

Caring Lives: What do young people who
care for family members need to thrive?
An empirical investigation.

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This thesis is submitted in fulfilment
of the degree of Doctor of Philosophy

School of Social Sciences

Cardiff University

2022

Acknowledgements

First of all, special thanks to the young carers and their families who participated in this study. Several talked candidly about their privacy and a reluctance to be widely known as young carers, and I am enormously grateful that they trusted me to talk openly about their lives.

This PhD has been an amazing and (dare I say it) fun experience, and part of the credit for that must go to my supervisors, Professor Donald Forrester and Professor G.J. Melendez-Torres. They've supported me while challenging my ideas and suggesting alternatives. Most of all they recognised my intention to do something different and saw the potential, even when it meant sometimes (i.e., often!) choosing the harder path. Special thanks to G.J. for continuing as my supervisor after leaving Cardiff University, and for supporting me to navigate the practical world of SEM software. Thanks also to Doctor Alyson Rees as my review panel convenor, and Hayley Reed for second-screening papers for the realist synthesis.

This is a Type Two PhD funded by the ESRC. Young carers are an understudied area of social care, and I am grateful to them for recognising the value of the proposal, and for their financial support.

Thanks to Professor Simon Murphy and everyone in DECIPHer where my studentship has been based. DECIPHer offers students the chance to be part of a research centre environment, work with and learn from successful researchers, and it has been an invaluable opportunity. Personally, I've also developed some good friends in the centre who have been especially important over the last 18 months, in particular Jordan Van Godwin, Caitlyn Donaldson, Hayley Reed and Doctor Nicholas Page who also runs the PhD student support group.

Thanks also to Doctor Nell Warner in CASCADE, and Doctor Amy Sanders and Verena Stein for much needed wanders and study breaks.

The last four years have been one part of a longer journey in children's rights and participation. Thanks to Lynne Hill, then Policy Director of Children in Wales, who

recognised my interest in research, gave me opportunities, and most importantly introduced me to the world of young carers.

And lastly, to the Janes clan for always supporting me and never questioning my decisions... even when I leave a good job to go back to university!

Preface

At the time of submission, one article has been published relating to content from this thesis. The article concerns the realist synthesis of young carers' mental health and psychosocial wellbeing, and is largely based on the realist synthesis procedure detailed in Chapter Three, and the synthesis results and model development reported in Chapter Five:

Janes, E., Forrester, D., Reed, H. and Melendez-Torres, G.J. (2021). Young carers, mental health and psychosocial wellbeing: A realist synthesis. *Child: Care, Health and Development*, pp. 1–13. <https://doi.org/10.1111/cch.12924>

Abstract

Research over the last thirty years has studied the lives of children who care for family members due to an illness or disability. The research has often highlighted the substantial roles and inappropriate responsibilities of a small population, but there is an increasing recognition of young carers as a larger population with broader experiences.

The mixed methods research design included a realist synthesis that enabled the development of a model of young carers' health and wellbeing and increased clarity concerning why the impacts vary depending on individual circumstances. This initial model was refined by using innovative methods within young carers research to target gaps in knowledge. Structural equation modeling enabled longitudinal analysis of young carers in comparison to children without caring responsibilities, while a longitudinal phenomenology studied young carers who were unknown to services alongside those accessing support.

A key result to emerge was the extent to which young carers felt in control of their caring responsibilities, and threats to this control were also identified. Positive support from family, friends, community and services had the potential to mitigate the impacts of reduced control, though poor-quality support could exacerbate the negative effects further. The impacts of caring and quality of support together informed the development of a positive or negative caring identity.

A model is presented of a young carer spectrum with multiple tiers differentiated on the basis of control. The needs of young carers in each tier are considered, including those who are broadly able to manage their responsibilities, those with reduced control, and those with elevated needs due to particular aspects of their caring, and recommendations are made for the support of each group. Additional recommendations concern the need for research to reflect the full young carer spectrum, and for a greater focus on service evaluation to inform provision.

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Chapter One

Introduction

In 1993 Aldridge and Becker published “Punishing children for caring: the hidden costs of young carers”. This study and the early research of Loughborough University’s Young Carers Research Group (Aldridge and Becker 1993a; Becker et al. 1998) was influential in raising awareness of young carers, children who provide support to family members with an illness or disability. The researchers argued that this support often includes inappropriate tasks, and that a lack of assistance from family, social services, health authorities and schools amounted to neglect. The work raised awareness of young carers as a population with additional needs, and they quickly gained a presence in policy and legislation including the Carers (Recognition and Services) Act Practice Guide (1995) and the National Strategy for Carers (1999).

