connection to services for children with special needs.

> **Fieldnotes 25/11/18**
>
> Kaya spoke about how many of the other young people in Amber’s school “came from chaotic and impoverished families,” who were “unable to help them with administrative tasks because they have not gained much from the educational system.”

Social workers, staff at the college for students with special educational needs and child psychologists were also figures in Kaya's interaction with the welfare state that had required her to confront hierarchies of class, 'race', ethnicity and migration.

Kaya's younger daughter, Alia, indicates some familiarity with these same structures of inequality and social categories of difference. Alia referenced class when she drew on her experience of defending herself because of accusations of superiority. It suggested to me that she also had to navigate divisions of class with her peers and that she replicated these difficult manoeuvres in recounting a family story during a research visit.

> **Fieldnotes 3/8/18**
>
> During [a story about her aunt's profession] Alia made two comments that added to the picture of social location. She said about her aunt being one of the top doctors and then said that she is "not boasting, that it's true. People at school accuse her of boasting. I wondered how this builds an idea of class, education and race that people might reject, through this idea of boasting. Alia also checked that I knew that Abu meant granddad, which I did. I think I knew that but maybe it was from context, just guessing. It was interesting the ways that Alia's questioning was showing how she saw the differences in me.

Public spaces were discussed at home, reflecting on the ways that ‘race’ and ethnicity impacted on these experiences.

The experience of educational institutions was a prominent feature of families care biographies set out in Chapter 4 (Introducing the Five Families). Educational institutions were important public spaces where ‘race’ intersected with class and gender (Lareau, 2011, Reay, 2017). Alia explained some of the ways that ethnicity and nationality fractured the social relations in her school.

> **Fieldnotes 3/8/18**
>
> Alia says that “the Bangladeshi girls at school” think that she is “weird” because she does not pray after school. Kaya said that “they are racist against them” [the family or Pakistanis, I’m not sure]. Alia said that “they are jealous because I was the only brown girl who would make friends with people who are not brown.” Kaya says that she thinks it is because they were jealous that she “did not have to live in that oppressive lifestyle.” Alia talked about how more recently the Bangladeshi girls made friends with a girl who was white and after saying white she quickly said “no offence” to me, which amused me. Alia said that people at school “tell her off and get uncomfortable” when she talks about race or talks about someone ‘as white’. She

> mocked people who are so uncomfortable talking about race. She is glad that her "friendship group is mixed because then they won't have problems about race. At primary school there were problems." Kaya said that her friends have "always been mixed." You then get a taste of "their own culture," they said. They seemed harmonious on this topic and enjoyed building on each other's ideas to mark out their views on race.

Noting a 'white' audience for this explanation embodied by the researcher, Alia describes frustrations and amusements about ethnic differences. These experiences were located outside of family life, while Alia enjoyed the freedom to associate herself with diverse people in her private life, as did her mother. The constraints and conflicts of public spaces were contrasted with the relative freedom and harmony of the private space of the home.

Alia's parents supported their daughter in diagnosing the prejudices that were encountered in public spaces and spoke of how they used family life as a space in which to respond creatively and resist these harmful currents. Alia's parents endorsed this approach and gave examples of the ways that they had sought to distance themselves from overbearing relations based on conformity and judgement.

Fieldnotes 4/6/18

> There is a “lot of pressure to conform.” Ben said if they lived in “the heart of the community” they would have people “knocking on the door and telling them how to live.” Ben said “they love being judgemental.” Kaya’s mum is “very religious but very liberal with Amber. If her mum can relax then everyone else does not matter.”
>
> Amber is dying her hair with her mum’s help. Amber’s mum and dad don’t worry about what they wear; they think it is up to them. Kaya sees it as grandparents or the wider community that “don’t like individuality.” Ben thinks they “dislike westernised things.” To combat this disagreement, Kaya said that she has learned off Alia a technique for diffusing criticism, “laughing it off.”
>
> As a family they haven’t lived in an area that has been “predominantly Muslim.” They had brief periods of going to the mosque. They were “picked on for being too Western.”

The contrast of public and private was a useful device for recognising but containing the hurts caused by inequalities and prejudices.

While Alia’s older sister, Amber, did not contribute views about ethnicity, ‘race’ and migration, she showed her commitment to the family’s Islamic practices and behaved in ways that indicate that she valued the elements of family life that connected them to Pakistani culture. The family had developed a shared culture of critical engagement with the Muslim community, taking pride in the migration of previous generations and rejecting forms of racialised or classed relations which curtailed social opportunities or the access to services that should have been there to help them. Their handling of ethnic difference, racism and religious expectations marked their collective boundary-setting against troublesome publics.

6.3. XD's family

Like Alia's family, the information that XD and his mother shared helps elaborate the way that the intersection of class, ethnicity, 'race' and nationality anchored a project to construct a separation of public and private. XD and his mother were Black. They had migrated to the UK from southern Africa. The process of arriving in the UK, to join XD's father, was the start of a difficult legal process. Tizzy, XD's mother was in the country under restrictive terms as since her separation from XD's father she no longer had right to be in the country as his dependant. Therefore, she did not have the right to work or to access a range of benefits. The disintegration of her relationship with XD's father, who was violent towards her, left her without financial support and unable to earn through paid work because of the laws applied to migrants. She was living with XD in poor housing. She felt lost and unable to be independent as she had used to be when she was able to work. Her mental health deteriorated and she struggled to look after XD. As her mental health improved, with support from social services, counselling and housing services she was able to reconnect with the responsibilities to look after XD. Unable to work she had to manage the welfare payments carefully to cover the costs of everyday life. She spoke with emotion on how the support that had targeted her mental health had supported them as a family, providing peer support for her experience of domestic violence and advice on problems with their housing. Tizzy and XD's circumstances were heavily imprinted by the criminalisation of migration and connect them to a picture of the ways that women and children have their lives shaped by violence against women (Walby et al., 2017).

Tizzy struggled to come to terms with their poverty and what the loss of resources meant for their position in society. Having lived with more resources, sending her son to private school and living a middle class lifestyle in southern Africa, she felt frustrated at the position she was now in. XD recognised the importance of class for understanding other people's backgrounds, although not sharing his thoughts about how it applied to himself. When reflecting on his mother's story of long hours doing housework and providing care for relatives when she was a child,

> **Fieldnotes 24/9/18**
>
> He said he did not know "if they were working class or well off but it was really hard" for his mum.

Class was a reference point but migration, nationality and mental health were prominent in their account of evolving care needs.

The family had been bullied and targeted for criticism because of the ways that people sharing the house interpreted their ethnicity and class. Tizzy had instructed XD to separate himself from a group of friends who were racist. Tizzy had been accused of being a spy for the Home Office by other residents in their shared housing because they were seen to be in a relatively favourable position (having a bedroom each, although this was required by the local authority housing rules because of XD's gender and age). Tizzy also explained that XD was perceived as being born in the UK because his accent placed him as local, rather than someone who was a migrant by background. Time spent with Tizzy and XD during fieldwork showed that they enjoyed recounting stories about the times in southern Africa, its landscapes, its culture, its economy and their family there. Nationality and migration were reference points for XD and his mother to tell their story, explain the struggles of the last few years and consider their options for the future.

Migration was a strong theme in their story, while ethnicity or 'race' were less openly explored. My positionality and habituation with the invisibility of whiteness (Clarke Mane, 2012) may have influenced me to be tentative in discussing 'race' and ethnicity in contrast to pursuing more extensive questioning about gender or disability. The lack of discussion about ethnicity and ‘race’ may reflect XD’s discomfort at representing his ethnicity to a white British woman, not confident about the response he would get (Konstantoni and Emejulu, 2017).

When Tizzy recounted a story of XD’s time spent with his cousins she gave an indication of her attitude towards the subject.

> **Fieldnotes 22/10/18**
>
> XD did not seem to know the cousins. Tizzy referred to them carrying him when he was little. XD asked if the cousin they are referring to “is the black man, the dark man.” Tizzy was laughing at the reference. She laughed “as if you were white! He is like your cousin!”. XD dismissed her jokes and said that he just did not remember what he looked like.

Their Black identity was something that Tizzy expected XD to be clear about, not to forget. The idea of him questioning it by implying their family were anything but Black was ridiculous to her. He seemed to see it differently, with lower expectations about the absolute nature of their Black identity and that of their family. He also questioned his mother’s instruction to reject his group of friends in the neighbourhood because of racist behaviour, implying that he did not see this as the correct judgement about them and regretting the loss of their friendship because it meant he was lonelier when away from school. Tizzy and XD had different interpretations of their social location. XD saw ‘race’ and nationality were less relevant to his life, while Tizzy felt their importance for the continuities in her life, herself as a Black woman from southern Africa. She struggled with the negative consequences of her migration status for the options ahead of her, with employment and material comfort heavily curtailed but her Black identity signalled a continuity.

This background informed their understanding of XD’s role as a young carer. He needed to step in when Tizzy was overwhelmed with distress and the after effects of the breakdown of her relationship, cut off from her family and without economic resources. In other words, the family found themselves disconnected from their middle class background and having to start again in a new position because of their migration status. They encountered a very different landscape of welfare services, which helped them get back onto their feet but did not remove the legal constraints because of their status as immigrants (Mirza, 2013, Kilkey et al., 2013, Berg et al., 2019, Jolly, 2019). They had to negotiate a new balance of responsibilities between themselves and learn to engage with the services that helped them, as long as they were on offer. ‘Race’ and ethnicity were important markers in exploring the family’s circumstances and the resources available for them to support one another.

6.4. Class, ‘race’, ethnicity, migration and nationality

The discussion of XD’s family and Alia’s family have pointed to the ways that ethnicity and ‘race’ took on importance, especially when the families felt the pressure of public authorities, the public spaces in which racism was expressed. Participants expressed their relationship to ‘race’ and ethnicity as a category of social difference, clarifying this relationship and questioning this category as it emerged in their encounters with public services and in their social networks. There were different connections between ‘race’, racism, religion and personal histories of migration but both families sought to contain the effects of this on their interactions with the staff in public services. There are also suggestions of silences about ‘race’ and ethnicity. It is informed by discussions on the potential for the ethnography of ‘race’ (Alexander, 2006) and the risks of essentialising ‘race’ by locating it in people’s bodies (Nayak, 2006).

By using an intersectional perspective, this discussion contributes to the way that this theory has moved across academic disciplines, not always with adequate attention to its politics and the requirement for attention to the positionality of the researcher (Konstantoni and Emejulu, 2017, Bilge, 2013). In this case, as a white, middle class, ‘able-bodied’ woman, I had limited embodied knowledge to build up the voices of those who are subordinated at the intersectional of ethnicity, class, disability and other categories of social difference (Hill Collins and Bilge, 2016, Konstantoni and Emejulu, 2017, Harding,1992, Mirza, 2013). Intersectionality draws attention to the way that privileged positions are present but more hidden, potentially taken for granted or obscured in the lived experience of ‘race’ (Hancock, 2016; Mirza, 2016, Spelman).

In this study I find that the category of ‘race’ and ethnicity intersect with class in ways that shape the experiences of young carers and their families and does not gain prominence in many other studies of young carers. Those in privileged positions are typically shielded from the expectation that they articulate the relationship to these categories (Spelman, 1988, Clark Mane, 2012, Tomlinson, 2018). There is a failure in the literature on Minority World young carers to attend to subordinated voices but also to articulate the intersections of privileged young carers’ subjectivities, thereby making intersecting inequalities invisible. By examining the interaction, concurrence and mutual constitution of these categories, I pursue a discussion about the different ways that families expressed subordinate and privileged positions. An exploration of care work, childhood and family life is one area in which we can see how the categories of ‘race’ and class intersect to inform the ways that family members explained their relationship to public services and interpreted the decisions about their entitlement to certain kinds of support and types of treatment.

The five families participating in the study contributed different views on the significance of ‘race’ and ethnicity in positioning their families and as a factor in their relationship with public services. The ways that families acknowledged 'race' or ethnicity were varied, ranging from deeply considered views about the complex ways that it emerged in their interactions and its intersections with other categories. Meanwhile other families gave limited expression to their experience of 'race'. Both points on this spectrum can inform an analysis of social location and its salience for understanding young carers.

6.5. Silence about whiteness

In the discussion of Alia's family I have argued that the public encounters defined by ethnicity, 'race', religion and nationality instigated close attention to the private realm, including measures for its protection. In the case of XD's family a reinterpretation of ethnicity, 'race' and migration in a changing context prefigured a disintegration of a private world, making the family vulnerable to the pressures and violence of racist public space. Alongside these approaches to 'race' and ethnicity from Alia and XD's family, other families did not offer discussions of these subjects. Aidan and Sapphire's family did not speak about their ethnicity. Sapphire's mother, Becky, shared some information about her migration from Latin America and the disregarding of her qualifications and work experiences so that she was unable to get a job. This was not connected to an idea of 'race' or ethnicity. Instead, she and her husband spoke about how anyone who was not born in the village they lived in was considered an outsider and looked on with suspicion. Aidan's mother, Marie, never spoke explicitly about the ways that she identified herself or her children in relation to ‘race’, ethnicity or class. One interesting allusion to this subject was when I asked her for her opinion or a statement about the support for families like her, with the idea that it might reach those deciding on service provision when the PhD was disseminated. Marie stated that “there is not enough. There is [a] young carers [service] but there is not support for the parents.” She went onto say that, ‘the government needs to look at their spending. They send money overseas but there is aid needed here and we are British citizens.’” (Fieldnotes 29/10/18). Rosie’s family was another in which ethnicity and ‘race’ were very removed from the conceptual reference points. Rosie and Poppy’s father was a South Asian man, who was born in present day Pakistan. The strained relationship between the three of them and the girls’ father occasionally drew on his background as a source of explanation for his conduct, but was largely left out of the conversation, as was the girls’ mixed ethnicity and their mother’s white British ethnicity. For these three families, whiteness was an unexplored reference point, whilst migration and citizenship were easier topics to come upon in the ethnographic encounter.

Other than point to this omission, what can we say about white ethnicity in this study and its connection to the earlier richer discussion about South Asian ethnicity and Black identity? Firstly, it is important than white ethnicity does not go unremarked in the analysis, despite its ability to slide out of discussion, as an unremarked-upon assumed state (Konstantoni and Emejulu, 2017, Clark Mane, 2012). The presence of a white British researcher would ease the invisibility of whiteness in these conversations, allowing it is be unremarkable or potentially harder to utter. It is also interesting to consider that the white families were able to exclude ethnicity from their consideration about relationships with services, while for Alia's family in particular, they needed to develop their knowledge, awareness and strategies to overcome the ways that racism might operate through the delivery or denial of services. The need to explain, to account for and to reconcile views within the family for some are connected to the ease of living without conscious reference to ethnicity, which some of the families were able to experience. Despite being absent, whiteness was important in that it soothed the tensions between public and private, but in ways that were varied because it intersected with migration and class status.

6.6. Representations of class

Class showed a different pattern in the data from that of ethnicity, 'race' and migration. White ethnicity, a more privileged position, was fairly obscure, but in terms of class it was working class identity, a subordinate position, that was rarely uttered. The experiences of families working from a middle-class status to engage with services was something that two families explained to me. They had learned which elements of their intersectional identity helped them, giving them greater control, extra resources, a stronger voice or some more power in the interactions with services.

For Rosie and Alia's families, their mothers drew connections between their class position and the ways it distinguished them from the rest of the people who were connected to state provision. In both cases, the mothers used education as evidence of their superiority and indicated that they felt out of place in the interactions with professionals or state representatives.

> **Fieldnotes 16/5/18**
>
> Dominique spoke of her anger at her treatment by the legal system. For example, [Children and Family Court Advisory and Support Service] staff acted "superior" but seemed not to be able "to handle" Dominique and her ex-partner because they are both "educated and intelligent." Dominique felt that they were "used to dealing with people who are more rough."

In this extract from fieldnotes and the extracts in the section above on Alia's family the women drew distinctions between their status and other parents who were placed in similar relationships to services because of circumstances such as children's special educational needs or disputes adjudicated through the family courts.

Both women also provided moments where I could observe the ways that they educated their daughters in reproducing class status. In Rosie's family, Dominique used the opportunity of Rosie discussing the consent form for the research project to encourage her to assert her right to ask questions of the process. Dominique also picked up on her daughters' pronunciation, gently mocking them and discouraging them from speaking in ways that exacerbated the West Midlands inflection in their words. Middle class performance was monitored in domestic interactions.

Middle class status had far greater significance when these two mothers had to navigate threatening or unwelcoming public institutions. In those cases, their middle class status was a valuable resource and this was conveyed through their accounts of services as presented here. The positionality of the researcher in this case, as a middle class woman, may have facilitated these discussions more than it would have for a discussion of working class experiences. My background meant I was tuned into the implications of these comments. I might also have been seen as more sympathetic or receptive. The limited discussion of working class experiences might indicate a wariness of using me as an audience for these experience. Alternatively, it might reflect my limited knowledge to draw on markers and shared experience of working class life, therefore a failure to identify and record the points about working class experience.

With this qualification about the problems of accessing these accounts, it is also interesting to consider whether the lack of working class expressions captured here may also reflect their exclusion from families' narratives. Whilst middle class status was indicated to be a helpful resource for the two families discussed above, working class status may have been put to one side in the interaction with services, not offering the same effects. Aidan's family and Sapphire's family, both working class, drew on other elements of their identity, such as whiteness, to navigate those services or had to operate with less powerful positions in those important relationships.