This first chapter places the study in the context of almost three decades of research. After detailing how young carers rose to prominence as a population of interest, the non-systematic background literature review introduces three articles that provide particularly useful overviews of the field. This includes an assessment of research impact on domestic policy and legislation (Aldridge 2018), a cross-national comparison of an increasingly international research field with the UK at the forefront (Leu and Becker 2017), and a narrative review of current issues and the need for a change in direction (Joseph et al. 2020). These three papers enabled the further identification of key studies and critiques that focus on these successes and issues in more detail, and it is argued that the lack of recent progress is due to long-term conceptual, definitional and practical challenges identified in the 1990s. While these were genuine limitations at the time, a failure to resolve them since has hampered the ability of research to meet the evidence needs of policy makers. This initial review enables the framing of the study questions and methods, ahead of more systematic techniques in Chapters Three, Four and Five.

1.1 Young carers: An old phenomenon but a new social problem

Before reviewing previous research there is a need to consider the increasing prominence of young carers as a population of interest but not a new phenomenon. While their prominence increased markedly in the 1990s, young carers had been researched previously (Page 1989; O'Neill 1989; Bilsborrow 1992, cited in Aldridge and Becker 1993a), and there is also evidence of a historical phenomenon, with McLaughlin (1974) referencing what would now be considered young carers in the 11th century, and Robertson (1974) identifying their presence in the 19th century. Young carers are also present in historical fiction with Dickens' literary depictions of Nell Trent in *The Old Curiosity Shop* (1841) and the titular *Little Dorrit* (1857) likely a reflection of society at the time.

Two possible causes are considered for the comparatively recent interest in the lives of young carers. The first, societal progress, concerns the conceptualisation of childhood as a time of vulnerability, with particular groups of children in need of additional protection. The second, the advent of community care as a solution to the social care crisis, resulted in family carers including children becoming more visible.

1.1.1 *Changing conceptualisations of childhood*

In *Enlightenment Now* Pinker (2018) argued that, despite concerns over crime, poverty and climate change, the human race is making progress. Basic parts of life that we now take for granted, for example living longer and improved health, are actually major human accomplishments achieved through our increasing ability to identify and solve problems through knowledge and reason. As an example, Pinker focused on how children were reconceptualised as a vulnerable group during the 18th Century Enlightenment, prompting major social change including the end of child labour, compulsory schooling and the criminalisation of corporal punishment.

Progress is not constant however, and James and Prout (2015) argued that the concept of childhood is shaped by the social, economic, religious and political challenges of time and place. Hendricks (2015) detailed the history of childhood in Britain since 1800 with children framed in turn as innocent, sinful, victims in need of protection from

child labour, and delinquents requiring education. The concept underwent another fundamental shift as a result of World War Two revealing extensive poverty and family problems for the first time, and the welfare state was developed to tackle these challenges and introduce legislation protecting children from harm. This social construction of children as being at risk of harm has persisted with childhood viewed in comparison to, and in many ways opposing adulthood; while adults are perceived as mature, rational, and complete beings, children are incomplete versions due to their irrationality, immaturity and dependence.

It is however recognised that this perception of childhood as in opposition to adulthood is an oversimplification, or an ‘abstraction from the particularities of individual children’ (Archard 2004). Instead Archard and Jenks (1996) referenced Piaget’s model of expected child development as containing multiple stages of increasing capacity, from an infant who is almost fully dependent on their parents to an adolescent on the cusp of adulthood and largely self-reliant. However, Piaget’s model has also been criticised as a general theory (Demetriou and Spanoudis 2018), with developmental psychology increasingly focusing on child development as containing multiple domains (e.g. spatial, quantitative, social behaviour) and individual children developing in each domain at different speeds.

Despite this, the protection of children from harm has underpinned multiple iterations of social care legislation in the UK, most recently the Social Services and Well-Being Act (2014) in Wales and the Children and Social Work Act (2017) in England. Domestic legislation also reflects the global children’s rights movement, with the 1989 United Nations Convention on the Rights of the Child (UNCRC) preamble referencing children as being immature and requiring additional rights in order to reach adulthood.

The UNCRC details the rights that all children should expect to have but also recognises that certain groups including children who are looked after, disabled, refugees and young carers need extra support to claim these rights. Becker et al. (1998) highlighted the UNCRC Monitoring Group’s concerns over whether young carers have their voices respected, and if they have access to education and leisure opportunities. He also suggested an additional ten rights at risk of being breached as a result of prolonged caring. This included rights in relation to health, privacy, and adequate standards of living, as well as whether caring is in the best interests of the child.

1.1.2 The effects of community care legislation

If the first reason for the increasing prominence of young carers is due to an increasing ability to identify social problems, the second is the result of policy decisions taken to solve a different challenge. The end of the twentieth century saw the advent of community care as a solution to the increasing cost of social care caused by an increasing life expectancy and more people requiring care in later life. In investigating the challenge, the Griffiths report (1988) recommended a reduction in residential care with people encouraged to live at home with the support of family, community and care services. The National Health Service and Community Care Act (1990) adopted the majority of the recommendations, and individuals who remained in care were expected to contribute towards their services. As a result, many moved out of the care system to live with family members. At the same time budget cuts reduced professional support in the community, further increasing family responsibilities (Dalley 1996; Walker 1982).

Understanding of family care and the different potential combinations of caregiver and receiver has increased over time. Prior to community care legislation, family care research focused on traditional gender roles dating back to the Industrial Revolution (Wilson 1982), with the man working while the woman looked after the home and raised their children. After a rebalancing of roles during the 20th century, community care policy was seen as a backwards step with Walker (1982) and Dalley (1996) concerned that the responsibility to care for disabled family members would fall disproportionately on women. However, this has been challenged with analysis of the 1980 General Household Survey (Arber and Gilbert 1989) indicating different care dynamics through the lifespan. For example, while women were the main care provider for their children and dependent relatives during early and mid-adulthood, large numbers of older men were caring for spouses during later life.

Despite this more nuanced understanding of care dynamics, there is little recognition of children as potential providers in family care research. Instead, the refocusing of family care research, and the growth of young carer research occurred at the same time yet separately. Rather than viewing the parallel changes as coincidence, they can be viewed as indirect impacts of the community care legislation.

1.2 Review of progress in young carers research

Having looked at the increasing prominence of young carers as a population of interest, three articles published late in the 2010s considered progress in research. Each had a different focus, and they are considered individually as a precursor to a more detailed assessment of past research.

In a commentary marking 25 years of research, Aldridge (2018) focused on the domestic situation and how policy, legislation and provision has been hampered by the challenge of unreliable prevalence estimation. Despite this, Aldridge highlighted progress in the 1990s when young carers were first recognised in legislation as a population requiring support (Carers (Recognition and Services) Act 1995). More recent legislation (Care Act 2014; Children and Families Act 2014) placed greater responsibilities on education and health services to identify and support young carers, though Aldridge highlighted the ongoing uncertainty over how to enable professionals to achieve this.

Leu and Becker (2017) considered the UK's progress as part of an increasingly international research field and classified countries on the basis of their young carer research, policy, services and legislation. The classification consisted of seven levels, from the top 'Incorporated' level for countries with sustained policy and awareness at all levels of government, to the bottom 'Awakening' level for those just becoming aware of the phenomenon. No country achieved the top level, and the UK was the only second-level 'Advanced' country due to the widespread awareness, extensive research, young carer services and legislation. The strong research base and presence of national carer organisations was cited as central to the UK's comparative success, but issues over resourcing and a gap between the legal intention and implementation were highlighted.

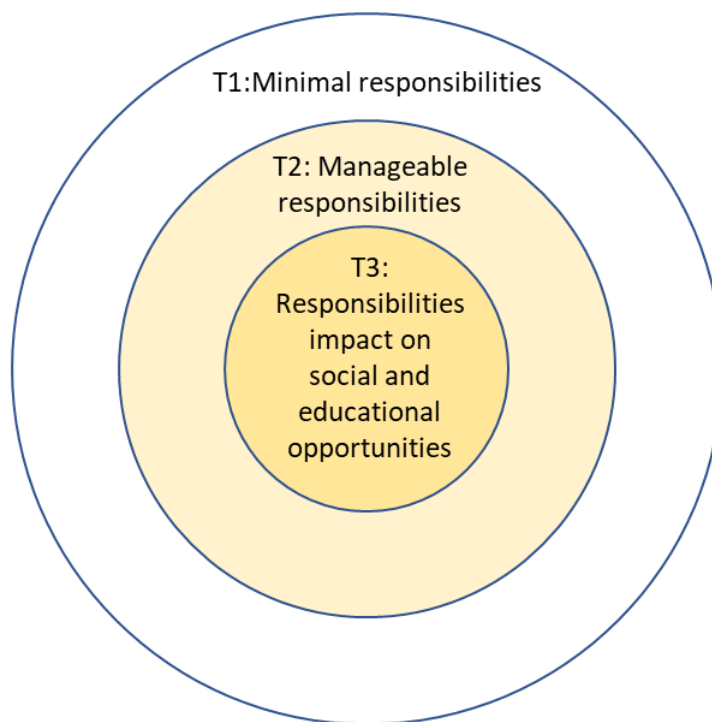
The third paper, a narrative review, had a more critical focus on the issues in young carers research. Joseph et al. (2020) suggested a need for fundamental change and suggested an agenda of six areas to prioritise. The first concerned increasing methodological rigor due to the increasingly saturated nature of qualitative research, and the researchers argued for a greater focus on quantitative research that compares young carers to children without caring responsibilities. The second was the need for theoretically driven approaches that improve causation between caring and impacts, and

the third concerned a greater focus on participatory action research with young carers and their families. The fourth and fifth were increased multi-agency provision and further research at an international level respectively.