The approaches of families with working class and middle class positions also have their connections to one another. Rosie and Alia's families could benefit from the way that their mothers deployed their class position, in the rhetorical tactic of being different from 'the rest'- i.e. from the working class people who were seen as the regular subjects of those services. This perpetuated the idea that services could usually work in ways that gave citizens little power, with the exception for middle class subjects who 'pulled rank'. The working class subject was reinforced as one who had to submit to the system and had to draw on other categories or work outside of them if they were to modify their experience of public services. Class operated as a modifier in the delivery of services at the boundary between public and private worlds. Middle class subjects were more explicit in sharing the ways they were tuned into knowledge about exclusive cultural resources for securing something better for their families.

Class was particularly important at the point when families were negotiating the interface between public and private worlds. It gave the middle class families the possibility of reinforcing the boundary between them, resisting intrusion and aspiring to the ideal of inviting welcome services in on the family's terms. This is a simplification and in the case of Rosie's family they were compelled to sustain close relations with the girls' father, required by a court decision, but resented. The working class families were in more cases the subject of compulsion. Aidan had to engage with the youth justice system following a caution for shoplifting. Sapphire's family had difficult memories of intervention from social services. Working class status was not a prominent rhetorical resource as recorded in this ethnography, although it may have helped families to frame and interpret the consequences of those contacts, rejecting those judgements where they were seen to diminish or be critical of the family. For Sapphire and Aidan's working class families they were able to take for granted the ways that white ethnicity conferred some advantages. Unlike XD and Alia's families they did not need to articulate ethnicity and 'race' at the boundary between public and private realms.

The intersection of ethnicity, 'race', nationality, class and, discussed to a limited extent, religion are important perspectives on how families established boundaries between public and private spheres of their lives. The details of these intersections in the examples of these families showed how privileged and subordinate positions affected the interactions with public services to the extent that the consequences of having a young carer in the family could be quite different.

6.7. Conclusion

I argue that ethnicity/’race’, migration, nationality and class inform the different power relationships between families and services. Social location is a useful explanatory framework for looking at the way that power is exerted at the interface between families and the state, as mediated by policies. Subordinate positions of ‘race’ and class are reference points for families to understand how they are positioned by those working in public services or as agents of policy implementation within the third sector. Families who occupied relatively strong positions were those whose ethnicity was characterised by whiteness but they observed a silence about ethnicity/’race’, not needing to use it as a reference point to interpret their position as recipients of services.

In contrast, a position of privilege in the category of class, a middle class identity, was important knowledge for explaining a strained but favourable relationship with services, although ethnicity marked out middle class families differently. Working class identity was less alluded to, but middle class identity was an important resource in pushing back against the instructions, intrusions or reticence of state provision. Families drew on the identification of subordination and privilege differently when a single category of social difference, of race or class, was the subject of discussion. There is a racialised and classed public and private politics of care that informs the implementation of policies affecting young carers and their families. This chapter puts forward the argument that an intersectional perspective and a prominent use of it within analysis is needed for an understanding of how policies take on a different character, more or less supportive, more or less punitive, in the ways they reach young carers and their families.

7. Social location in families

7.1. Introduction

In contrast to the previous chapter, which examined the intersections of categories of social difference that were brought out by ethnographic research and which operated collectively for families, this chapter focusses on the individual construction of social location. The focus is on the intersection between disability, gender, age and sexuality as expressed in relation to ideas of children and young people's safety.

The topic of safety is useful because it brought about strong reactions from participants who expressed the interwoven lived experience of these categories. This discussion contributes to the wider exploration within this study of what it means to separate public and private, and how families apply these as contrasting ideas to the practices of family life. This section develops the argument that subject positions within the categories of gender, disability, and sexuality are understood as qualities to be nurtured and protected in the family environment. This is done whilst making reference to the way these categories matter in the public world. These concerns and associated actions were embodied and personalised in the context of emotionally charged family relationships (Smart, 2007, Mason, 2018). Therefore, one element of family life was to mark out and shore up each family member's relative position. I understand this as a development of social location in the family. It was a process that had uneven consequences for children in the family because depending on how they were categorised they were given more or less freedom. Delineating these positions and their implications for young people offers a greater appreciation of the nuance of young carers' experiences, as the basis for exploring a more socially just and equality-minded politics of young people's participation in care (Akkan, 2019b).

This chapter argues that families' ideas about forms of gender, disability, sexuality and age are shaped into actions that aim to control and make safe interaction in public spaces. These concerns are incorporated into rhetorical tools that can be brought to bear on encounters with those wielding authority as representatives of public powers (Cooper, 1998). These ideas are expressed, tested, and formulated in the private environment of the family home. These categories make the separation between public and private feel real and necessary. The public/private boundaries are reconstructed and individualised in response to an evolving understanding of how to keep different family members safe. Whilst the focus of this chapter is on events within the family, more contained within its private world, it does not lose sight of how the private is inherently defined by its pairing with ideas of the public. Intersectionality theory makes a different contribution from that expressed in the argument in the previous chapter about the mutability of the public/private boundary in the context of intersecting inequalities of ethnicity, 'race', class and migration because here it builds on it to contribute an understanding of social location in the space of the family home.

7.2. Private nurturance of gender and disability

The observations of family life showed that the private space of family homes was an arena for nurturing the ideas of gender differences and the defining quality of disability. Adults and children participated in conversations which illustrated the ways that disability defined a sibling or gender categories that justified restrictions. These observations show how this activity was located in the family home and was part of the creation of family knowledge. It was an explanatory pursuit, which put the actions of family members into a system which explained why people behaved as they did. It explained why a person would do something that was troublesome to their sibling, parent or child. Alternatively, it explained why one family member, most often a parent or a child that was acting as responsible for their relative, would constrain the opportunities for another family member. Femaleness, youth, and disability often coincided in these observations of constraint.

Families with young carers construct and reconstruct the separation of private and public (Rose, 1987, Berlant, 1997, Warner, 2005), explaining to themselves and others the separation of public and private. They use the freedoms of privacy to deliberate, prepare and act in anticipation of public encounters yet to take place (Jupp et al, 2019). At the same time, this privacy is undermined by the omnipresence of ideas on how each family member is defined and socially located in public. Drawing attention to the construction of public/private helps us balance attention to the way these concepts are meaningful, whilst also seeing the ambiguities that trouble this contrast.

7.3. Articulating safety through the home

Elements of the home and its surroundings take on a particular significance for boundary-ing privacy and representing safety. On a sunny July day during the summer holidays, Rosie took me out to the garden to see the sandpit, the plants, the grass, and the trampoline. Her mother, Dominique, was inside the house with Rosie's sister, Poppy, who was being entertained by her mother hoovering the house. Outside Rosie told me that she happily remembers the sand on the beach when she plays at the sandpit in her garden.

> **Fieldnotes 25/7/19**
>
> She showed me the new gate along the side of the house. Dominique's dad [Rosie and Poppy's grandfather] built it. She told me that he said it "makes it more private". I was interested in her understanding of the concept of privacy and how that relates to the home. I asked Rosie what private means and she said "you can't

> look out the cracks, you can't see through." I asked if it was so "you can't look out or so people can't look in" and she said "so people can't look in".

For Rosie, adults instigated the safety precautions and these marked a difference between the inside and outside of the home. Her mother and grandfather were looking after her and the privacy of the home through physical barriers. The priority was to anticipate and prevent the actions of others within that space but it also restricted those inside because they were less able to look out. Rosie acknowledged the relationships of care, of motherhood, of grandfatherhood that constructed safekeeping.

In contrast to this example where Rosie talks with acceptance and satisfaction about the boundaries of her home, in another case a young carer, XD, expressed his anxiety about how porous their family space was, the ways it dissolved at the edges, leaving him feeling vulnerable and unsafe. He asked for research visits to take place outside of his home, feeling discomfort and shame. He did not like the place he lived, two bedrooms divided by a corridor, with a bedroom each for him and his mother. This family space was set in a shared house provided by the local authority as temporary accommodation while they waited for something permanent, something with more privacy. The place they visited during this fieldwork did not create the feeling that either XD or Tizzy wanted of privacy and safety necessary for it to feel like a proper home.

This view of their accommodation was bound up with a picture of multiple ways in which Tizzy had felt hopeless and was depressed as her relationship with XD's father broke down. She struggled with her residency status in the UK and poverty as a single mother. Tizzy gave me an account of the area where she and XD lived, in the context of her story of how her health had deteriorated.

> **Fieldnotes 16/7/18**
>
> I asked about the area. XD had some friends in the neighbourhood but it did not last. "They were racist. In the area you would occasionally hear that people were burgled." Last year someone "went through the house." They did not report it. Someone had come in through the bathroom window. There were "footprints on the toilet seat and on the basin." The bedrooms were locked so nothing taken. More recently there was a burglary that they did report. The doors were broken in but they "shouted and screamed." They called the police, although the police never came, but recently Tizzy had a call from victim support. She was given an alarm for the window and the door.

The new lock was pointed to by Tizzy during the preliminary visit to discuss the research project. In addition, she and XD would place a chair against the door at night for extra protection. They tried to increase security but for XD particularly it did not feel like a comfortable or acceptable home.

XD was clear about his unhappiness about their housing while Tizzy was more ambivalent, explaining the many difficulties of their shared housing but keen to minimise its overall significance. She encouraged XD to accept a research visit to their rooms later in the process.

> **Fieldnotes 29/8/18**
>
> We arranged a visit for a week Monday. I asked if Tizzy would like to meet at Waterstones again. Initially she agreed and then she turned to XD to ask if it would be ok for me to see them at home. He looked worried but his mum asked him quite forcefully, then she said that if I met them at their house this time they could go out somewhere else next time. He did agree so I will see them at their house next time. It will be the first time I have seen them at home since the first meeting.

XD and Tizzy negotiated the way that they would handle the problem of their home, but Tizzy was the one with more authority to set the approach. She steered the research process towards a recognition of their home as an important location in their family life, as a place that could be (or should be) used to frame their narrative.

The lack of comfort and security at home conveyed by XD was also carried into his behaviour in public space. Out of the house, in cafes, restaurants and museums where the meetings were usually arranged, XD repeated gestures of insecurity in these public places. He would keep his backpack close to him, sometimes sitting with his backpack on, squashed onto his back whilst on a café sofa. He could be noticed looking around him carefully, scanning the environment for signs of threat. He also used his backpack to signal, although unspoken, his disengagement from the discussion after an hour or two. He would pull his backpack onto his back, picking it up from its careful placement by his side. In a drawing by Tizzy for the visual ethnography exercise, she drew her son as an astronaut in the right of the image, with a characteristic backpack, marked ‘bag’.

Figure 2 Tizzy's drawing of her family in space 10/9/18

XD felt unsafe at home and also showed signs of wariness in the world outside. It alluded to an emerging masculinity in public spaces, in which he had to guard against threats (Valentine, 2004, Nayak and Kehily, 2007, Thomson, 2011). His youth and family role, in which he deferred to his mother’s decisions, meant he was relatively powerless to resolve this troubling public/private boundary. Young people articulated the significance of safety to explain domestic activities but also these were embodied across public and private spaces.

7.4. An ethnographic interpretation of safety

The ethnographic method draws attention to judgements of safety by placing the research in a multi-layered and ongoing relationship with the participants. The exploration presented in this chapter represents an element of the study of relationality in family life (Tronto, 1993, Gilligan, 1986). This prompted reflections on feelings about the participants' relative status as safe, contextualised by developing feelings on understanding, empathy and responsibility. One example of this comes from a reaction recorded in fieldnotes after one meeting with XD and Tizzy:

> **Fieldnotes 29/8/18**
>
> I woke up this morning remembering a thought I had had during the visit, although not a very clear one but it is important to write down. When Tizzy told me about their plan to visit family and I looked over at XD stoically wheeling his suitcase, I felt afraid for him. I worried that they do not know these relatives well and that he might be staying there on his own. I was afraid that he could be exploited or abused and Tizzy might not be able to stop it before it happened. This is quite an extreme thought and based on nothing, but partly it was based on him not seeming confident about where he was going or at least not telling me anything much about it. It was as if he was walking into the dark, as far as I could see. Also, Tizzy did not seem in control of the visit. She did

> not know if she could stay there too, for instance. XD seems cautious of the world around him, often subtly bringing his backpack close and scanning the scene he is in, as if to check his own safety. I had a nightmarish thought about XD being taken advantage of. I was drawing on ideas of vulnerability. I don’t know enough to make those judgements and I had no way of expecting that to happen. I think this reflects my fears about their circumstances, that they feel quite alone and without protection.

These safety judgements become connected to the feeling of being a participant in a private work. There in the background is the question about the responsibility of a researcher to act in line with codes of safeguarding. These fieldnotes record a concern about a child’s safety, not based on warning signs but on feelings and fears. These did not justify a formalised action in my judgement but they were due interpretation within the analytic framework. They were drawn back into the frame of analysis, rather than the frame of professionalised risk assessment. A mode of questioning for this approach is to problematise the deployment of vulnerability. The overreliance on the idea of vulnerability (Parr, 2017, Clough, 2017) signals a moment of obligation within a professionalised role but in this context becomes a point for considering the ways I read feelings of insecurity and lack of safety.

7.4.1. Participants’ embodiment of safety

There was a sensory quality to the ways that families established security. Information from a range of senses fed into their assessment of safety (Ferguson, 2016). Marie, sat in the garden, called to her son, Aidan, to check on the front door. She suspected that it was not closed, opening up the house to the street:

> **Fieldnotes 26/3/18**
>
> We heard the door bang. Marie shouted at Aidan to check the door, even though he had said that it wasn’t open. Aidan shouted back that it was open, “someone had left it open” and I assumed that was when I came into the house. Marie said “I know my house. I know the sounds.” I liked that representation of the sensorial knowledge of home.

In the fieldnotes, by connecting myself with this breach of security, I echoed the way that family members were drawn into cooperating with one another to establish and secure the boundaries of the home. Aidan was the one instructed to react to this problem but Marie’s explanation, of knowing the sounds of her home, gave some insight into the ways that she was physically attuned to the information around her, listening, watching, and feeling for whether the home was safe. I encountered the collaborative requirement to create safety.

Two book recommendations from participants added to the theme of the sensed tensions of the home. Sapphire recommended *Matilda* by Roald Dahl, which conveys the dysfunctions resulting from ill-deserved and failed adult authority through the mischief that the character of Matilda could enact by subverting objects such as hair bleach, newts and parrots. Another book recommended by Dominique was the *Diary of Anne Frank*. This subtly recounts the way that the senses were attuned to the peril that threatened a temporary home, when hidden from hostile authorities that patrolled the streets during war and genocide. These books show the fascination with the sensory quality of home spaces that weaves through both fiction and real life.

7.4.2. Ritualising safety

Other families had established complex rituals that created standards of securing the home. In Alia's family, there was a rule that the front and back doors were locked shut using a key. Alia herself had a key, as did her mother Kaya and her father Ben, but her older sister Amber did not have a key. To leave the house Amber had to ask for someone's key to unlock the door and then follow that person to the door, who would lock it behind her as she left. This process singled Amber out to be contained and protected in the house. It also increased the necessity of her communicating her motives and plans for going outside of the family home.

In family life the ritual of securing the house was used in a way that differentiated between family members. On one occasion, I saw this process, watching from a seat at the kitchen table, I had a view through to the entrance hall of the house. I had been sitting at the table with Alia and her mother Kaya talking about what it had been like so far to be part of the research project. Alia gave me her thoughts and then posed the question to her mother. As the discussion progressed to other topics, Alia said that her peers at school had ignorant attitudes about disability and autism. Kaya presented information she had received recently about a genetic condition that affected Amber, which she found interesting but was also troubled by it because “it is everything you don’t want to know”. Nevertheless, she advised her younger daughter to read the newsletter from this interest group on the genetic condition because it would make her feel “more ‘normal’ but it is hard to take too much in”. Through this conversation they shared their fears with each other about the ways that their family life was different to other people, maybe harder, because of Amber’s condition.

The conversation moved on again, so Alia talked about how she had made a friend at the new young carers group that she attended. She had switched to a new group, run by a different organisation, because they were in a different local authority area since moving house. Alia and this other girl “clicked” and could relate to one another, both being from a Pakistani background, she explained. They also have friends in common, knowing people at each other’s schools.

The conversation paused when Amber came downstairs and into the kitchen. She needed their help to leave the house to go to a meeting with a support worker who was training her and building her confidence in using public transport. This was working towards her acquiring skills that could make her more independent. In the fieldnotes I recorded:

> **Fieldnotes 3/8/18**
>
> Amber had to leave. They argued about letting Amber out, unlocking the door. Amber gave her mum a kiss and shouted at her mum to let her out rather than Alia. She put on her new trainers, which she got for her birthday. I commented that they were really nice and Amber lifted her foot up so that I could get a good look.

Amber had support from her family and from her school to learn some techniques that could help her be more independent. Yet her parents had established the rule that she depended on them and her sister to move into and out of the house. These measures were part of concerted efforts to keep her safe, in a different way from her sister. These restrictions were about her safety but they operated alongside her family’s support in other ways for her to move more freely.

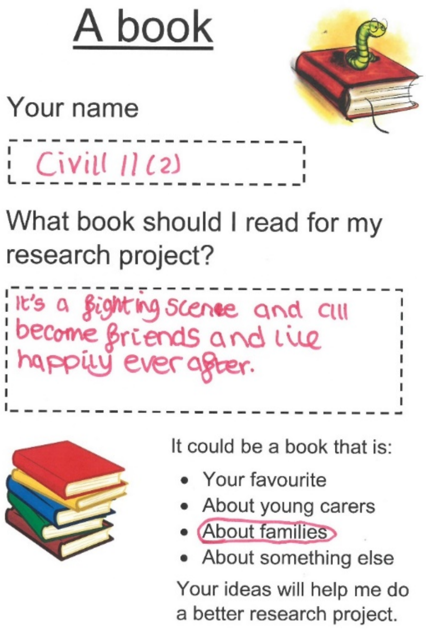
7.4.3. Socially locating the rituals of security

The measures of securing the house and increasing safety exerted more control over some members of the family than others. Family members were also allocated different levels of responsibility in the rituals of home safety. In the case of Alia's family, Amber was kept removed from the responsible role of key holder. Alia had the freedom associated with her own key but was also drawn into the work on monitoring and gatekeeping her sister. As a young woman this drew her into a practice of care for her older disabled sister, Amber. Dependency and vulnerability were tied together in these routines of security and care (Engster, 2019).

Amber was marked out by these safety processes and rituals as an object of care. Her parents, Kaya and Ben, discussed in detail their concerns about her safety. Her sister, Alia, said that Amber "doesn't realise that the outside is dangerous for her too". (Fieldnotes 27/5/18). They were preoccupied with Amber's safety and organised themselves to make her safe in a different way to their understanding of the safety requirements of the rest of the family.

Amber, positioned as having different needs, recognised that her family's scope to direct her was limited. In a conversation with Amber about her family and in response to a question about how she would describe her family, she said that they have "ups and downs" but that she is "the naughtiest." She says "no" to chores and “it is because of autism.” She has “autism, dyslexia and a little bit of anxiety.” She accepted that “the family all argue,” and she says “‘no’ constantly.” Amber said, “I think I know it all but don’t really. Must not tell mum that because she would burst out laughing.” (Fieldnotes 4/6/18). She expressed her disagreement with the expectations put on her and contested the limits to her scope to act within and outside of the home.

Amber also indicated the emotional strain these negotiations about limits and safety, representing a desire for greater harmony and alignment between herself and her parents. During a later visit, when asked to provide a book recommendation for the study, she showed a copy of a graphic novel and explained that this was one way she thought about her family because it illustrated the way that people can come together and make friends after a fight (See Figure 3). She hoped her family would do the same. Amber conveyed some of the ways that she wanted to manage how her family saw her but also the difficulties of achieving the image she desired. She accepted the frustration of the arguments in her family but she had interests beyond these repeated conflicts. At college, she managed fears about the sustainability of her friendships and whether to trust the people she spent time with. These fears were more vivid for her than those encountered from her parents to keep the house secure and the front door locked. The desire to express wider freedoms in her friendships provided an important arena to express herself that was contrasted with the limits she felt through the security rituals in the family home.



A book

Your name

Civil II (2)

What book should I read for my research project?

It's a fighting scene and all become friends and live happily ever after.

It could be a book that is:

- Your favourite
- About young carers
- [✓ About families]
- About something else

Your ideas will help me do a better research project.

Figure 3 Amber's book recommendation: the space on the form for Amber's name is filled with the book title. She recommends the book that includes "a fighting scene and all become friends and live happily ever after" which is relevant to the way that she thinks about family.

7.5. Socially locating family members through the categories of sexuality, gender, age and disability

The categories of social difference of sexuality, gender, age and disability intersected, finding expression in the personalisation of safety. For example, a preoccupation for Alia, Kaya, and Ben for Amber's safety was potential romantic or sexual relationships. Alia said that part of her care role was being a “therapist” but another part was “telling [Amber] to stay away from boys.” (Fieldnotes 27/5/18). Kaya saw a particular danger for Amber because she was a young woman and autistic, talking about “how difficult it was for girls with autism compared to boys.” (Fieldnotes 4/6/18). This coalesced around fears for the way she expressed her heterosexuality. In response to some writing found in a notebook, Kaya stated that her daughter had “the boy’s version of the hormones. She can’t help herself.” (Fieldnotes 26/7/18). Kaya and Ben worried about how to keep their daughter safe and planned how to chaperone her in public spaces such as the gym where they saw her as at risk from strangers.

> **Fieldnotes 27/5/18**
>
> Gradually [Ben] told her that “it was not safe to go back [to the gym], she knows the real reason.” Kaya says, “if she does consistent exercise, treadmill and jogging on the street with Ben. If she shows consistent commitment… But she was doing the same thing, peacocking by the pool and at the sauna.” Kaya said she knows that “[Amber] struck up inappropriate friendships with at least one person. Could go from neutral to extremely risky. It’s not unusual behaviour for Amber, at school, but schools were safe because children reported it but outside she could be seen as vulnerable and exploited.”

The need for adapting routines, saying ‘no’ to Amber, were explained with reference to her age, sexuality, gender and disability simultaneously, so she embodied a social location that was perceived as more vulnerable therefore subject to restraint.

These concerns weighed on the family’s ventures into public spaces. Amber’s parents allowed their daughter freedoms and some privacy in the home because the perimeters were secured. Alia was allowed to pursue her own interests or to focus on her school work because was not seen to need the observation carried out for her sister. Kaya and Ben could relax more themselves. They made use of their close relationship with Alia and Amber’s aunts, uncles and grandparents who provided a variety of private and safe places where Amber could be secluded away from the feared predatory strangers.

7.5.1. Responding to new knowledge of publics

Stabilising mechanisms were disrupted when Kaya and Ben arranged for Alia to attend a summer activities week and for Amber to attend a similar scheme. Meeting them after the activity weeks were over, Kaya was angry and upset because Amber had been found planning to run away from home. Fieldnotes recorded that Kaya felt that Amber “has had more things to give her freedom: travel training and the summer camp.” These had “backfired. Amber has focussed it in the wrong direction. The attempts to give her freedom have been misused in a risky way.” They had given her a phone as well and she was “crazy about ringing everybody.” (Fieldnotes 9/9/18). Amber’s parents were uncomfortable about the way that the gift of further opportunities to their daughter resulted in behaviours that added to fears about her safety.

These changes intensified uncertainties about how to socially locate Amber within the family home and the consequences for the network of relationships and safety practices that surrounded her. Kaya recounted what had happened to make her confront the problem Amber’s freedom:

> **Fieldnotes 9/9/18**
>
> Kaya looked tired and pulled her knees up on the sofa, hugging them. She looked worn out, as if there was a lot of strain. She explained that Amber came back from camp really happy. Kaya said that it was like “she had had a personality change. She was totally changed. Normally there is an argument every hour, or a dozen arguments in a day. She did not argue once or throw a tantrum. It was so out of character. Slowly, slowly she started acting more emotional. She revealed that she had a boyfriend at camp.”

The story was interrupted with Amber calling to say that she had arrived [at travel training]. Kaya instructed her that she was not allowed to leave without them agreeing [so they knew when she was travelling back].

Returning to the story of Amber at camp, Amber had decided without telling them that she would go to see her boyfriend [after the camp had finished] and stay with him for a week. She had written a letter saying she was running away and was taking her bags, which she had taken to her grandmother’s house. Kaya found this letter when Amber was at her grandmother’s house. When questioned about it Amber “was contrite”.

Kaya had spoken to the boy’s mother. “The boy is quite vulnerable too and would never have agreed to it. Luckily Amber did not get close to actually going. It would have been possible that she could buy a ticket and could get on a train and then she could be talked into anything.”

Kaya told me this story and then called on me to give my opinion, saying “as an adult, Chloe, I don’t know what you would think of

> this?”. She said that she is “shocked with [herself]” that she is not more upset but she said she has run out of feeling.
>
> She said that for Amber, the crux of her issue seems to be that she feels she does not have a life. Kaya says that Amber does not make an effort to improve her life. She described Amber as “spoilt but also unappreciative” as Amber thinks that other people get better things than her. For Kaya it is getting to the point of saturation. She said she feels that she has “done more than my best.”

After the moment of crisis about Amber’s safety after the summer camp, Ben became more closely involved in monitoring Amber. This induced a renegotiation of care work, calling for redefined gendered parental roles (Marx Ferree, 1990, Jensen and Imogen, 2012, Pearse and Connell, 2016, Thornham, 2019). This episode crystallised the unsustainability of the current arrangements in the face of Amber’s desire for greater freedom, but the way she was understood with reference to categories of social difference that fixed her into a certain position within the social world of the family, using ideas of girlhood, disability and heterosexuality, made it hard for the family to respond.

There was also a feeling of trepidation about what the future would hold. Later in the visit, Alia and Kaya were talking about how to manage a future of care for

Amber, specifically a future that might leave Alia and Amber as the surviving members of their family if Kaya and Ben were no longer there. Kaya comforted Alia and advised her on the extent of her responsibilities and the resources she could draw on if she became the custodian and sole carer of her sister. They anticipated how Alia would keep her sister safe if she lived in supported accommodation with staff. Alia said that she would want to know that she could “trust them” and Kaya told her that she could “check up on them. If they weren’t good she could move her or could look after her herself.” The goal of keeping Amber safe stretched out into a future beyond her parents and was something that Alia may take on more extensively in the future.

Safety habits were compelled to change in response to the altered circumstances that took form in the fluid picture of family life. Kaya, Alia and Ben strove to keep Amber safe, in a particular way that rested on their understanding of her as a disabled heterosexual young woman (Morris, 1991). Amber saw herself as more than this, as exceeding the limits that they put in place for her. She felt a powerful need for comforting words from her mother, her sister’s companionship and her father’s treats, jokes, and indulgence. Each other family member could also likely tell a story of the way that the family both constrained and enabled them but this was modified through an interpretation of their social location within the family.

7.5.2. Safety in socialisation

Another way that families scrutinised the outside world and interpreted the potential for concerted action in private spaces that made their members safer, was to assess children’s friendships. For Amber, she was seen to be influenced by her friends at college. In another family, the family in which Sapphire was a young carer, her mother, Becky, saw Luke, her son, as at risk of being adversely influenced by children in the neighbourhood. Luke himself was cautious about associating with others of his own age, particularly in a school environment, but in the streets around his house he had friends who he ran around with:

> **Fieldnotes 22/6/18**
>
> Luke came back a few minutes after Sapphire and Becky. He was with a girl. Becky commented that she does not like the kids to be in the street. She looked restless and concerned. She talked to me seriously and wanted to invite me to understand or see aspects of their lives. On the subject of Luke she said that if he is with girls, that is ok with her. She does not like it when he is with “naughty chunky boys. He is learning to be horrible.”

Echoing Becky’s concerns, when Luke responded to a question from the researcher about key points for others to hear, he pointed to the importance of a longed-for friendship: “Be calm. Sometimes people need a little something in life. Maybe like a friend or something.” (Fieldnotes 24/10/18). The limits imposed on friendship by parents in pursuit of keeping their children safe from physical dangers or adverse social influences were problematic in the context of childhoods marred by loneliness. This was particularly acute for disabled children and young people, something brought up by both Luke and Amber.

In Sapphire’s family, the eldest child, Jane, used the space of the family home to shut people out and keep herself safe. She could curl up on the sofa with a book, make drawings and write stories. Their boisterous and affectionate dog was trained to bark loudly and ward off strangers. The home was a place where each of the children could carve out an area amongst the piles of toys, papers, snacks and half-way-through projects to pursue activities in peace, but this did not provide the friendships that each of the three children needed:

> **Fieldnotes 23/5/18**
>
> Becky talked about Jane and her worries about her. She explained that Jane did not seem to have easy friendships with her peers. She had friends at school but she did not behave like them and was left out. Becky says that she is worried because “children bully Jane,” which is related to her difference because of

> her health. She does not socialise in a way her mother would expect. She is often reluctant to go out and is “unhealthy” staying inside. Becky feels protective and wants to supervise her elder daughter although she is warned by her sister that she should give her more freedom. Becky described Jane as like a turtle because she relies on her shell, puts her head out tentatively but often draws back in. Jane herself said how much she prefers to stay inside and said it was unusual for her to be outside. I think that my presence meant that she wanted to join the trip to the playground on the corner rather than stay inside.

The opportunity to play outside with her siblings, to talk to someone new (me, the researcher) or to join in a family cycle ride were opportunities that tempted her to venture out but she remained wary. Her mother, Becky, allowed her choice and freedom to find the place to enjoy her time away from school but she returned to these worries about how to understand what her daughter needed and to provide it, as well as to keep her safe.

7.5.3. Cultivating social location in private

Becky was concerned about how gendered friendships had different effects. She was wary of the male influence upon her son and encouraged him to develop friendships with girls in the neighbourhood. Valentine’s work on the views of parents towards their children’s gendered needs to be protected helps us see how these attitudes fit into a wider pattern of parenting boys and girls differently (Valentine, 2004). Valentine found patterns in the ways that parents estimated threats towards daughters or sons, seeing these threats as different and these gendered interpretations interacted with their understanding of the significance of age for children’s ability to manage in public spaces. In this study, parents nurtured ideas of masculinity and femininity in their children in private, in the home, involving family members in conversation that refined the interpretation of what these characteristics meant for the way that a young person should understood. A child’s status as disabled or as not disabled was also nurtured or cultivated in the private world of home. Public spaces, then, were a test of children’s accomplishment of these characteristics, of their ability to integrate and assert the multiple characteristics assigned to them. Their parents watched and assessed their children’s safety in ‘wearing’ those characteristics and kept an eye on the response they received. The efforts to control behaviour or interactions in public settings, alongside the securing of the home allowed for an iterative process of teaching their child to be the type of person they needed to be at home and a congruence with their public presentation. They needed to accommodate their identity to a public world to the extent that they could be welcomed and made safe.

We can extend Valentine’s analysis to incorporate the consideration of care roles central to this study. Indeed, parents saw connections between the expectations of care and the gendered place that their child developed in the world. Three examples of this are from the families of XD, Aidan and Sapphire.

7.5.3.1. XD's family

XD and his mother disagreed about the suitability of him having a girlfriend. XD's mother, Tizzy, said that he was too young. She feared that it could have serious consequences, if his girlfriend became pregnant or if a sexual relationship threatened his health. He was not seen as ready to take on an adult masculinity necessary for him to navigate these risks. Meanwhile, XD portrayed his mother as unfamiliar with contemporary culture that made his relationship acceptable in his eyes and dismissed her concerns. XD disregarded his mother's views because of her age and background based on a different culture of relationships from Southern Africa.

Fieldnotes record the setting out of the conflict between Tizzy and XD, drawing the researcher into the opposition between the participants. This interaction echoes the ethical dilemmas outlined by Forbat and Henderson (2003), with the researcher learning about but also being drawn into conflicts between participants. As recorded in fieldnotes, there is discomfort about how to deal with the disagreement when Tizzy explained the impasse they had reached where XD would not stop his relationship despite his mother telling him he should:

Fieldnotes 24/9/18

She thought about this for a few seconds and then said that one issue I might be interested in is that at the minute XD has a girlfriend. They disagree about this. She believes that “you are just 13, you don’t work and you are too young to have a girlfriend.” XD said that Tizzy “sees it differently because of her background.” Based on the experiences that Tizzy has had she said that “it does not end well, where young people have a girlfriend/boyfriend. It ends up being disaster.” Tizzy said she knows that “they are growing up in different times. People here are more casual” although she wonders how things work. “With the example of HIV, it spreads through unprotected sex but back home people know that they need to use protection, they need to abstain. ABC, be faithful. They don’t take things casually the way it is here. Back home, if someone is starting a relationship with someone, they want them to provide for them, money for their hair. Here it can be by saying a few nice words and you are good to go. When you look at the rates of STI infections you tend to wonder how it is lesser or fewer than back there. People tend to restrict themselves in a way. Some of it is not HIV but Hep B. Hep B is more dangerous because you can get it from other ways. There is a lot of stigma, so people stay away from testing. Medical personnel are not professionals, spread information,

> spread the word." She concluded that the culture here is different. She expressed worry and some anger about the issue.
>
> Tizzy asked me what I thought. I said that I was not a good person to talk to about it. I said that I could see it was difficult because they each had their own view. I said that XD would feel like he wanted to make his own decision but he is still young. Also that Tizzy would see it differently. I feel like Tizzy was disappointed that I was not clearer about her authority. I did not say anything like that, about her being in charge, but then I felt that maybe I contributed something too vague. I said that I was sorry that I was not able to be more helpful. I said that maybe I could look for some information that might be helpful. I feel like there might be useful parenting advice out there that I could point Tizzy and XD in the direction of, about navigating teenage relationships.

Tizzy saw that XD's pursuit of this relationship could potentially connect them to a new wave of care needs, if XD became a father or if he became ill from a sexually transmitted infection. She saw this behaviour as coming too early, referencing ideas about the right time for taking on responsibilities to care for others, although XD saw this as an acceptable part of his youth (Skeggs, 1997, Heyman and Heyman, 2013). Instead, she hoped to put an end to the relationship and avoid these risks, protecting her son and giving her greater stability.

Tizzy's frustration at XD's refusal to heed her warnings, his disregard for her experience, left her struggling to find ways to control him. This severed the connection between the use of private conversations and rules to wield authority over his behaviour in public. Instead, XD was carving out for himself his own private decision-making domain; a domain that was not his mother's. She questioned his entitlement to take control of this area of his life, to make it private from her, because of his age and because he had not attained the markers of masculinity and adulthood that would show that he was ready.

7.5.3.2. Aidan's family

Another family provides an example to explore the complex ways that the lack of control over encounters in a public space prompted families to make reference to categories of age and gender to understand how to reassert safety. In this case an older brother, Aidan, spoke about how he protected his younger brother. He was walking to MacDonald's to get food for his mother and brother and commenting on the sights of the neighbourhood:

> **Fieldnotes 5/6/18**
>
> We were passed by a man riding a quad bike loudly along the pavement. Aidan described him as a “road boy” and we talked about his balaclava. Aidan said that this was so that he could steal. The way that Aidan talked about it interested me. He looked around at the man and the group he was with. He told me that previously someone had driven along the pavement fast in a quad bike and scared Joey who was with him at the time. He had “told them off because Joey was young and had been upset. The guy had said sorry and had not realised Joey was so young.” Aidan said that Joey was “tall so looked older than he really is.” Aidan sounded protective, and confident in this story.