The final item concerned definition, and Joseph argued for a broad definition that incorporates all young carers, rather than those with more substantial responsibilities. In recognising this larger, heterogenous population of young carers with a wider range of experiences and impacts, Joseph conceptualised a descriptive model of young carers as three concentric circles. The model is visually represented in Figure 1.1.

The outer circle concerns young carers with minimal caring responsibilities due to family disability or illness, with these responsibilities potentially comparable to the chores taken on by children without caring responsibilities. The second concerns young carers who have greater responsibilities which rarely interfere with their wider lives, while the inner circle contains those whose responsibilities affect their education and social opportunities. Overall, the model conceptualises a spectrum of young carers, though further consideration is needed concerning the impacts and support needs of young carers in each circle, as well as how to differentiate between them.

Figure 1.1 Visual representation of the descriptive model detailed by Joseph et al. (2020)



These three articles considered progress, challenges and the need for a change in direction. At the same time further questions are raised concerning the issue of prevalence and why estimation has been difficult, whether support for young carers is properly resourced, and why there has been a lack of quantitative research to date. In order to ensure that this study is fully informed by past research, the field is reviewed in further detail, starting with the successes of early research and the impacts on policy and legislation. Issues of conceptualisation and definition are considered, before focusing on the practical limitations during the 1990s and more recently.

1.2.1 Early success and the expansion of young carer research

Aldridge and Becker (1993b, 1993a) studied the experiences, lives and needs of a small group of young carers, and produced a rich picture of their family situations and caring roles. In particular the personal and intimate caring responsibilities of some participants were highlighted, and the exploratory research was critical of family members who were unwilling to provide care, and health services who were withdrawing support. Their caring responsibilities were affecting their education and social lives, and there was evidence of strain that was compounded by them often having no one to talk to. Benefits were also identified including high resilience and positive self-worth.

The research led to an increasing academic interest in young carers. This included a continuing focus on inappropriate caring responsibilities but also more specific studies on the experiences of children caring for people with particular illnesses including dementia, multiple sclerosis, Huntington's Disease, AIDS and HIV, cancer and Alzheimer's. The original focus has also been extended to include caring during transition to adulthood (Dearden 2004; Dearden and Becker 2000), and expanded internationally with studies in Africa, Europe, North America, Asia and Australasia (Leu and Becker 2017).

1.2.2 Young carers policy, legislation and provision

As referenced by Aldridge (2018), this early research also had a substantial impact on policy and legislation, with the Carers (Recognition and Services) Act (1995) the first

legislation to define young carers. The legislation also detailed how young carers should be able to request assessments of their caring responsibilities, receive information on support services and attend young carer projects. However, with the young carer content in the accompanying Practice Guide (1995) rather than the legislation itself, there are questions over whether the provision is evidence of government thinking and expectation, rather than legally binding duties. The National Strategy for Carers (1999), also guidance rather than legislation, reinforced the right to an assessment and stated that schools should support young carers as part of their duty to ensure the welfare of all children.

In terms of provision, the Carers (Recognition and Services) Act (1995) and accompanying guide led to the development of young carer projects at a local authority level, evidenced by a notable increase from two projects prior to 1993, to 37 following the Act, and over 100 by 1998 (Becker et al. 1998). These services have been recognised as making a major difference to the lives of young carers who access them for support, advice and respite.

Despite the project provision there was little evidence of assessments becoming regular practice. As a result, the more recent Care Act (2014) and Children and Families Act (2014) have placed legal duties on English local authorities to assess and provide for young carers. This current legislation is also more directive with authorities instructed to assess whether the child is a willing carer, if their responsibilities are appropriate and what support is required. The assessments then inform decisions on the provision of support.

With health, social care and education becoming devolved issues, Wales now has separate policy and legislation. The Carers Strategy for Wales (2013) detailed the Welsh Government's commitment to young carers, with guidance for health professionals to train staff in identification and support, and local authorities to raise awareness in schools. This was followed by the Social Services and Well-Being Act (2014), the first relevant Welsh legislation. Similarly to the UK legislation, the Act details the duties of local authorities to assess the needs of carers and specifies the content of assessments.