Aidan used the observation of the man on the quad bike to draw attention to his ability to step in and protect his younger brother who had not acquired the same knowledge and who needed Aidan to stand up for him. Age, youth and masculinity were implicitly referenced in Aidan’s account of the caring relationship between him and his brother, cutting out the idea of disability that imposed the characteristic of him as a recipient of care.

In walking along the streets that circled his home, Aidan used the observations and interactions to develop and solidify his identity, aiming towards a masculinity and adulthood that embedded him in his neighbourhood in a way that he could be respected for his knowledge of the ways things were done. He savoured his connection with the bus drivers that let him on for free, or the staff at MacDonald’s that remembered the time he fixed the cash till. He signalled a knowledge of gangs and criminalised behaviour, embedding his identity in the familiarity with the tightly defined neighbourhood (Nayak and Kehily, 2007). This built up an air of worldliness and confidence but also suggested its brittleness, because it only held within a small geographic area and it might not always protect him, even there. There was also the risk of misrecognition, that in the same way that Joey was wrongly seen to be older than he really was, Aidan could be dismissed as not being the unassailable man he wanted to be seen as.

Joey spoke with familiarity of his neighbourhood too, but he talked about a wider world. He established contrasts between the neighbourhood and other places outside it that interested him. In a pair of drawings that he sketched out during one research visit, Joey drew the buses that took him further afield. In one image a bus was captioned as “it is go to the big town”. The big town was not their neighbourhood and this place was more exciting for Joey, so was the focus of his games. The safety or familiarity of the neighbourhood did not have the same significance or appeal as for Aidan. Instead other publics offered him more opportunities to explore and learn, having less concern than his older brother for the way that the neighbourhood could affirm his maturity. Their different approaches suggested personal interest but also different points in a lifecourse, allocating specific cultural relevance to their expressions of exploration and neighbourhood.

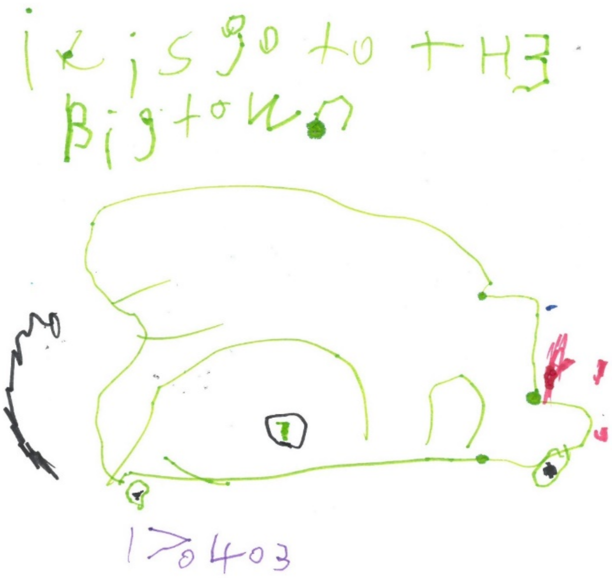


Figure 4 Joey's drawing of a bus: 'it is go to the big town' 9/8/18

7.5.3.3. Sapphire’s family

Sapphire and her siblings used categories as tools to explain how they were different. They saw different labels as hierarchical, so some were favoured while others were scorned. In several instances the siblings spoke of the way that being older showed that you were superior. In the following example from fieldnotes, Sapphire spoke with pride at being treated as nearly the same age as her sister even though she was in fact younger. As Sapphire understood it, Jane’s status as disabled explained why the meaning of age became modified, however it still held its ability to define different levels of skill for her.

Fieldnotes 22/6/18

> Sapphire told me that she was the oldest in her dance group and Jane was the oldest in hers. Jane should be in the older age group but Sapphire said that "because she is disabled she stays in the younger age group." Jane objected to this explanation saying that her "legs work fine." Sapphire retorted that some people have autism, they are disabled and their legs and hands worked fine. Jane waved her hands around in mockery of Sapphire's explanation [dismissing her] and then went back to playing on the PlayStation. Jane seemed upset when Sapphire said that in October she will be moving up to the older age group and will be in the same group as Jane. It seemed that Jane did not like this idea. She seems to keep herself quite distant from Sapphire.

The category of age, used by Sapphire to make a point about potentially uncomfortable similarities between the two sisters, had additional resonance because it intersected with gender to socially locate them alongside one another, with contrasting ramifications for each of them. To interpret these further, the similarities stripped away ways of distinguishing the sisters, to isolate a difference based on disability status and making the more privileged positions visible (Spelman, 1988). This exposed Jane to the troubling suggestion that disability meant her sister was 'catching her up' despite being several years younger.

The sibling age order, girlhood, boyhood, being disabled and different types of impairment were important categories for the children to explain themselves and each other. However, these labels were interpreted through a wider knowledge of what it meant to be a member of those categories. In this extract from fieldnotes of the siblings' conversation and explanations to the researcher there was ambiguity about what age meant. Sapphire and Jane were using the idea of age groups as a proxy for skills and status, recognising their symbolic power in marking parts of the lifecourse both for young carers and disabled young people (Priestley, 2000, Hamilton and Adamson, 2013, Day and Evans, 2015).

In the background of this story, adults were making decisions about where each child should fit. Jane's position out of the place set by her age put her into proximity with Sapphire and this worried her. The categories were platforms for negotiation, not just forged within the family's shared understanding but bringing in the understanding of people outside the family home who organised dance classes, who allocated wheelchairs and who ran young carers services. The siblings were attuned to these connotations and they participated in conversations that showed the emotional impact of these terms. Young people, like their parents, deployed hierarchical ideas of difference to exert pressure on one another, maybe in pursuit of their preferred iteration of family life.

7.6. Conclusion

Security is a concept of unexpected relevance to studying the intersectionality of gender and disability in family life. The interpretation of it here shows it as a hierarchical practice, determined and standardised by those with more authority, but it also functions as a collective undertaking to collaborate on a project of security. In some instances, it is the conduit for restricting certain family members in private and holding them back from entering public spaces unless under particular conditions. The families show varied examples of how security is understood, chosen and achieved. At its most serious it continuously acknowledges a threat of violence from which the family needs to be protected. As with Rosie's family it is also about obstructing sight - installing a new gate - so overcoming the threat of being observed against your will, with the associated fear of unwanted actions following that observation. Despite these overarching comments about the way that security emerges as a relevant concept, the way it was encountered in this study was through the different ways individuals needed to be made safe. There was a sense of the uneven nature of threats against family members with vulnerability to danger falling upon each person differently because of their social location and personal qualities.

Through research, the ethnography negotiated these measures, leaving me experiencing the ways that behaviour was watched, assessed for the impact it may have on the secured space of the home. This was applied both to physical behaviour but also to the words that were used which could cause emotional harm or could indicate the ways that the research might endanger the protection of information from outsiders. These things were reassessed and adapted to increasing knowledge of, and confidence in, the researcher's conduct, alongside an awareness of the way that the research imposed on carefully constructed privacy. By gaining permission to access these private spaces I could observe the ways that social location was embodied in family life with uneven and individualised consequences. Some family members had perceived weaknesses to be watched, others held more knowledge of these weaknesses and could therefore be obligated to take on greater responsibility (Engster, 2019), although we must be cautious about how ideas such as disability and gender culturally determine the idea of vulnerability (Parr, 2017, Clough, 2017).

The negotiation that delineated family members' roles in the work of care was a process that politicised the way that safety concerns hemmed in or freed up family members. The different expectations applied to young family members, through the ideas of disability or being a carer and were refracted through gender, age, disability and sexuality. The space of the family home, understood as a private space, was crucial in the ways that families evaluated and practiced safety. Understanding the movements into and out of homes has implications for the opportunities that are supported at different moments in the life of families.

8. Layers of knowledge about family care

8.1. Introduction

As has already been discussed, the public/private politics of care is evident in the process of negotiation. It is shaped by being imbedded in and fuelled by inequalities that mean it produces different constructions of the separation between public and private in families. It also tells us about the ways that family members are socially located in the family home. This chapter builds on the points made previously, to argue that the differences and inequalities between the five families are accommodated by the existence of multiple and conflicting embodied knowledge about care in the home. This was accessed methodologically by using a selection of methods of data collection: visual data and book recommendations alongside participant observation. It was also accessed by working with whole families to document the ways that they lived with an awareness of the difference between their members and between them and other families. The argument for accepting and working with the layers of knowledge about care in academic work on young carers is built on the outcome of a particular methodology that produces broad and irreconcilable knowledge. It requires us to consider families as peopled by individuals with their own intense experiences and divergent perspectives (Smart, 2007) but also as collective endeavours (Morgan, 1996). The layers of knowledge about care help us work with data on multiple thematic ideas but also to remain attentive to the simultaneous importance of individuals and groups.

This chapter begins with a section on the layers of knowledge about care, starting with an analysis of Sapphire's family, illustrated by data from a drawing exercise. This leads into a discussion of themes of layers of knowledge about care across the five families. Three themes are discussed, using groupings of visual data, looking at the ways that families expressed their knowledge about family care and its potential to change by freeing people, freeing the environment of care and freeing the emotions about care. A second section looks at the techniques of layering knowledge about care within families. Two techniques are considered, firstly, engaging and disengaging, and, secondly, working with the knowledge of layers. The chapter argues that recognising the layers of knowledge about care in families shows the potential for working with the complex results of ethnographic research but also indicates some practical messages for improving the ways that services engage with families at places of knowledge.

8.2. Layers of knowledge about care in family life

Care was politicised in private and in public for young carer as their families negotiated care and used care practices to create boundaries and safety. These spheres of politics were intertwined as was demonstrated in the detailed analysis of family negotiation. In the political processes that imprinted themselves on the organisation of care, family members drew on knowledge of care and of categories of social difference. I argue that this knowledge cannot be seen as coherent or reconcilable between family members. It should be understood as layered in order to incorporate its complexity into our analysis and to allow us to work with recognition of the way that families were both a collection of individuals and were a grouping bound together. This section begins with an examination of layered knowledge about care in Sapphire's family. A later part looks at themes within families' layers of knowledge about the problems of care and desire for change.

8.2.1. Sapphire's family

Sapphire's family's engagement with a drawing exercise provides an example of layers of knowledge about care. Her family were asked to take part in a drawing activity, responding to the question of what their family life would look like if they moved to space, living an astronaut life. They were invited to respond to the theme of space, drawing and labelling a piece of A4 paper with an image of how their family would interact in a different landscape, cut off from the physical and social world that they knew. Fieldnotes from a visit on 27th July 2018 introduce each drawing.

I came back into the house and Becky gathered Luke and Jane around the table. I had said before the visit that I wanted to try a drawing exercise. Jane was keen and then self-effacing. Luke was a bit sardonic and keen to impress. Becky was going to watch and said she would not draw, then when she said she saw that I was drawing too she said ok she would do one. I gave each of them a piece of cartridge paper and scattered around the pens and pencils.

Luke finished first. These were my notes from the conversation I had with him about his drawings:

Luke - earth explodes, sun has expanded and is shown big in the drawing. They all die, falling into a black hole. Jane is floating aside. He says that Jane would not know how to survive. She got drawn in ways that showed her on fire. Luke was saying things to criticise her. He said that she was too stupid to know how to survive with putting her suit on. I was shocked and worried for Jane hearing these words as they seemed very hurtful but she seemed to continue ok.

Figure 5 Luke's drawing of his family in space 26/7/18

Luke talked about how the sun is expanding and talked about the new discovery of water under Mars. He was amazed at his own knowledge. It was hard to engage with him on these subjects because he did not seem to welcome contributions from me, instead he wanted me as an audience for him to share his knowledge. I tried to please him but I also found it hard to sustain that kind of interaction, especially with other people around.

Becky finished next and these were my notes from our conversation about her drawing:

Becky - the sun is too hot for the trees. The leaves fall off. The family are resting on a large [leaf] and they float away on the river on a leaf. All the life issues are affected. They will always survive. The trees are getting burned. They talked about human's fault that the planet is suffering.

Figure 6 Becky's drawing of her family in space 26/7/18

I felt that she was channelling her discomfort in the heat. Also, it conveyed an image of ease, with the five of them floating down a stream, lying on a giant leaf. It also conveyed her close interest in the environment, plants and horticulture.

Next Jane finished. She had drawn carefully and taken her time. We also discussed the possibility of her writing a story because I know that she loves creative writing. When she described her drawing to me it came out like reciting a story, quite poetic and carefully punctuated. My notes from the discussion are below:

Jane did a drawing of the planet Azuria. Pluto exploded and a new planet was created. Scientists found out about the new planet. On this planet are icicle chasms. In the centre her family would live. That is where all the plants would grow. The outside is like a shell and the inside is beautiful. In there you would be able to breathe. There would be no anger. It would be a free zone. No fighting, with happiness, courage, kindness, emotions.

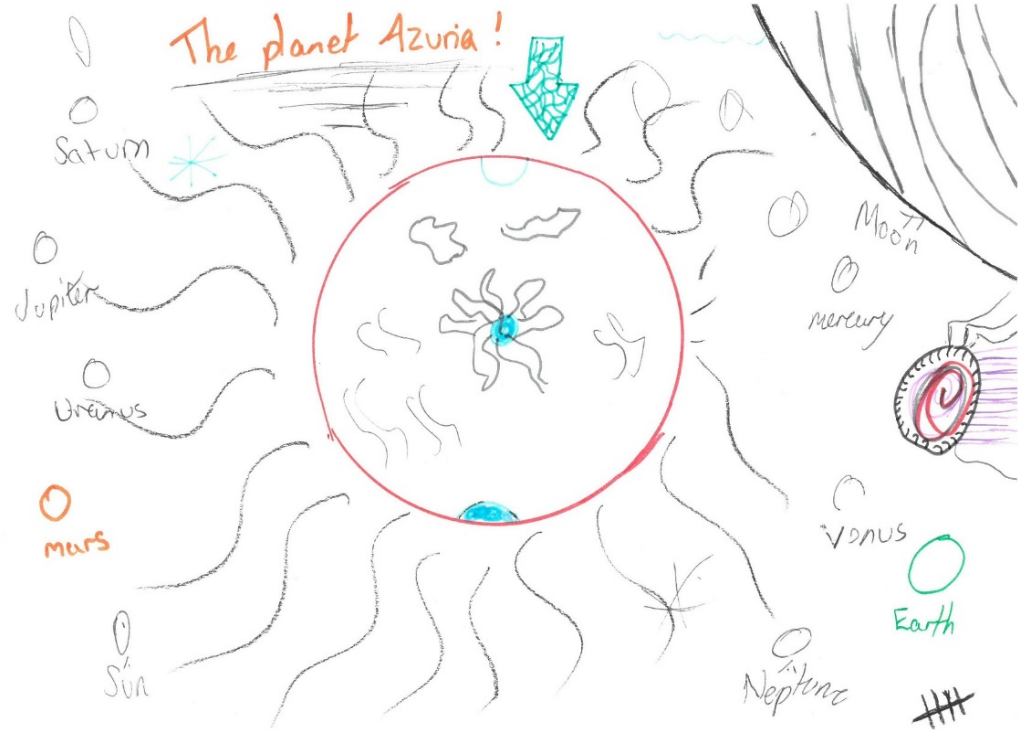


Figure 7 Jane's drawing of her family in space 26/7/18

> Jane then showed her mum who expressed approval, as she had done for Luke. Jane read from my notes to repeat the account of her drawing to her mum.

Later in the visit Sapphire returned from a day trip with friends. My notes record her involvement in the exercise after her siblings and her mother had finished their drawings.

Figure 8 Sapphire's drawing of her family in space 'no fights family' 26/7/18

> In Sapphire's drawing she drew her family holding hands and she wrote the words 'no fights family'. Jane came over and stroked her hair. The figures in the drawing had helmets on as part of space suits. They all matched. They were all lined up with the three children in age/size order. They are near the moon, floating around in space.

The emotions and longings represented by family members in discussions of their drawing connect us to the difficult circumstances and changes that the family were undergoing. During a family cycle trip, Luke pulled Sapphire to one side.

> **Fieldnotes 26/7/18**
>
> Near the end of the return home I was stopped at a junction with Luke and Sapphire. I was shocked to hear Luke ask Sapphire if their parents got divorced whether she would want to live with her dad or her mum. He said he would choose his dad definitely because he actually looks after them and lets them have fun. Sapphire did not want to answer and then when Luke insisted, she said she would choose her dad because he has the car and could drive them to visit their mum. Sapphire tried to argue with Luke about his choice, saying that their dad gets angry and that once he

> hit Luke with a keyboard. Luke said that had happened because he hit Jane. Then he disputed the details of the story and told Sapphire to get her story straight. Even so he would choose his dad.

This incident was troubling, introducing a hitherto private topic of the parents separating that I had not been aware of and the suggestion of violence in the family. Separate conversations between siblings showed the ways that layers of knowledge coexisted and helped family members find some way to manage the pressures of family life. Each family member could be seen as a layer within the family but also there were topics and areas of knowledge, some shared more freely and others not, representing layers of privacy in family life.

As well as the children's conversations that set out divisions between knowledge, adults also kept information private or chose to share it. Becky and Chris had conversations away from their children in which they talked about serious, upsetting or daunting subjects.