While young carer projects have been successful and assessments difficult to implement, other research findings have had little impact on legislation or provision. This includes the need for services to actively identify young carers, schools to improve support, and health services to inform and train them (Aldridge and Becker 1993b). Insert 1.1 contains a reflection of the researcher's prior experience of working with young carers in 2010-11, and his perception that the issues and challenges reported at that time were largely similar to those reported almost two decades earlier.

1.2.3 *Conceptualising and defining young carers*

Having highlighted the successes in research but suggested limited impact on provision beyond specialist projects, three sets of long-term challenges dating back to the 1990s are considered. The first two challenges go hand in hand: conceptual problems concerning the lack of an agreed meaning of the young carer phenomenon; and issues of definition in research studies as a result of that lack of consensus. Consideration of a third set of practical challenges follows separately. The chapter ends with revisiting these challenges when considering the current research picture.

Insert 1.1 Researcher reflection on previous work with young carers

Prior to this PhD study I was employed by Children in Wales, a national children's rights organisation. As a Participation Development Officer my role included developing and involving children in participative research and engagement, and I worked with young carers on two occasions.

The first occasion in 2010 involved facilitating regional residencies to develop content for a young person friendly poster and film highlighting young carer issues. A final national event supported them to work with a design company to develop the materials. The second project, a year later, included further residencies to inform a report. The two pieces of work were funded by the Welsh Government and informed the Carers Strategy for Wales (2013).

My involvement in the work highlighted two things. Firstly, the young carers that I worked with did not feel valued, with many reporting negative experiences including limited personal and social time, a lack of understanding in schools, problems collecting pharmacy prescriptions, and a lack of information from health services. Secondly, in developing the literature review for the report, the lives of young carers did not appear to be improving. Despite an ongoing presence in policy, the issues around recognition, inappropriate care, training and poor school awareness in 2011 were similar to those of the early 1990s.

In developing the application for this doctoral study, I revisited the literature again in 2017. While the Carers Strategy for Wales (2013) and the UK-based Care Act (2014) and Children and Families Act (2014) had all had limited time to impact on practice there was again little evidence of progress being made. That prompted the approach used in this study which seeks to identify and revisit long-term challenges, in order to inform innovative methods.

Conceptualising young carers

At its simplest young carers are children who help care for a family member due to an illness or disability. However, this summary belies the heterogeneous nature of a group that remains contested despite multiple attempts to conceptualise. This is partly because there is no single event or threshold that causes someone to become a young carer, though there are potential indicators. For example, a child cannot be born a carer, but they might be born into a family where someone has an illness or disability and, at some point, transition to caring for them. This transition is similar if a family member becomes ill during their childhood and requires care. However, as argued by Olsen and Clarke (2003) and Morris and Keith (1995), it is problematic to assume that all disabled people require care, or that a child would be the provider rather than another family member. Therefore, it cannot be assumed that all children in these families are young carers.

Equally it is relatively common for children to take on increasing chores as they grow up, with this often recognised as a healthy part of their development towards adulthood. This raises the question of how we justify the distinction without a clear young carer concept. The difference may seem simple if a young carer is spending several hours a day undertaking responsibilities while another child's chores take a fraction of that time, but it becomes problematic if reversed. This may seem unlikely initially but not all young carers have high-level responsibilities while, in the case of abuse and neglect, not all children without caring responsibilities have occasional chores.

In the absence of a defining event researchers have struggled to agree on a young carer concept. This is partly due to the complexity of the young carer system that includes the child, the care receiver and the wider family. To demonstrate this complexity, the symptoms of the care receiver's illness or disability affects the support that they need. This informs the responsibilities of the young carer, but it does not determine them as the child may be one of multiple carers from within and outside the immediate family, each taking on an amount of care and potentially specific responsibilities.

While the concept remains undefined, studies have progressed towards identification of a number of component attributes. This includes their age and the fact that they care for someone, as reflected in the 'young carer' term. The challenge is that the specifics of

each attribute have not been agreed, but instead vary across research studies. At this point the issue of conceptualisation becoming one of definition.

The challenge of definition

The inability to agree on the boundaries of the concept have resulted in the population being defined differently throughout research studies, policy and legislation. Becker et al. (1998) identified this lack of a universally agreed definition in early research, and Aldridge (2018) indicated that this is still the case more recently. Some definitions have however gained traction in terms of underpinning subsequent work, with two early definitions from policy and research considered alongside two more recent examples.