> **Fieldnotes 23/5/18**
>
> Chris looked strained and Becky also seemed upset and weary. Chris explained that he had received Personal Independence Payment for 4 years at one level but it was cut so now they were getting £100 less every week. It was difficult. Since the change they were often

overdrawn and it was hard to adapt. The kids don’t know about this change apparently. The conversation happened with the children out of the room. Becky went to a food bank yesterday for food supplies. This was something they “never expected to have to do.” Chris was angry that other people have been complaining but they have only lost very small amounts of money from disability benefits. Chris said that it’s “a shock” having less. During the holiday the kids have clubs, gymnastics and film.

Financially they have to meet the costs of the clubs and they are very important for the children to continue. He said, what can you do? Becky added her thoughts about how difficult it was and the activity clubs. She said that it is important for them for their social life and gaining responsibilities. “Participating in those things makes you more interesting, otherwise life is boring for the children. Otherwise all day they will be watching TV or playing PlayStation in bedroom. The clubs keep their minds busy.” It also connects to their particular needs. “Luke has improved doing drama because he is autistic.” Jane had the stroke and the brain injury so drama is important to help her “control her interaction and improve so she has a better life. It is a struggle at the minute with money.”

> Sapphire came into the room and the conversation was curtailed. It developed into an argument between the three of them on the subject of the children snacking and whether this went against rules about eating.

Two examples have been provided that show that way that layers of knowledge were distinguished, recognising the ways that certain subjects needed to be contained within particular relationships, such as been siblings or between spouses. Two subjects discussed by these pairings were the financing of recreational or educational activities and the restructuring of parent child cohabitation in the face of parental separation, both selected because they needed to be kept separate from other family members who should not be part of the knowledge exchange or would bring influence that was unwanted. The use of careful groupings to consider particular subjects controlled the dissemination of knowledge. This is another aspect of organising care in the context of the public/private politics of care.

8.2.2. The contribution of visual data to the layers of knowledge perspectives

The visual images presented here were developed in ways that referenced a visual environment. Family drawings were already displayed around family homes and they were involved in a language of visual culture. To look more closely at these images this section draws on the framework for analysing visual images as part of qualitative research set out by Banks (2001). This has the benefits of engaging with visual elements as made objects, standing apart from a range of other guides to this subject which tend to focus on photography or filming. Banks (2001) argues for the analysis of visual data to be a response to three questions. These questions are: what is the image of; what is its content; what is its internal narrative? Secondly, who made it and what is its external narrative? Thirdly, how did it fall into current possession, why, what do they do with it and what do they think of it? The third question is not greatly relevant to this analysis because the images are all explained as the direct result of an exercise in a visual ethnography. The first and second questions from Banks are more helpful, encouraging us to think about what is contained within the image, and then the context by which that image was created. This provides a prompt to think about each image as having an internal narrative and an external narrative. It highlights the display of the imagination (Edgar, 2004) in the context of relationships and visual culture (Rose, 2014, Pink, 2003). We are able to analyse these images by using relevant knowledge to interpret the image in its own context and in the context of academic discussions.

The drawing activity aimed to provide moments of expression and crystallisation. This potentially contrasts with the ambiguity and open-ended conversations of the participant observation methods. By creating a more structured interaction within the context of ongoing data-collection, these elements provide a distillation of ideas. The responses to these questions coalesced around three themes, each of which suggested an alternative imagination of care, liberated by a shift of people, place or feeling. These suggest three key layers of knowledge about care, and especially about desire for its potential to change, drawing on creative knowledge. Visual data was especially helpful in accessing these layers.

8.3. Themes in layers of knowledge about care and its problems

The visual exercise asked families to re-imagine their care for one another in the setting of space, as if they were astronauts situated in a new terrain but with the same relationships. The families imagined anew their private worlds, with a loosening of the constraints they felt because of their socio-economic circumstances and in their interactions with different publics. This exercise drew attention to the construction of private space and the constraints that were felt by families when they practised and displayed family life within it.

There were three groups of answers across the five families to the question of, ‘how would you and your family care for each other in space?’ Sapphire and her family are represented across these categories. I understand these three groups as different collections of external narratives, because the analysis focuses on the relationship between the image and the drawing exercise, rather than its internal narrative and content. The external narrative groupings are presented here with a brief caption that summarises the internal narrative. For reference, each individual is connected to the young carer who lends their name to the family group in this study.

Three responses reflect the interpretation of the dominant mode of engaging with the exercise, so the drawings are grouped under three headings themed around a critique of care and its potential to be reimagined in space. These three themes are freeing people, freeing up the environment of care and freeing up the emotions of care.

8.3.1. Freeing the people that care

Included in this theme are drawings from Alia (a young carer), Kaya (Alia's mother) and Poppy (a young carer).

Figure 9 "Poppy drew and had lots of imaginative ideas about different planets. She did not want to continue drawing and draw people. She explained that she would live on the candy planet and live there on her own, so she could have all the candy." Fieldnotes 31/8/18

Figure 10 Alia's drawing of her family in space. The original version had initials identifying each family member but these have now been removed. Alia's sister Amber sings along to the song on her headphones, her mother Kaya worries about the chores and her father, Ben, is in his own world narrated in binary numbers, reflecting the way he is absorbed by a world of computers. Alia herself stands apart and misses her favourite food, chicken curry.

Figure 11 Kaya's drawing shows each of the family members apart, pursuing their own interests. Her husband, Ben, frets about the possibility of a return journey, her elder daughter, Amber, enjoys dancing to music, her younger daughter, Alia, is absorbed in a book. Kaya, herself, explores this mysterious new place, living in the moment and following her natural curiosity.

Figures 10 and 11 are drawings that appear like a pair, as similar interpretation of the visual premise. They were created at the same time as mother and daughter sat alongside one another, while Amber, Kaya’s eldest daughter expressed a different response to the question (one which is shown as Figure 14). This may reflect the way that characterising difference, as discussed in the previous chapter on intersectionality, was a strong theme in the conceptualisation of family life for Alia.

8.3.2. Freeing the environment for an ideal of care

Included in this theme are Dominique (Poppy's mother), Marie (Aidan's mother), Becky (Sapphire's mother), Jane (Sapphire's sister) and Sapphire's (a young carer).

Figure 12 "Dominique did a really detailed precise drawing and explained how it represented an ideal life. It showed a quiet area for sleeping, a hydroponics area for growing tomatoes, peppers and potatoes and a giant climbing frame with speakers that could play music." Fieldnotes 31/8/18

Figure 13 Marie's drawing of her family in space. There are comfy sofas for watching the view and flowers near the landed spaceship.

Becky and Sapphire's drawings described and shown in the previous section contribute to a conversation about how the family could live a better and happier life, free from the constraints of the physical and social world.

Jane's drawing showed an interest in engaging with the activity as a technical or artistic challenge, however, her description of the drawing recorded above indicates that she underpinned it with detailed thoughts about a better life for her family.

The other drawings in this category by Dominique and Marie were both explained by their creators as showing the way that their core family activities of spending time together, relaxing, eating or being part of a natural world could be better liberated from the physical or social constraints that they currently encountered. These were moving ideas that showed a longing for greater scope for family happiness.

8.3.3. Freeing the emotions of care

This theme includes drawings from Amber (Alia's sister), Joey (Aidan's brother) and Luke (Sapphire's brother).

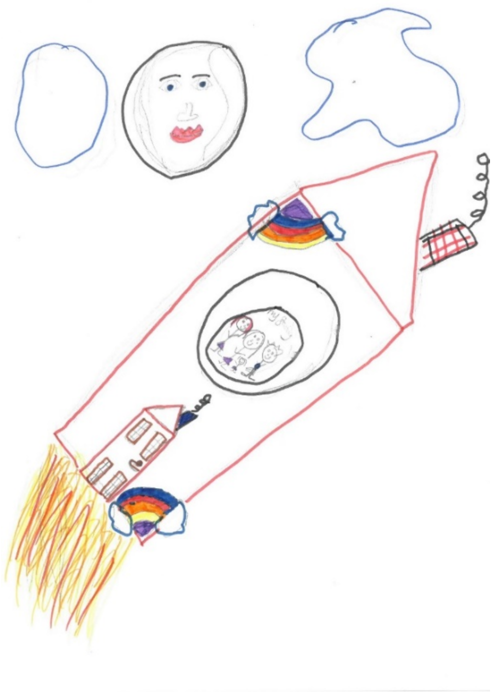


Figure 14 Amber's drawing of her family shows their cosy family home turn into a spaceship on the move. The family look out excitedly from a window. Rainbow

motifs decorate the spaceship and a smiling moon looks down on their journey. Originally the figures were demarcated by initials, which have been removed.

Figure 15 Joey produced a series of drawings on the theme of his family in space. This one shows him alone in a quirky spaceship, propped up on two legs. He has captioned it with the following words: “I jumped to space to have fun.”

One image from Joey is shown here, although he produced another that gives additional insight into his ideas about what it would mean for his family to live in space. This has been typed up, replicating the poem-like structure of the conversation.

In the spaceship there is a play area and a kitchen,

Sometimes Joey will visit earth.

What would it be like on earth?

good.

He would [be] playing + Mum + Aidan would do

The learning. Marie would learn to

Count to a million billion.

Aidan would learn about

reading to read stories.

The literature on family life captures the importance of the imagination and creative thinking as part of the nature of families. For example, Morgan (1996) encourages us to appreciate the way that family exists through ‘doing’, as a practice that brings it into being. Another example comes from Gillis who acknowledges that there is both “the families we live with and the families we live by” (Gillis, 1996, p.xv), so an important side of family is the imagined aspect, as well as its reality. Like this work on the family, we should recognise the creativity and political desires about a different way of caring, represented across these drawings.

Also these different interpretations of the same question show the diversity of ideas contained within each family. They existed alongside one another so that the ways the family was bound together still provided space for different ways of seeing the world. One family contained multiple and maybe conflicting understandings of what it was to be that family. This shows the ways that its construction as a whole and as a private space contained contradictions but also enabled a freedom of thought, strongly emphasised by the use of visual methods.

8.4. Techniques of layering

This chapter argues for seeing knowledge in the family as layered because it is a useful device for accepting and working with the complexity of family knowledge. As well as pointing to layers such as the individual perspective on care within the collective and thematic layers of ideas about the potential of care to change, we can also explore the techniques that individuals used to create these distinctions. The example of Sapphire's family showed the multiplicity of perspectives and the ways that the family was networked by separate conversations that established different communities of knowledge and held them together. It is now an opportunity to look at other methods from across the five families that showed ways that the layers of knowledge were maintained.

8.4.1. Engaging and disengaging

A series of book recommendations was incorporated as a research method. This developed from an idea from one of the participants. Kaya, Alia's mother, suggested some books as recommended reading for providing context on the medical conditions and experience of autism that were relevant for understanding her family. This was developed by me into the idea of inviting all participants to share book recommendations that would contribute to understanding: their favourite book, on young carers, families or something else. The recommendations from the families are listed below:

Table 3 Book recommendations

Alia's family
Kaya • "Social Animal" by David Brooks • "Neurotribes" by Steve Silberman Alia • "Differently Normal" by Tammy Robinson (about young carers and about families) Amber • "A comic – Civil II" (about families and arguments)
XD's family
Tizzy • "Testament" by John Grisham XD • "Face" by Benjamin Zephaniah

Rosie’s family
Rosie • “The World’s Worst Children” by David Walliams Dominique • “The Diary of a Young Girl” by Anne Frank
Sapphire’s family
Luke • “My Autism” by Gloria Dura-Vila and Tamar Levi Sapphire • “Harry Potter and the Philosopher’s Stone” by J. K. Rowling • “Matilda” by Roald Dahl • “Clarice Bean” by Lauren Child • “Diary of a Wimpy Kid; Double Down” by Jeff Kinney • “Wonder” by R. J. Palacio
Aidan’s family
Marie • “Why Mummy Drinks” by Gill Sims • “A Boy Called ‘It’”; by David Pelzer • “The Lost Boy: A Foster Child’s Search for the Love of a Family;” by David Pelzer • “A Man Named Dave: A Story of Triumph and Forgiveness” by David Pelzer

Engaging with these books provided a way of learning about these families and individuals at a distance without relying on them to do so using their own time. It also suggested a pattern in the way that individuals spent time in leisure or learning (depending on how you characterise their relationships with these books), understood as a technique of engagement and disengagement with family life. Whilst inhabiting the same domestic space, family members can use books, alongside other methods, to temporarily deepen or loosen their connection to the family in that moment.

For some, books may provide a way of disengaging. For example, Rosie, Sapphire, Jane and Amber suggested literature that provides an escape from the everyday. However, others suggested books that explored identity. They reflected on that person and their family's relationship with a range of publics (Warner, 2005), or books that delved into ways of understanding a vexing family issue. Kaya, Marie, XD, Luke, and Poppy suggested books that showed their critical engagement with some of the problems of family, care, conflict and abuse. They drew on other voices or more distant groups to reflect on the circumstances that they were embedded in. Thus, books suggest the ways that family members seek solutions to the intensity of family care, gaining knowledge or escaping it through fiction.

8.4.2. Care work and the knowledge of layers

A second drawing exercise as part of the visual ethnographic element of this study explored directly the multiple perspectives of individual family members that were drawn together in the collective organised practice of care. It brought physical form to the idea of layers within families and can tell us about the techniques families used to work with those layers. The exercise developed into a standard format of each family being presented with a selection of themes, each symbolised by a picture printed in a square on a blank A4 page set out in a landscape format. I chose the themes specifically for each family based on commonly occurring or important activities conveyed in earlier conversations. They were also chosen because they related to multiple family members and were connected to the daily activities of care. The family members who wished to take part were asked to choose one of these themes for them to work with as a group and were then invited to draw their reaction to the theme using tracing paper, black fine liner pens and felt-tip pens in an array of colours. This process typically took approximately fifteen to thirty minutes.

The activity asked the family members to be engaged in a fragmented but collaborative conversation about care in their family life. It brought additional visibility to the performativity of family life and care (Butler, 1993). Then those elements were arranged in composite revealing some beautiful patterns, clashing arrangements, similarities and divergences.

Summarising the approaches from each family shows the varied ways that families worked with layers of knowledge about care. XD’s family and Rosie’s family show a fuller realisation of this idea. Aidan’s family drawing was different because it was introduced as a less structured exercise, without the prompt of the pre-selected themes. Marie rejected the suggested themes when they were verbally presented and instead advocated that the family draw something more positive than the daily labours of housework. Instead, they drew a trip to the beach. Alia's family drawing is also different but because of concerns that by presenting it as a composite it would reveal initials that might compromise confidentiality, each leaf is presented separately the other families' drawings.

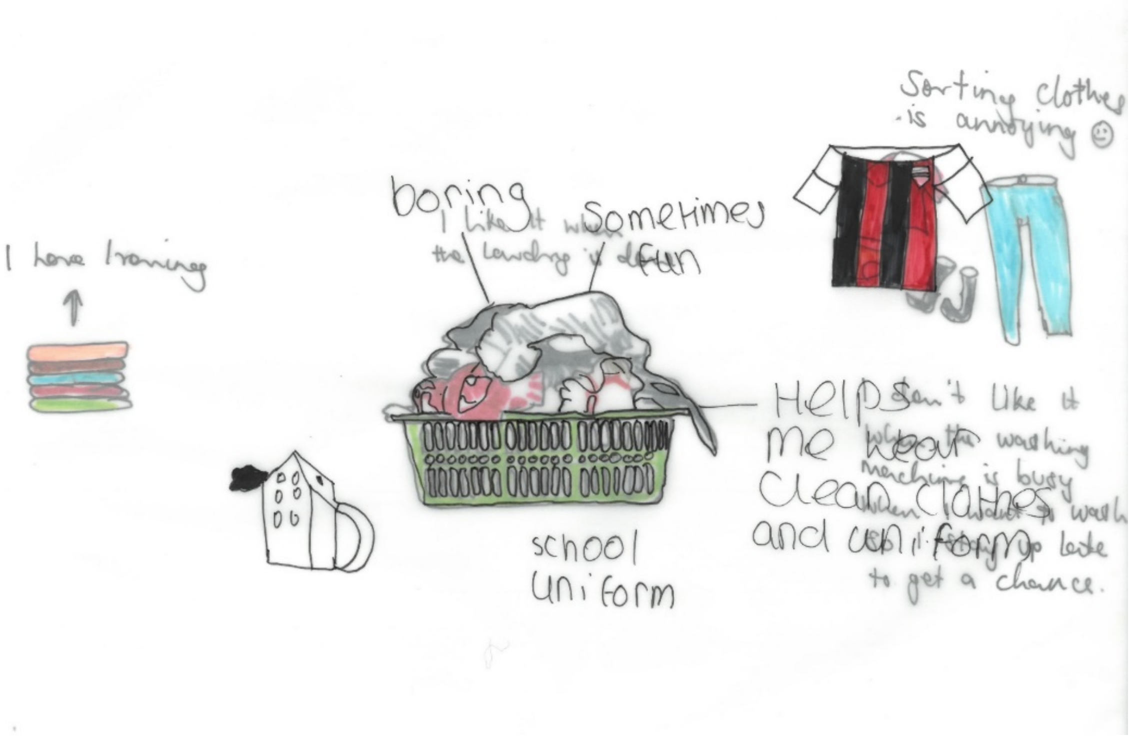


Figure 16 XD and his mother, Tizzy's, drawing on tracing paper in response to an image of a laundry basket.

Figure 17 Rosie and her mother, Dominique's, drawing on tracing paper in response to an image of a table set with plates, cups and cutlery. Rosie said and wrote on the page that she saw the image as a starting point for a drawing about using the table for painting, not meal times.

Figure 18 Aidan, Joey and Marie's drawings about their trip to the beach. Aidan and Marie used tracing paper but Joey chose to use opaque paper. The theme of the drawing was chosen by Marie to show a happy shared memory.

Figure 19 Amber's drawing on tracing paper of her family's batch cooking activity. The original had figures labelled with initials which have been removed.