The Carers (Recognition and Services) Act Practice Guide (1995) defined young carers as “children and young people (under 18) who provide or intend to provide a substantial amount of care on a regular basis” (p2). The second, more detailed, definition in the Blackwell Encyclopaedia of Social Work (Becker 2000) is as follows:

‘Young carers are children and young persons under 18 who provide, or intend to provide, care, assistance or support to another family member. They carry out, often on a regular basis, significant or substantial caring tasks and assume a level of responsibility which would usually be associated with an adult’ (p378).

These sources define young carers as under 18 and providing care. In addition, the use of ‘substantial’ reflects the intention in early research and legislation to identify those who were providing higher levels of care, with Becker equating their responsibilities as similar to those of adults.

These early definitions can be considered alongside two recent examples from legislation and policy. The UK Care Act (2014) references young carers as ‘a person under 18 who provides or intends to provide care for an adult’ while The Carers Strategy for Wales (2013) defines the population as:

Young carers are children and young people under the age of 18 who provide care, support or assistance to a family member with care needs. The majority of young carers care for a parent, but the person with care needs may be a sibling, grandparent or any other family member. (p24)

A major difference in the recent definitions is the removal of ‘substantial’. Warren (2007) attributed this change to criticisms of the term as being difficult to quantify, as well as the objection to the application of a threshold based on quantity of care. In addition, the Carer’s Strategy for Wales definition explicitly references multiple family members as possible care receivers, as well as referring to them as having needs. These additions reflect the growing complexity of the term.

This snapshot highlights the challenges of research with an unclear central concept, and the lack of a universally accepted definition has the potential to result in arbitrary definitions in individual studies. Alternatively, an older but accepted definition such as Becker (2000), is used despite it not reflecting the move away from ‘substantial’ care that is seen in more recent policy and research. These issues raise legitimate questions over whether studies recruiting participants on the basis of different definitions are investigating the same population and highlights a need for a theoretically based conceptualisation and definition of young carers.

This study includes a concept analysis of definitions in previous research, enabling consideration of the main attributes of the young carer concept and their evolution over time. Chapter Three introduces the method and details the procedure used while Chapter Four presents the results and defines the young carer phenomenon for this study.

1.2.4 Practical challenges in research

In detailing three sets of early challenges in young carers research, the first two related to conceptualisation and definition. The final set, practical challenges, include the reluctance by young carers and their families to be identified, a historic lack of large-scale quantitative data, and a perceived negative depiction of disabled people. The first two challenges limited the methods that could be used to study young carers, leading to criticism in the 1990s that the evidence was weak and needed to be strengthened.

Stigma and reluctance to be identified

Stigma, potentially due to either the care receiver's condition or the child being a young carer, can cause families to be private about their home circumstances. This led to researchers theorising the presence of hidden young carers who were not known to services despite them attending school and their care receiver potentially accessing support from health and social services. This assumption has been criticised, but research with known young carers has found evidence of stigma prior to identification. Recent prevalence studies have also increasingly confirmed this larger population though the exact size of this group is unknown. The reasons for this variation in prevalence are considered later in this chapter as a separate challenge.

This reluctance to be identified impacted on qualitative research as studies struggled to recruit from the general population. Instead, it has become standard practice to work with young carer projects and recruit young carers who were known to services and accessing support. While Newman recognised the merits of the qualitative research, he was one of several critics who argued that the exploratory approach with small groups of identified young carers resulted in weak evidence (Morris and Keith 1995; Newman 2002, 2003).

The lack of cohort studies

As a result of recruitment challenges limiting qualitative research participants to those accessing projects, there was potential for large-scale quantitative research to strengthen the exploratory evidence. In particular, child cohort studies collect an array of data in relation to the health and wellbeing of children, and the presence of young carer status variables would enable reliable estimations of young carer prevalence among children, as well as comparisons of children with and without caring responsibilities. There is also confidence in the accuracy of these quantitative studies. This is due in part to the respondents being the children themselves, with a parent or adult being a gatekeeper for their overall participation but not how they respond. In addition, the confidentiality of the survey means that children are able to respond without concern over identification.

However, large-scale quantitative studies were not possible due to a lack of data on young carer status during the 1990s. This prevented the identification of young carers

in datasets, and therefore analysis of the impacts of caring. Traditional prevalence studies were also not possible, resulting in the use of alternative, often problematic methods to estimate prevalence.

Young carer prevalence studies

Prevalence studies have been conducted since the mid-1990s but the findings are unreliable due to the variation in estimates. This variation can potentially be attributed to two of the challenges already considered. First, prevalence studies have defined young carers differently and measured different phenomena, therefore producing varying estimates. Second, in the absence of suitable quantitative data, a number of different and often flawed methods have been used. Brief examples follow.