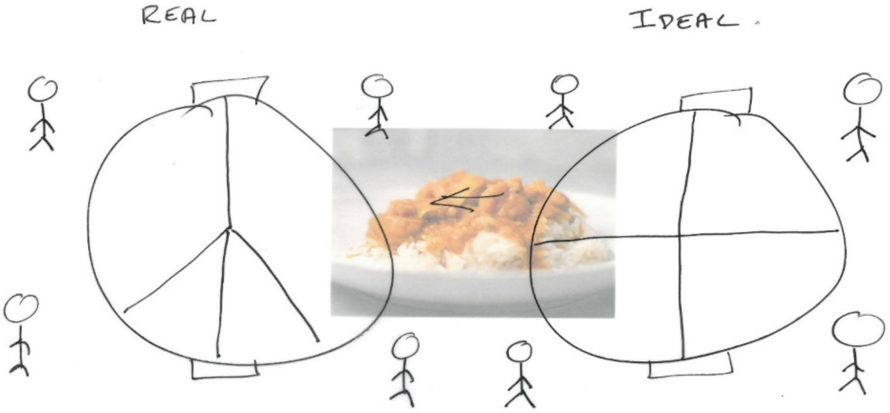


Figure 20 Ben's drawing on tracing paper of his family's batch cooking activity. The original had the figures labelled with initials which have been removed. His

drawing analysing the contribution of each family member (real) and it is contrasted with the balance he aspires to. In the representation of the real allocation of work, he and his elder daughter Amber are represented as carrying out a smaller share of work than his wife, Kaya, and his younger daughter, Alia.

Figure 21 Kaya's drawing of her family's batch cooking activity.

The families engaged with the activity in ways that convey a feeling of family and its layers in the way they worked comfortably with the drawing activity based on layers but also in the daily experience of negotiation which brought together multiple and irreconcilable perspectives. Conversations would contain overlapping voices, houses would have objects belonging to different owners obstructing one another around family rooms. The idea of layers reflects on the physicality of home, its sounds but also it as a container of knowledge, where differences coexist and evolve alongside each other. Together these drawings show some techniques of working with layers. Firstly, it needed time and patience for family members to work through the exercise, collaborate and share resources with each other. Secondly, it showed curiosity about and acceptance of their different ways of seeing the subject, which formed a basis for pursuing a collective activity for which the outcome was uncertain. These techniques of attention, patience, curiosity and acceptance were hinted at by Jane who said, “you should remember that everyone has a family. You have to listen to one another.” (Fieldnotes 24/10/18).

8.5. Conclusion

The analysis of layers of knowledge is the final element in the exposition of the theory of the public/private politics of care in this thesis. As well as contributing to a picture of family as a complex arena of knowledge, in which this care politics operates, it has some resonance for a discussion about practice and the implementation of policies. Sapphire considered the potential for the researcher who had learned so much about her family life to see her at the young carers group. In fieldnotes I recorded that “she said it would be fine. She said that she thought that it would be better because I knew what things are like at home. If she came in and was quiet I would know something about why.” (Fieldnotes 24/10/18). Families, operating through layers of knowledge, may welcome the application of this framework in organisations that formalise support for young carers because it might entail an appreciation of the complexity of family life and the necessity of exploring the rich understandings of care contained within it. From another perspective, Becky reflected on how families might look outwards from their struggles when there are services potentially offering help. Despite the complex ways they were handling the requirements of care, Becky said that families should realise that “if you need help, like we need help. In the past we have difficulties. Don’t get let down by the authorities, by the government. Get the help when you need it.” (Fieldnotes 24/10/18). Out of these layers families and services can speak to each other and potentially do so more meaningfully.

These layers are contained within families, which unite around the construction of a collective privacy in which the labels of social difference are nurtured. Families operate with contradictory forms of knowledge about care but these contradictions do not, therefore, have to be resolved. Instead this creates a great deal of breadth to the ways of understanding, held by each family member. These layers are confusing, can create a stasis and a stability. However, they also liberate family members from agreeing with one another, allowing different interpretations to co-exist and supporting a freedom for a range of understandings to cohabit. Public policies seeking to reach the families of young carers may be improved but are also limited in the extent to which they can capture or set any particular understanding which would form the basis for changing the organisation of care work and children’s roles in it. The repercussions of understanding the public/private politics of care for policies on young carers are a subject that will be discussed further in the concluding chapter.

9. Conclusion

In this conclusion I will draw the thesis to a close with a summary of the eight chapters and an overview of key findings and contributions. Following this review, I will summarise the policy implications of this work. I then reflect on the research process as methodological innovation and a personal experience of research, full of unexpected developments. Finally, I will outline the intentions for disseminating the outcome of this research process beyond the thesis and indicate some plans for future research.

9.1. Summary of the thesis

Chapter 1 introduced the thesis as a response to the question of what an ethnography of family life contributes to understandings of young carers. In addition to this overarching question, it addressed three sub-questions about the intellectual agenda, the methodology and the nature of policy impact uncovered through this study. The thesis uses methodological and theoretical innovation to understand the family life of young carers, which hitherto has been underexplored. It also pointed to a biographical side to the PhD, connected to an experience of work and a professional engagement with policy-making on young carers in the UK. I stated a personal commitment to unpacking the ways that inequalities are an unacknowledged feature of young carers' experience which have been inadequately researched as a required element of making a valid contribution to knowledge about family life.

Chapter 2 outlined the field of research on young carers, arguing that it has emphasised young people as individuals and made a valuable contribution by promoting their voices, but this has been alongside a neglect of their connection to family life. Furthermore, care should be understood with reference to the way it is situated and organised within families. In order to respond to the complex diversity of families, it was useful to draw together research on young carers and categories of social difference, although this chapter noted the limited amount of research that connects these strands or uses an intersectionality framework. The final section of this chapter surveyed work on the politics of care, which contributes to ideas about the politicisation of the home and the politicisation of care as a public issue. Drawing together these areas, I proposed that by working with critical theories of public and private we can extend theory in this area in a way that helps structure the study of young carers' family life. I outline a theory of the public/private politics of care to be developed and applied in the analysis of ethnographic data in this study.

Chapter 3 provided a detailed description of the methodology and methods employed in this study. Firstly, I argued that the use of ethnography as methodology was well suited to the sensitive exploration of private realms, in this case family homes. Secondly, I argued that the use of participant observation, visual methods and book recommendations aided the study of family life and family homes, providing a wide range of detailed perspectives. Thirdly, I set out a methodological response to the challenges of studying categories of social difference within an intersectionality framework, which were operationalised in the recruitment of participants, the methods of engaging in participant observation and the practice of reflexivity. Lastly, I drew together key ethical issues that were recognised and addressed through the study.

Chapter 4 introduced the five families who participated in the study. This chapter used my interpretation, built from nine months of participant observation. It described the families' care arrangements, as the collaboration of different family members with their own approaches to care. Each section noted key changes and continuities across the time spent with participants. This provided the background information that the analysis chapters built on to explain the picture of care organisation across families and explore the theory of the public/private politics of care through the ethnographic picture.

Chapter 5 is the first findings chapter, which argues that family members engaged in negotiation about care. This process is crucial for the organisation of care in families, which young carers participate in, but it also shows the importance of recognising the political nature of care in the home. Negotiation is given its contours by the ways that families interact with policies, as a factor in the local economy of care. The chapter begins with one case study from the ethnography, Aidan's family, to detail a family's experience of negotiation and then makes a wider claim about the importance of studying negotiation in order to unlock knowledge about care, young carers and family life. The chapter then goes on to explore negotiation as a component of family life, the participation of children, the way it is informed by the notion of young carers embedded in policies and the emotional side of negotiation. Lastly the chapter argues one of the impacts of policies on young carers is the way it features in negotiation about care. This attention to policies in the study of negotiation shows how the private realm of the home is a place to study interpersonal politics but, also a space that is connected to public ideas and regulations about children's care work.

Chapter 6 builds on the recognition of negotiation in family life as a facet of the public/private politics of care to consider the way that the separation of public and private is constructed by families. This is undertaken despite the way that the boundaries between the two are contested or blurred as argued in the preceding chapter. As an explanation of this process, I look to the ways that families informed me about their social location, formed at the intersection between ethnicity/'race', class, gender, religion, disability, nationality and age. This provides a way into comparing the different ways that families constructed a sense of privacy in contrast to public spaces. I focus on the intersections between ethnicity, 'race', class, migration and nationality to argue that subordinate and privileged positions affected the ways that families encountered the public world and their private-making response.

Chapter 7 extends the intersectional perspective to look at social location within the family. Individuals were socially located differently and I use the example of safety to analyse how gender, sexuality, age and disability were ideas that family members applied across relationships of childhood-parenthood and siblinghood. Whilst this looks into the families' detailed methods of interpreting one another, understanding difference and hierarchies of social location, it again finds that this process is undertaken in a way that draws on knowledge of the public world and the inequalities found there.

Chapter 8 adds a final element to the development of the theory of the public/private politics of care by sharing insights into the ways that families formed and shared knowledge about care. This chapter argues that these knowledge practices indicate one of the resources by which families accommodate inequalities and the divergent pressures produced by different social locations. It therefore emphasises the scope to act within families, in part by allowing and creatively responding to different perspectives and experiences of family members. I put forward a suggestion that the use of an ethnographic research design with a set of different methods is an important approach for accessing this complex world of knowledge within families, both for researchers and potentially for those working to support families that include young carers.

9.2. Keys findings and contributions

Here I highlight three key findings that have the potential to impact on the way we think about the academic topic of young carers and offer one key methodological point. This is followed by a summary of the theoretical contribution of the thesis.

9.2.1. Findings

Firstly, future research on young carers should proceed in recognition of the importance of family life to young carers. Family life provides rich insight into the daily practices of care that are fundamentally important for the definition of this group, but we can understand this more fully if care is put into the context of a family's organisational practices and emotional attachment. I would exhort qualitative researchers to design projects in ways that improve its receptiveness to the complexity of family life. It makes methodological requirements to consider relationships as well as individuals, to use methods that can support complex analysis and to give participants time to contribute knowledge about care, which is not static.

Secondly, I have found that intersecting inequalities have a powerful impact on the lives of young carers, so future research should see this as central to understanding the experience of children's care work. It should be taken on as a strand of research on children as carers that is in need of further development in order to understand this group. It is also an important area for future research if it is formulated with the intention of speaking to the policy-makers in a way that recognises the divergent and unequal experiences of this group, rather than relying on an inappropriately homogenous form of representation.

Thirdly, the study found that public policies are a presence in family life that shape and influence the processes of care. However, the presence of policies in family life does not reflect the intentions of English public policies on young carers, especially in terms of supporting children as young carers. There is little indication of a connection between policies and reductions in children's care work, while there was much more data showing ways that policies increased the demands for care within the family and cemented children's roles. This suggests that policies have a problematic role, and again, understanding the intersecting inequalities that impact on family life helps identify ways that policies, working through these inequalities, are burdening families with difficult and complex circumstances in which to care.

9.2.2. Methodology

In addition to the key findings, I have documented a methodologically innovative approach to research with young carers, chosen for its suitability for exploring the private realm, family life and intersecting categories of social difference. Ethnography has provided an insightful approach to studying young carers and family life in these five cases. The use of ethnography to study young carers does not appear to have been used elsewhere and the methodological literature does not seem to consider people’s book selections as a potential method, despite much to recommend it within an academic framework dominated by engagement with bodies of literature. This study has developed some new visual ethnographic methods which could be taken up by other researchers. The overall approach could be replicated for the further study of children’s care work, the local economy of care and policy impact, for example, to compare local constructions of the young carer role or to delve into studying particular groups of families.

9.2.3. Theory

Lastly, this thesis outlines a new theoretical approach, developed from close study of family life and young carers. The theory of the public/private politics of care has taken on knowledge from family homes and from examining the ways that policies made a presence in that environment. This theory is offered as an intervention into the field of research on young carers, which has overlooked the political side of care and the young carer category. It also aims to show the relevance of the topic of young carers to discussions in feminist theories of care and research on the political shaping of everyday life.

Based on this research I concur with others that research on young carers would benefit from theoretical development (Olsen, 1996, Aldridge, 2017, Joseph et al., 2019) and this thesis is intended as a contribution to remedying that problem. There are rich theoretical resources that we can draw on to critique or expand ways of thinking about young carers and in the case of this study I have drawn on Black Feminists' theorisation of social categories of difference as intersectional. However, arguments about the lack of theory in research on young carers have overlooked the potential for working within this topic as a site of theory development. I advocate recognition of the potential to develop theories through research with young carers and their families. Echoing Evans' (2019) argument about the way that Minority worlds are privileged by preferences for theorising on the basis of this favoured geography, the orientation in this thesis is towards seeing the lives of young carers and their families as theoretically rich, already full of creative and analytical process that researchers can work with. This encourages us to pay attention to more varied forms of knowledge amongst our participants, to work in a more empirically grounded way and to challenge any assumption of this group as marginal subjects whose lives are made relevant by connecting them to ideas based elsewhere.

9.3. Policy implications

The establishment of support for young carers, alongside research on this topic, has transformed domestic recognition of children’s care work in positive ways. Taking stock of this progress, and based on the findings of this study, I outline a series of points about policy at different levels. A shift in approach would mean this group are be served better by public services that recognise the intertwining of their circumstances with a range of social justice issues such as poverty, disability rights, racism, sexism and socio-economic inequality.

The research findings are significant for the ways we reflect on current policies focussed on young carers and on the ways that they are structured within local authority implementation mechanisms. In this section I summarise the implications for policy at local, national and international levels. This reconnects the study with intersectionality theory that exhorts researchers engaging in this approach to take seriously the political ramifications of their knowledge work (Bilge, 2013, Mirza, 2015, Konstantoni and Emejulu, 2017). In addition I anticipate that as the research is disseminated and is shared with people interested in this topic they may see other resonant issues, so that the research is owned and used by the communities it comes from (Butler, 1993).

9.3.1. Local

Local authorities in England play a crucial role in building institutions and systems that support young carers. This research highlights the importance of the local context in which young carers take on their role. Based on this research, I advocate considering the local economy of care as shaping children's care work and their family life. A series of prompts and questions for local authorities was shared at an event at the University of Birmingham as a starting point for local authorities or local support organisations interested in developing a perspective on young carers and their families informed by knowledge of the local economy of care. This was discussed by Solihull Carers Trust at the event in July 2019 and found to provide useful lines of questioning to build up insight into the local economy of care and its relevance to local service design (See Appendix J).

This thesis found significant impacts of inequalities of ethnicity/'race' and class, which affected children's access to support as young carers. The supportive quality of services was compromised by these persistent inequalities, with families disadvantaged and facing discrimination. Therefore, the implication for local services is that they should consider and address the lesser support that may be on offer to working class families and Black and Minority Ethnic families. This adds to existing calls for services to improve their support to this group made by Jones et al (2002). It would also be beneficial to consider that ways that improving the circumstances of young carers is dependent on wide efforts to confront inequalities of ‘race’, class and disability and promote social justice.

Existing services tend to focus on support and respite opportunities for young carers. The young people taking part in this study, reflecting on the possibility of a researcher with extensive knowledge of their private circumstances being present at future support sessions, welcomed this prospect. They were positive about the idea of services being better informed about their family circumstances. This would have consequences for the privacy of family members, particularly disabled parents and disabled siblings whose home life may be reported on, so it needs careful consideration. Nevertheless, services could explore ways for support sessions to be grounded in conversations about family life and increase the opportunities for young carers to discuss happy and troubling issues of family life.

9.3.2. National

The research, although locally based, speaks to national policy considerations. Four key points from the research have implications for the evaluation of current policies or suggest the potential for developments based on the evidence gathered here.

Firstly, this study shows that there is an urgent need for policies on young carers to be informed by a greater commitment to the position of the 'care recipient', rather than be limited by an exclusive focus on young carers. We should reignite the debate about the consequences of the young carer concept and its institutionalisation for disabled adults and children, taking into account the progress made on the realisation of disability rights but also the harms done by a decade of austerity. The current design of young carer provision is unfortunately limited by a reliance on viewing the child outside of their family and has not sufficiently engaged with the way their life and care role is shaped by an economy of care, with the person designated as receiving care as but one component in the potential to alter the position of that child. This could present an opportunity to broaden collective efforts to address a social reliance on children's care work, informed by the rights of children and of disabled people.

Secondly, based on this study I would add to the critiques of the 'young carers' label used in policies (Jones et al., 2002, Molyneaux et al., 2011, Evans and Becker, 2019). Critiques about its imposition across a system of support should continue to be made and to be considered nationally. It is still a problem that the idea of 'carer' imposes a role of need and care-reliance on disabled children and adults, in conflict with their right to live without being defined for the benefits of others. Recognising children's substantial and valued care work can develop in recognition of their simultaneous reliance on others' care for them. Freeing up the labelling of children's care work will improve the prospects of adding valid and practical knowledge about care in the context of intersecting inequalities.

Thirdly, the Whole Family Approach that guides the current ideal of support nationally is worth revisiting. ‘Whole family’ should be an aim in terms of experience rather than service organisation. The emphasis in policy efforts has been to translate the idea of whole-family into an institutional design rather than an outcome. Based on the experiences of my participants this approach is not realised in a way that benefits young carers. To start addressing this we need better information about the existing experience of policies for families and set up responses from services that would improve those experiences. When improving information about families with young carers, this study has shown the value of pluralistic qualitative methods for information gathering which could move into the realm of practice. In particular, I would support the continued and expanded use of visual methods of information gathering and engagement. Another message is that should practitioners not set the expectation that working with families will result in easily simplified information. Producing information on families not defined by coherence or consensus may signal its quality, rather than being unfinished.

Lastly, the role of young carers is related to the way that families see the need of children and adults to be supported. Prominent ideas about disability, gender, sexuality and age encourage needs to be heavily stated, whilst other family members are seen as more independent of support. This means that the fates of children inhabiting young carer roles are intertwined with existing and future prejudices about disability, gender, sexuality and age. Efforts to explore these prejudices in the general population and in family cultures and challenge discriminatory attitudes could unpick some of the basis on which children are required to be involved in care work. The campaigning work of disability advocates, feminist campaigners and LGBTQ+ advocates to challenge those attitudes could lead to a shift in the family negotiations about care. This should be recognised by those seeking to influence policy at a national level and those making policy decisions in government and public sector organisations.

9.3.3. International

As young carer research is circulated internationally amongst academic communities and policy-makers, the most influential interpretations of this topic are dominated by Minority World conceptualisations of young carers (Evans and Becker, 2019). Even these have not yet adequately been informed by the depth of listening required to take into consideration the experiences of more marginalised young carers in these locations, which are fundamentally shaped by poverty and inequalities. Therefore, international policy work on this topic should take into consideration the critical gaps in knowledge on young carers in the Minority World and its limitations as a template for approaches elsewhere.

9.4. Dissemination and plans for future research

The fieldwork, analysis and writing has been followed by activities and plans for taking the research further. I see this as an important responsibility to make the greatest use of the data that families created with me. In the dissemination process power differentials and issues of privacy continue to be relevant and require careful attention in order to share the opportunities for engagement and for research to promote a range of voices (Evans, 2016).

I intend to share information from this thesis with academic audiences. I have already shared findings and theoretical developments at conferences (see Appendix K) and I will explore options for creating a monograph based on this thesis. I am also planning to draft journal articles. Some key elements of the thesis that I am keen to disseminate to academic audiences are: layers of family knowledge, intersectionality and young carers, the public/private politics of care theory and ethnographic methodologies for studying family life and care.

Directly following the completion of the thesis, I have planned a series of activities to share this information in different formats. I will produce a briefing aimed at families with young carers. This will be sent to the families that took part (who gave their permission to received follow-up information) but will also be made available for other families who may be in similar circumstances if they are interested in the research. This would hopefully be circulated via young carers organisations and other groups whose experiences are touched up by this research. I will produce a separate briefing aimed at local and national organisations working on this topic, for example, carer organisations and disability rights organisations. I will also organise a community event, which will build on an event already held in July that shared early findings with social workers and local authorities in the West Midlands. The community event will be an opportunity for participants, local organisations and people interested in this topic to discuss this research and explore its applicability to their own lives. These resources will make the thesis findings more accessible, but they are also intended to created opportunities for me to learn more about this topic because I will find out how others respond to the information and the potential they see in it.

This research has been undertaken in recognition of some important gaps in understanding young carers and a recognition of the urgency of addressing lack of knowledge about the intersectionality of their experiences and their family life. Whilst it has attempted to answer a research question, this also opens up subsequent questions that I am keen to respond to in future work. Some outstanding questions are about the way that the local economy of care has shaped young carers' role and the care needs in families. This study explores one example but there is a lack of comparable studies that would facilitate an exploration of the distinctive local experiences of young carers. Therefore, I would be interested in developing comparable studies applying this methodology to other areas so that I could provide insights into the way a local economy of care shapes the role of young carers and socially constructs disability. A second interest is to consider how the varied interpretations of children's care work, its contestation and negotiation could stimulate discussion about new public representations of children's care work. One way to pursue this is to use ethnographic and participatory methods to work with young carers on alternative histories and representations of children's care work.

9.5. Reflections on the research process

The choice of topic and methodology for my thesis have pushed me into a very reflective state of mind but here I will just note a selection of key observations on the study to draw it to a close.

Firstly, I hope that this thesis celebrates the potential of ethnographic research to capture the imagination of the researcher and hopefully an audience too. This is challenging and it posed extensive demands on my participants and on me. It is a methodology that is highly relevant to this topic and I hope its use here might encourage others to engage with and apply it to knowledge creation on children's care work, family life and policy presence. However, I wish to stress the limitations inherent in this approach and in my abilities as a researcher because of my positionality. My background prepares me to pick up information easily about some people's lives, whereas for others I am more likely to miss the nuances of the experiences people shared with me. This makes it all the more important that part of the subsequent work following this thesis is to engage others in the wider project of building an intersectional picture of young carers’ lives.

As a final word I wish to reiterate the political and politicised nature of young carers lives, both in the ways they are reached by policies embedded in political processes but also, should we choose to recognise it, in the interactions of family life. Recognising this facet of the lives of young carers indicates the value in engaging in further interdisciplinary spaces in which we can enrich the knowledge of the public/private politics of care.

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Appendices

Appendix A- Partnership agreement with Carers Trust

School of Social Policy

University of Birmingham

COLLABORATIVE PARTNER RECORD

PhD Researcher	**Chloe Alexander**, Doctoral Researcher, Department of Social Policy and Social Work c.j.l.alexander@pgr.bham.ac.uk	
PhD Research: Title	An intersectional study of young carers in England	
Supervisors	**Prof Saul Becker**, Pro-Vice Chancellor and Head of the College of Social Sciences S.Becker@bham.ac.uk **Dr Harriet Clarke**, Senior Lecturer, Department of Social Policy and Social Work h.clarke@bham.ac.uk	
PhD Research: Summary	The research will explore the experiences of young carers and how these are shaped by aspects of inequality such as gender, ethnicity and socio-economic status.	
Name of Collaborative Partner	Carers Trust	
Contact Details at Partner Organisation	Anna Morris, Senior Policy Manager [redacted]	
Nature of Collaboration (Please include details of the link and benefits of the student's research to the collaboration. Please also advise if the student will be expected to spend time at the collaborative institution during their registration)	• Collaborate to assist in the identification of research participants through the Carers Trust network of services • A named contact within Carers Trust will maintain links with the research • Assist in dissemination of research outputs.	
Collaborative Co-Supervisor?	N	If Yes, co-supervisors must be approved by the University.
Is the Collaborative Partner providing additional finance?	N	If Yes, a contact must be agreed confirming this.
Anticipated outcomes, including benefits/impacts	• Information shared with Carers Trust can inform services working with young carers in the UK	

for collaborating organisation and student, and wider intellectual and public/commercial outcomes	• The research findings can inform engagement with policy-makers and other campaigners • Research findings can be shared with young carers and young adult carers in an accessible format. • Student will have a good channel for recruiting participants and checking in about the policy-relevance of the research.
Does the proposed collaborative research raise particular ethical issues and/or intellectual property issues and if so, how is it proposed that these should be resolved?	Additional consideration will be needed to ensure that young carers or staff at Carers Trust network services are aware that they are under no obligation to take part in the research or to give their consent. This will be addressed through the University of Birmingham ethics process. Information derived from the research project will acknowledge Chloe Alexander as the author.
Is it anticipated that any restrictions will be placed on public access to the thesis and/or publications or other outputs arising from it as a result of the collaboration and, if so, what will these be?	No
Describe briefly the types of activities the student is likely to be engaged in during the period of placement or internship in the collaborating organisation (Max. 300 words) *(If applicable)*	• Annual meetings between Chloe Alexander, the academic supervisor and the Carers Trust named contact, • An annual short report about progress to inform members of the policy and research directorate • A briefing about implications of the findings for policy on young carers • A briefing about how the findings can inform services that work with young carers • A briefing about the findings in a format accessible to young carers and young adult carers • Inviting the researcher to relevant Carers Trust or third party events

Appendix B- Ethical approval for the research

Dear Dr Harriet Clarke

Re: "An Ethnography of Intersectionality in the Family Life of Young Carers" Application for Ethical Review ERN_17-1247

Thank you for your application for ethical review for the above project, which was reviewed by the Humanities and Social Sciences Ethical Review Committee.

On behalf of the Committee, I confirm that this study now has full ethical approval.

I would like to remind you that any substantive changes to the nature of the study as described in the Application for Ethical Review, and/or any adverse events occurring during the study should be promptly bought to the Committee's attention by the Principal Investigator and may necessitate further ethical review.

Please also ensure that the relevant requirements within the University's Code of Practice for Research and the information and guidance provided on the University's ethics webpages(available at https://intranet.birmingham.ac.uk/finance/accounting/Research-Support-Group/Research-Ethics/Links-and-Resources.aspx) are adhered to and referred to in any future applications for ethical review. It is now a requirement on the revised application form (https://intranet.birmingham.ac.uk/finance/accounting/Research-Support-Group/Research-Ethics/Ethical-Review-Forms.aspx) to confirm that this guidance has been consulted and is understood, and that it has been taken into account when completing your application for ethical review.

Please be aware that whilst Health and Safety (H&S) issues may be considered during the ethical review process, you are still required to follow the University's guidance on H&S and to ensure that H&S risk assessments have been carried out as appropriate. For further information about this, please contact your School H&S representative or the University's H&S Unit at healthandsafety@contacts.bham.ac.uk.

Kind regards

Susan Cottam
Research Ethics Officer
Research Support Group
C Block Dome
Aston Webb Building
University of Birmingham
Edgbaston B15 2TT
Tel: 0121 414 8825
Email: s.l.cottam@bham.ac.uk
Web: https://intranet.birmingham.ac.uk/finance/RSS/Research-Support-Group/Research-Ethics/index.aspx

Appendix C- Information for young carers projects about the research

Information for Young Carers Services

- The Young Carers' Family Life research project –

What is the research project?

This research project is about understanding family life in families that include a young carer. There is very little research about the family life of young carers, their parents, siblings and other relatives. This is a worrying gap in research knowledge because when we talk about young carers we are often trying to represent events and experiences related to the home environment. It is useful for us to understand the family environment better when most of the care that children and young people do is happening there. Many councils and voluntary sector services are already trying to engage with young carers and their families at home, and may benefit from knowing what research can tell us about family life.

This research project will take place in collaboration with a small number of families in the West Midlands region. Half a dozen families will be asked to take part, giving their permission for the researcher to spend time with them, making multiple visits for up to one year. The aim is to get to know the families, understand the different experiences they have at home and how family members care for one another.

The motivation for this research project is an interest in how disability and care feature in family life. Another area of interest is in how categories such as gender, ethnicity, age, class and sexuality play a role in the family lives of young carers and whether these categories might help us understand what care means to different people. The research may be able to help inform local services, policy-makers and people with personal experiences of care and disability.

Why are you being provided with information about the project?

As a voluntary sector organisation that supports young carers, you are being asked to pass on information to families so that they can decide whether they want to participate in the research. The researcher will ask for the relevant staff at the organisation to contact specific families with some information for them to consider. Your staff will be provided with copies of leaflets that explain the research project to young carers and their families. The leaflets will include contact details for the researcher and her supervisors.

After passing on information, the involvement of your organisation will cease. The rest of the process will be managed by the researcher and there will not be a need for your organisation's involvement. However, you may be interested in the results of the research. At the end of the research, which is expected to finish in 2019, you can receive a report with a summary of findings. This report will not include information that identifies the families involved.

Who is involved in the project so far?

This research project has been set up by Chloe Alexander, a PhD student at the University of Birmingham. The research is based in the Department of Social Policy, Sociology and Criminology.

Chloe's background is in working with young carers and young adult carers to influence national policies. She has worked with young carers and young adult carers to set up campaigns on changing UCAS forms and improving mental health services for young carers. She has recently been volunteering with a number of young carers services in the West Midlands.

There are three academics advising and overseeing the research project:

- Dr Harriet Clarke, Senior Lecturer, Social Policy and Social Research (h.clarke@bham.ac.uk, 0121 415 8479)
- Dr Nicki Ward, Lecturer in Social Work (n.j.ward@bham.ac.uk, 0121 414 5713)
- Dr Kayleigh Garthwaite, Birmingham Fellow (k.garthwaite@bham.ac.uk, [redacted])

Alongside these three academic supervisors, Professor Saul Becker is an advisor to the project.

Carers Trust have stated their support for the project and they encourage local young carers projects to be involved.

Will the research be done in a way that is safe and ethical?

It is the responsibility of the researcher, the academic supervisors and the University of Birmingham to make sure that the research is done in a way that is safe and ethical. The research can only begin once it has the approval of the University of Birmingham Ethics Committee. The University of Birmingham ethics review process has not yet been completed but the project has been allocated a reference number (ERN_17-1247) and you will be updated when this process is complete.

The research will involve spending time with families in their homes and there will be procedures in place to make sure people are safe. The researcher has had an enhanced DBS check for work with children and adults.

The research visits will be arranged to fit around the families and the aim is not to inconvenience people or intrude on their privacy.

Before the research starts, families will receive detailed information, which the researcher will talk through with them, so they know what the research will involve before they agree to take part.

The families involved in the research can stop their participation in the research project at any time while it is running and do not have to give a reason. This will be made clear at the start of the research and again during the process.

Next steps

Please contact Chloe Alexander to let her know whether your organisation is able to assist with contacting families and inviting them to get involved. If your organisation is happy to be involved, your staff will be asked to assist with contacting two or three families, who will be identified by the researcher.

You are very welcome to send questions or request for extra information about the research.

Contact details

Chloe Alexander

PhD researcher

University of Birmingham

Email: c.j.l.alexander@pgr.bham.ac.uk

Mobile: [redacted]

Appendix D- Letter to potential participants

Do people understand the family life of young carers?

Hello,

I am student researcher. I think that most people don’t understand very much about the family life of young carers and I want to change that.

I am planning to do research about what it is like when young carers are at home and how family members care for each other.

Are you a young carer? Or are you a parent of a young carer?

If yes, then I would like to talk to you about how you and your family could be part of the project. You can help because you know what family life is like for you.

If you are happy to spend some time talking to me about this then ask someone from the young carers service to pass your contact details onto me. I will get in touch to arrange to meet you and tell you about the research so you can decide if you want to be involved.

If you prefer you can contact me directly using my details below.

Thank you,

Chloe Alexander

PhD student

University of Birmingham

c.j.l.alexander@pgr.bham.ac.uk

07821 801099

Supervising academic at the University of Birmingham: Dr Harriet Clarke (h.clarke@bham.ac.uk)

University of Birmingham Ethical Review reference number: ERN_17-1247

Appendix E- Information leaflet

Information about the person doing the research

Hello,

I am a PhD student at the University of Birmingham.

My aim is to do research that adds to what we know and that is meaningful for people who get involved. The subject that I am most interested in is young carers and family life. With the help of a few families I hope to do research that gives people a new understanding of how families care for one another.

If you are part of a family that includes a young carer or if you are a young carer yourself then I would really appreciate you considering getting involved. Let me know if you are interested. I can tell you more about what is planned and how you could take part.

Thank you!

Chloe

Email: c.j.l.alexander@pgr.bham.ac.uk

Mobile number: 07821 801099

University of Birmingham Ethical Review reference number: ERN_17-1247

UNIVERSITY OF BIRMINGHAM

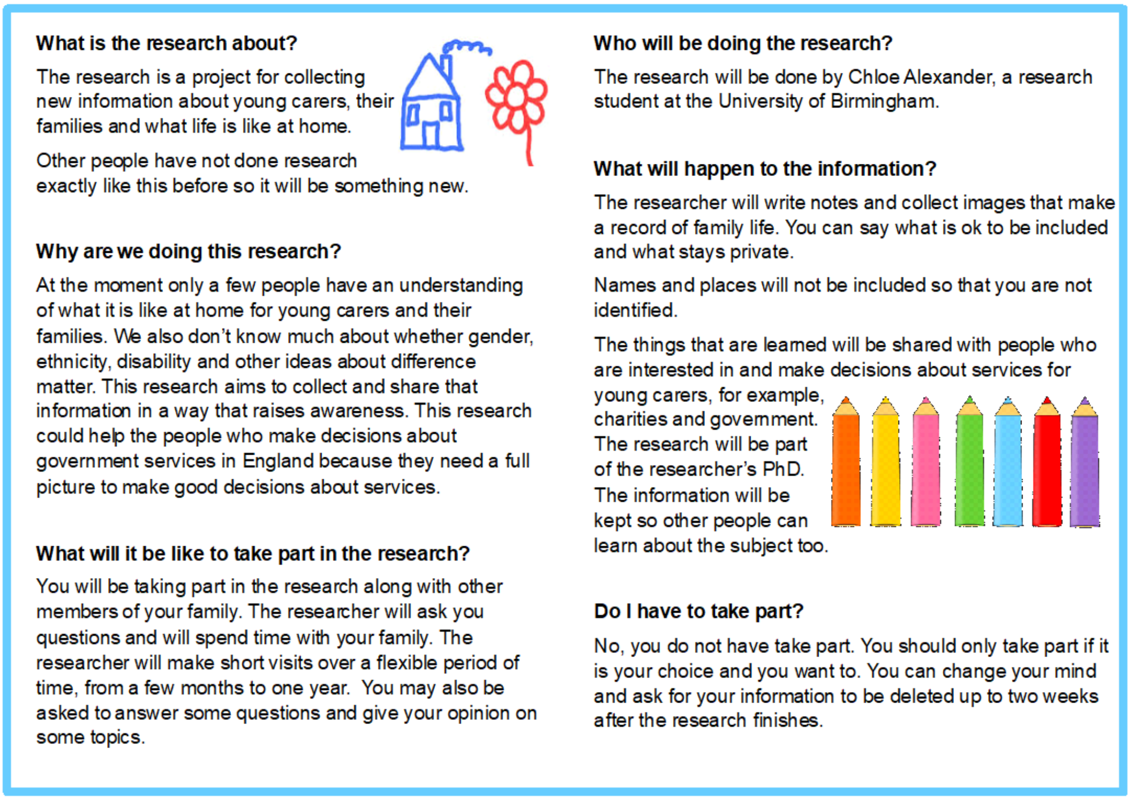
Research on young carers and family life

This research is looking at what it is like at home for young carers and their families.