In considering the issue of definitions first, Becker et al. (1998) cited the publication of results from a local survey (O'Neill 1988) that included the question 'Are you a carer?'. The study identified 50-60 young carers in 17,200 households but, due to the complexity of the term, the lack of question detail and the low awareness of young carers in the 1980s, there are doubts over whether respondents were informed enough to understand and accurately answer this question.

The Office of National Statistics (1996) conducted the first national quantitative study as a result of the increasing interest on young carers. With a similar definition to the Carer's (Recognition and Support) Act Practice Guide (1995) the research specified young carers as children who were 'carrying out substantial caring tasks', with 'substantial' defined as ten hours a week for secondary carers and five hours for primary carers. Children who identified as young carers but who did not meet this threshold were excluded, leading to identification of 18 young carers in 12,000 households, upscaled to a national estimate of 19-51,000 young carers (95% confidence interval). At the time this study was noted for having a recognised sample method (Newman 2003) but, with definitions of young carers moving away from the focus on substantial care, the estimate is of little value when considering all children with caring responsibilities. Additional criticisms of the method related to the large estimate range and concerns over the confidentiality of a postal survey (Becker et al. 1998).

Considering the flaws in alternative methods, Becker et al. (1998) cited a school-based survey (Page 1988) requiring staff to estimate numbers of young carers. The study identified 95 definite and 74 possible young carers among 16,000 pupils but, with families known to be reluctant to inform schools, staff awareness of individual young carer is often limited.

Newman (2002, 2003) highlighted the methodological flaws in prevalence studies and the uncertainty over the size of the population. Arguing from a children's rights perspective he felt that the evidence needed to be stronger and warned that a failure to achieve a reliable estimate could hamper the ability to meet the evidence needs of policy makers, inhibiting further impact on legislation, policy and provision.

Representation of disability

The beginning of this chapter looked at the increasing visibility of carers as partly due to community care policy. Disability studies also grew in prominence as a result of the same policy but, unlike carers, this was a reaction to the perceived problematisation and marginalisation of disabled people in society. The marginalisation included an exclusion from research with the exception of medical studies that focused on the disabled person as the research subject and their impairment as being within the person. Opposition to this medical model of disability resulted in the development of the alternative social model (Oliver 1990) that framed disability instead as the inability of society to meet the needs of disabled people and therefore fully integrate them. The success of the social model culminated in the Disability Discrimination Act (1995) which legislated for the removal of barriers and the greater inclusion of disabled people in society.

Despite being closely related, the respective care and disabilities research fields have often been seen as representing the interests of different populations. Disability studies have criticised caring studies, including young carers research, for focusing on disabled people as care receivers rather than parents, and the incorrect idea that all disabled parents need additional support (Morris and Keith 1995; Olsen and Clarke 2003). Olsen and Clarke also argued that the problematisation of parenting capacity predisposed young carers research to identify negative outcomes, and suggested that research should

be reoriented away from young carers and towards disabled people with the question ‘What support do disabled parents need that will enable them not to rely on children for assistance?’ (p14).

Response to criticisms

This section has highlighted conceptual, definitional and practical issues in early research. This resulted in a number of criticisms, most notably from the disability rights field but also from children’s rights experts.

In responding to these methodological criticisms, Aldridge and Becker (1996) argued that the decision to work with young carers through support projects reflected known challenges around recruitment from the general population. They accepted the potential for further research with other methods but also argued that the explorative approach was typical for investigating a new population. Becker et al. (1998) also recognised the increasing need for large scale quantitative data, particularly for the purpose of improving prevalence estimates and studying the impacts of caring, but the lack of data, potentially due to young carers being a new population of interest, was a genuine limitation during the 1990s.

Considering the representation of disability in young carers research, Aldridge and Becker (1996) argued that the two fields should not be in conflict. While they viewed family illness or disability as a major cause of a child becoming a carer, they highlighted their recognition of the lack of support for the disabled person and their family as also key. In addition, they rejected the charge that young carers research is oriented towards identifying negative outcomes, highlighted their reporting of benefits, and suggested that the imbalance towards negative impacts reflected the lives of young carers.

1.3 Revisiting these challenges: The current state of young carers research

A substantial part of this chapter has considered the challenges of young carers research during the 1990s and early 2000s, and how they placed genuine limitations on the methods that could be used. At the same time there was, and continues to be, an acceptance of the need to progress methods but, in revisiting these challenges a generation later, it is argued that this progress has been limited. Instead, research has largely continued to pursue a similar exploratory qualitative approach with those that are known to services, rather than investigating possible ways to identify and recruit unknown young carers or utilising the cohort data that now exists.