What do people know about the family life of young carers?

Most people don't know much. Lots of care happens at home so it is an important topic. So far, it is missing from the research on young carers.

With your help we can create research that tells the story of young carers' family life.



What is the research about?

The research is a project for collecting new information about young carers, their families and what life is like at home.

Other people have not done research exactly like this before so it will be something new.

Why are we doing this research?

At the moment only a few people have an understanding of what it is like at home for young carers and their families. We also don't know much about whether gender, ethnicity, disability and other ideas about difference matter. This research aims to collect and share that information in a way that raises awareness. This research could help the people who make decisions about government services in England because they need a full picture to make good decisions about services.

What will it be like to take part in the research?

You will be taking part in the research along with other members of your family. The researcher will ask you questions and will spend time with your family. The researcher will make short visits over a flexible period of time, from a few months to one year. You may also be asked to answer some questions and give your opinion on some topics.

Who will be doing the research?

The research will be done by Chloe Alexander, a research student at the University of Birmingham.

What will happen to the information?

The researcher will write notes and collect images that make a record of family life. You can say what is ok to be included and what stays private.

Names and places will not be included so that you are not identified.

The things that are learned will be shared with people who are interested in and make decisions about services for young carers, for example, charities and government. The research will be part of the researcher's PhD. The information will be kept so other people can learn about the subject too.

Do I have to take part?

No, you do not have take part. You should only take part if it is your choice and you want to. You can change your mind and ask for your information to be deleted up to two weeks after the research finishes.

Appendix F- Information and consent form

Information about the research

To start with

There is a lot of information here. Don't worry if it looks like a lot. You don't have to read it yourself. The researcher can talk it all through with you.

There is lots of writing here is because there are many things that the researchers are excited to tell you about the research plans. The purpose of the information sheet is to explain the plans. That way you can have a good understanding before you make a decision about whether to be involved.

There are also some more serious bits that the University of Birmingham says we must tell you. They want to make sure that we don't just get started before talking it all through.

The information is meant to be helpful. It is here to help you make a choice based on knowing all about the research. It should be something that most people can read, whether you are age 9 or 90 but if there is anything that you do not understand, then please ask me.

Sorry this information sheet has so many pages!

This information is written by Chloe Alexander on 22nd February 2018.

The exciting stuff!

What is it all about?

Why are we doing research?

The reason that I am doing this research is to find out about the family life of young carers. No one has done research on this before so young carers and their family have not had a good chance to share information about this part of their life. People are interested in understanding it better because it is an important subject. I think that different people will be interested. Those people might be other researchers, government officials who decide on services, politicians, people who run local services and other people too. That is why I am asking you to get involved. You will be one of a small number of families taking part in the research. It is really interesting to hear from adults and children in the same family.

I hope that this research will make a positive difference by helping people understand more about families that include a young carer. I hope it will be a positive experience for the people who are part of the research.

What will happen during the research?

The biggest part of this research is that I will be listening to people and seeing some of their family life. I will also be having conversations with you and asking you to create drawings. As the researcher I will write down things that I hear, see and learn so that there are lots of notes. Parts of that record will be shared to help other people understand too.

In the process of writing it down and collecting images this will become research data. What happens to the data is explained later in this information sheet.

This will continue for up to 12 months, so 1 year.

It is a type of research called ethnography. It may be a type of research that you have not heard about. You are welcome to ask lots of questions about it.

The first time we meet will be to discuss this information and for you to say if you want to be involved or not.

If you want to be involved then we will meet for a second time to agree how the research will happen. That will be a joint decision between me, the researcher, and the people who are getting involved from your family.

Why you have been asked to be involved

You have been asked to be involved because you are part of a family that includes a young carer. You have been approached because the research study has links with the local young carers service.

You know so much about your family life so you are an important person to be part of this research. You can share that information to help other people understand better. You may help people to be more aware, to change what they think or help them to know something outside their own experiences.

You do not have to say ‘yes’ to being involved. You can say ‘no’ if you do not want to be involved. You do not have to be part of the research and you have the choice not to take part. You should decide what is right for you. No one will mind or do anything if you say ‘no, I don’t want to be involved’.

Your role in the research

To be involved you need to agree to the researcher spending some time with you and your family in a way that you are comfortable with. By doing this you will help the researcher understand some of your life by seeing what happens, hearing conversations and talking to you.

You may spend some time with me to create a drawing or collage that explain how care happens in your family. This will mean the data includes words, pictures and numbers.

I will agree with you at the start of the research how we can arrange to spend time together, in what places, for how long and during what times.

You may also be asked if you would like to have a separate interview where you talk in more details about a particular subject. You can say yes or no to being interviewed. If you are interviewed you will be asked if it is ok for a voice recorder to be used to help make a record of your words.

How much of your time will it take?

If you are involved in the research you will be asked to allow the researcher to visit you and this will take some time. It will help the research if we agree that I can make lots of visits so that I can get to know you, get to know your family and can understand the things you do to care for each other. I expect that there will be a lot for me to learn, which is why I have asked for you to consider setting times for repeated visits. These visits will be spread out over weeks and months so that it should not feel like it takes a lot of time at once. Also with the visits spread out it will help the research because I can get to know you over time. The number of visits and the amount of time for a visit will be up to you. To give you an example, we might agree 15 visits to your house, roughly every week, with some short visits and some longer visits. When the visits are happening you will be asked to carry on like normal and not let the research get in your way. This is just an example, so we can discuss what you would like. The plan for visits can change as we learn what works for you.

The end of the research

The research is expected to last for up to 12 months. It can be for a shorter period of time if that is better for you, for example 4 months, 6 months or 9 months.

I will talk to you about how to decide when to finish the research.

When the research is finished I will be working on my ideas for how to tell people what I have learned. This will include writing information to share with other researchers and other people who have an interest in young carers and their families. At the end of the research I will give you written information that tells you what I found out when I was doing the research. I can also talk to you about what I learned on the phone or in person.

During the research some information may be shared online or in documents so people can learn about the subject of young carers. This information will not use the names of people involved.

The serious stuff!

The data and what the data will be used for

Data are what a researcher is making when they are doing research. It is the record of what we have found. It can include words, numbers and pictures.

In this research the data will be used to understand more about the family life of people whose families include a young carer.

Data will be shared with other people by:

- using quotations that show what people said
- numbers that count how often things happened and give information about the people that took part, for example their age
- descriptions by the researcher of what happened, people's emotions and reactions
- drawings and images that were created during the research
- records of what the researcher thought about and wrote down
- documents that show how you and the researcher agreed to work together

The data will be shared in different ways that include:

- being published in the journals, books and blogs read by other researchers and academics
- being included in presentations and teaching
- being shared on the internet (blogs, twitter and other sites) so that people can understand more about the research
- being shared with the media to improve understanding of the lives of young carers and their families
- being shared with politicians and the officials that make decisions about services related to young carers and their families

Who will know about your information?

Information from the research will be shared with lots of people but we do not want everyone to know exactly who you are. Your name will not be used when the data is shared, written about or talked about. I will not use details that would identify you, for example, the name of your street. This is so that people do not know who the information comes from. There should only be a few people who can link the information to you. They are:

- The researcher
- You
- Your family and other people in your life who know you are taking part in the research
- The researcher's supervisors at the University of Birmingham
- The service who shared your contact details

The researcher may share the name of the young carers services that helped the research but will not give details about the individuals and families that were involved.

The information that is collected will be used sensitively. If something is sensitive I may check with you about whether you are ok with the record that I have.

You do not have to share everything. It is your choice to keep some things private.

When information might be shared including your name

The researcher may share information if it seems that someone is in danger. This applies to both children and adults. If someone is in danger then names, contact details and other information may be shared with a person who works for an organisation who is responsible for 'safeguarding' (keeping children and adults safe). That may be someone in the local council and/or someone at the University of Birmingham. If someone is in urgent danger, information may be shared with the police.

If this is going to happen the researcher will try to tell you in advance.

Your data when the research has finished

The data may be looked at again by the same researcher and other researchers in the future to understand it in new ways. This will be because people are interested in learning from your life and understanding more about young carers or other topics. The data may be shared again to tell people more about what the research teaches us. The research data will be kept in a secure University of Birmingham archive. It will be kept by the University of Birmingham for at least 10 years but possibly longer if people need to see it and keep a copy. The University will store it electronically, using a 'cloud' storage system and also physical storage to make sure it is safe and will not get lost.

A copy may also be kept by me using secure storage.

This will be kept for as long as it is needed for research.

In the future the researcher may wish to talk to you again. This would be because I would like to find out more about your experiences, what has happened since the research finished and what has changed over time. I would use the record of your contact details to ask you if you want to be involved in more research. You could say yes or no; it would be up to you. If you agree that I can contact you again for future research, I will keep a record of your contact details.

I will also ask you for your permission to contact you again to tell you about what I have done with the research data and any updates relating to the study.

Who is carrying out the research?

The research is being carried out by Chloe Alexander, a PhD student at the University of Birmingham (in the School of Social Policy).

The supervisors, who gives advice about doing the research, are Dr Harriet Clarke, Dr Kayleigh Garthwaite and Dr Nicki Ward at the University of Birmingham.

The research plans have been checked by the University of Birmingham Ethical Review Committee. They have said the plans are ok and have given the project a reference number (ERN_17-1247).

Who is paying for it?

The research is paid for by the School of Social Policy at the University of Birmingham. The research has a small budget that pays for the researcher’s time.

You will not be paid for being part of the research.

The intention is that you should not face any extra costs because you are taking part in the research.

Withdrawing from the research

You can withdraw from the research at any time when data is being collected. This means you can decide not to be involved anymore. You can have the information that you have given deleted. You can ask for this at any time up to two weeks after the end of the data collection period.

Once the research has finished you can ask for some things to be taken out of the research but it may not be possible.

Even more serious stuff!

Possible harm or discomfort

The research is not meant to cause you any harm or make you feel uncomfortable. However, there may be times that you feel that you need to protect your privacy by changing the research plan. Or you may find that the research makes you feel bad. Please talk to me, Chloe, about this. It is very important that this research does not cause you any harm or make you uncomfortable so I will want to listen to you about this.

If you feel negative emotions about the research you may want to talk to someone to get support. You could talk to any professionals that you work with, so maybe the young carers service. You may be given some information by the researcher about services that could help.

Complaints

If you think that something has been done during the research which is wrong you can make a complaint. You could make a complaint to the person doing the research- Chloe Alexander (email: c.j.l.alexander@pgr.bham.ac.uk).

You can make a complaint to the research supervisor who checks the research is going ok. The supervisor is Dr Harriet Clarke (email: h.clarke@bham.ac.uk).

Another way you can talk about problems with the research is making a complaint to the University of Birmingham by contacting the Governance Office using this email address: researchgovernance@contacts.bham.ac.uk

Your decision!

Do you agree to be part of the study?

If you now feel you know enough about the study and want to take part, you can agree to be involved. The phrase used is “informed consent”. This means that you agree and you have all the information you need to make that decision.

At the end of this form you will be asked to sign your name to show that you agree. If you are aged 17 or younger your parent/guardian/carer will also be asked to sign to show that they agree that you can take part.

It is your choice if you want to be involved and no one will mind if you say no. It is also something that your family should be happy about together.

If you have any questions or anything that you want as part of this record we can add it here

____

Do you agree with the following points?

	Please add your initials
I have read and understood the information sheet, and have been able to ask questions about the research.	
I understand that my participation is my choice and that I am free to withdraw at any time until two weeks after data collection finishes.	
I understand that: • The research involves observation of my home, family interactions and situations outside of the home. • The research involves interviews and informal discussions between the researcher and participants. • The researcher will make notes of what has been seen, heard and discussed. • The researcher may collect pictures, drawings and documents with my permission.	
I agree for the researcher to use an audio recording device.	
I agree for data to be created, stored and archived as described in this information sheet.	
I agree that the researcher may contact me again in the future to share updates.	
I agree that the researcher may contact me again in the future to discuss possible future research. If you do not want to be involved in future research DO NOT add your initials here >	
I understand that the research findings may be made available in the ways documented in this information sheet.	

Sign to show that you give informed consent to being involved

I give my informed consent to be involved in the research as described here.

Your name:

Your signature:

Date:

If you are aged 17 or younger then a parent/carer should also give their consent here:

I agree to my child's involvement in the research as described here

Your parent/guardian/carer's name:

Your parent/guardian/carer's signature:

Date:

Researcher name: Chloe Alexander

Researcher signature:

Date:

Appendix G- Family research plan

Date:

Family research plan

1. What do the family think should be part of the observations?
2. What do the family think should not be part of the observation?
3. What are good times to do observations?
4. What are bad times to do observations?
5. How will we discuss changes to this plan?
6. When should Chloe next arrange to be there? And a follow up meeting?
7. Any comments on how to decide when the research will finish?
8. Who was involved in this discussion?
9. Who was not involved in this discussion?

For each person list any points about what should and should not be included in observations:

Person	Notes

Any agreed actions:

Appendix H- Book recommendation form

A book

Your name

What book should I read for my research project?

It could be a book that is:

- Your favourite
- About young carers
- About families
- About something else

Your ideas will help me do a better research project.

Appendix I- Visual data use consent form

Your drawings for the research project

Thank you for creating fantastic drawings as part of my research project. I think that your drawings can help other people to get excited about the project and look at things a new way.

I want to check that you are ok with me using them in a few different ways. This adds to the discussion we had at the start of the project where we talked about how I will collect data.

Do you agree that it is ok to:	**If you add you initials here you are showing that you give permission.**
Keep your drawings as physical copies and scanned versions as digital copies, including using cloud storage?	
Write about your drawings and use them as research data?	
Change or edit your drawings? This might include removing details that would tell people who you are or focussing on one part.	
Reproduce and publish the drawings in any format, including books, journals and blogs? This may be printed or online.	
Not give your name as the creator of the drawings because I want to protect your privacy?	

Your name: …………………………………………………………..

Your signature:……………………………………………………….

The date:……………………………………………………………..

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If you are aged 17 or younger, a parent/carer will also need to sign

Parent/carer name:…………………………………………………..

Parent/carer signature:……………………………………………….

\- - - - - - - - - - - - -

Researcher name:……………………………………………………

Researcher signature:……………………………………………….

Appendix J- Handout from the Department of Social Work Seminar

Young carers and family life: a West Midlands perspective

Thursday 4th July 2019, University of Birmingham

Chloe Alexander, PhD Student, School of Social Policy, University of Birmingham

Presenting new research on the family life of young carers and putting that into the context of the economy of care.

Email: c.j.l.alexander@pgr.bham.ac.uk

Twitter: @chloealexander0

Gina Ward, Young Carers Team Manager and Deputy CEO, Carers Trust Solihull

Presenting a local picture of young carers and services in Solihull.

Email: [redacted]

Twitter: @carerssolihull

Putting families and young carers into the economy of care picture[2]

Item	Key questions	Aim

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[2] The economy of care includes paid and unpaid care work, as well as the work taking place through formal structures and informally. To understand it we should think about the scale of care work, its distribution across the population, its value, its financing and the way it is regulated (Connelly, Dong, Jacobsen and Zhao, 2018)

Improving information about young carers, their families and the local economy of care	Do we understand how young carers fit the local economy of care? Do we ask open questions about what has a negative and positive impact on people's experience of providing care? What could we do to encourage people to answer in the belief that these questions are genuinely open?	Better knowledge can inform broader policy remit for young carers and seeing the connections between policy areas.
Impact on families	What are the impacts of policies on young carers' families? How would we know? Do we measure this? Does knowing about this change the way we should plan services for young carers?	Re-focussing the implementation of whole family onto the impact on citizens rather than its design for professionals.
Intersectional perspective on inequalities	How does children's involvement in care cut across those with different backgrounds? How does this change what children and their families need from support services?	Awareness of young carers as a group within which there are inequalities. Policies may be allowing these inequalities to continue or worsen.
Valuing care work	How are we increasing acceptance and celebration of children's care work? Does this include promoting the acceptance of those who depend on children's care work?	Challenging the undervaluing of care work and cultural discomfort about our dependence on those who care.
Public/private	How have we decided where responsibility lies and how it is divided between private individuals/family groups/public services?	Increasing discussion about the public and private politics of care work.

Appendix K - List of conference papers

Social Work Academy Masterclass, 4 July 2019, University of Birmingham, UK

Young carers and family life: a West Midlands perspective

Social Policy Association Conference, 8-10 July 2019, Durham University, UK

Title: Opportunities to localise policy-making on young carers: learning from an ethnography of children's care work and family life

IAFFE Conference, 27-29 June 2019, Glasgow Caledonian University, Glasgow, UK

Title: Socially locating children's participation in care work: empirical data from a qualitative study of young carers in the UK

Family Research Group Seminar, 6 March 2019, University of Oxford, UK.

Title: The interaction of national, local and domestic in the organisation of care: an ethnographic case study

Women's Budget Group Early Career Researcher Network Launch Event, 24 January 2019, Manchester University, UK.

Title: Toys cars and cups of tea: The challenge of giving an ethnographic account of care and intersectionality in family life in the West Midlands

BSA Postgraduate Forum Regional Event: Adaptive Ethnographies for a 21st Century Sociology, 1 June 2018, Royal Holloway University, UK.

Title: Let's go home: re-imagining ethnography in researching children's care work

10th Biennial AAGE Conference, 8 – 9 June 2017, Oxford Brookes, UK.

Title: Representations of young carers and the public/private divide