1.3.1 Exploratory qualitative studies

Despite the expectations that research would move beyond the exploratory focus, there has instead been a greater specificity of research exploring the experiences of young carers. This has included a focus on young carers of different ages and in different countries, who have different responsibilities for people with different disabilities. This is not an issue of quality as studies continue to be of a high standard, but the result is an accumulation of impacts. These impacts continue to be predominantly negative and have proliferated to include more specific effects such as anxiety and depression, frustration, confidence, risky behaviour and isolation from friends. The positive benefits have also been expanded to include independence, empathy, resilience and the development of caring skills. While interesting, this accumulation fails to consider how impacts vary for individual young carers depending on contextual information, and how the individual impacts interact together.

In addition, the challenge of identifying and recruiting young carers that are not known to services remains. This was accepted as a limitation during the 1990s but, instead of leading to the development of innovative methods to recruit young carers as a hard-to-reach group, there seems to have been an assumption that reaching them is not possible. In the narrative review considered at the beginning of this chapter, Joseph et al. (2020) argued that qualitative literature is increasingly saturated. This might be true for those

accessing young carer projects, yet there is still huge potential for investigation of young carers as a whole population.

1.3.2 Quantitative studies

The last twenty years have seen an increase in quantitative studies conducted through young carer projects. The sample sizes in these studies are substantially higher than qualitative research (e.g., 329 participants in Cassidy and Giles (2013), 130 in Pakenham and Cox (2014), 108 in Early et al. (2006) and the findings have strengthened the evidence of the explorative studies. While undoubtedly a positive step, this is further research with project users rather than the whole population.

There are however a small number of cross-sectional studies comparing young carers and children without caring responsibilities, with Lloyd (2013) analysing happiness and wellbeing data from a Northern Irish cohort of 4,192 children in Year 10 and 11, and Nagl-Cupal et al. (2014) comparing the mental health of young carers to non-caring peers in a large-scale study of 7,403 Austrian children aged 10-14. There is also evidence of this beginning to accelerate with comparative studies on the health, wellbeing and aspiration of 11,215 young people in Scotland (Robison et al. 2020), the wellbeing of 7,477 young people in England (Sharpe et al. 2021), and the health, wellbeing and education of 7,146 adolescents in Europe (Lewis et al. 2022). Despite this increase, there is still limited evidence of the relative health and wellbeing of young carers in comparison to other children, and this limits the potential to attribute impacts to caring responsibilities.

In addition, flawed methods continue to be used to estimate prevalence. This includes the 2011 UK Census that estimated that 2.1% of children in England and Wales were young carers, up from 1.7% in 2001 (Office of National Statistics 2013). While benefits of the census include the participation of every family, there are issues around the main respondent to the census being an adult. The carer question is part of the individual section and should be completed by each family member, but it is not possible to ascertain whether the child completed it and if their response was confidential.

The Department for Education (2017) recently conducted a major research project in England. The research was in two stages with an initial survey of 75,000 households followed by interviews. While the research emphasised the importance of interviewing the child, the initial survey identifying them was completed by an adult. In addition, at least one young carer aged 5-17 was reported in 420 households, with the prevalence incorrectly reported as 0.5% (Aldridge 2018). As only 16,503 households included a child aged 5-17, the young carer prevalence rate is 2.5%, not including additional young carers in families.

The use of large-scale quantitative data to estimate prevalence is rare but also increasing, with estimates of 4.5% in Austria (Nagl-Cupal et al. 2014), 12% in Northern Ireland (Lloyd 2013) and Scotland (Robison et al. 2020), and 13% in England (Sharpe et al. 2021). While three of these estimates are substantially higher than previous studies, this is backed up by a prevalence of 17% in the 2017 SHRN (School Health Research Network) cohort study of 83,153 pupils in Wales (Hewitt et al. 2019).

Of concern though is the fact that cohort data has been available for some time. The first Longitudinal Study of Young People in England (LSYPE1: What Next) published data with the inclusion of young carer status indicators from 2004 to 2010 (University College London 2020), enabling prevalence studies but also the cross-sectional and longitudinal analysis of young carers in comparison to non-caring peers. LSYPE2 (Our Future) has published data since 2013 (Kantar Public 2020), with single-year data also available for the 2018 wave of the Millenium Cohort Study (University of London, Institute of Education 2020). With the lack of large-scale quantitative data accepted as a legitimate limitation in early research, not making use of available cohort data is a missed opportunity.

1.4 Aims and objectives for this research

This introductory chapter has considered three key articles summarising the progress made in young carers research, as a precursor to a more detailed literature review of key articles and critiques in early research. This enabled identification of conceptual, definition, and practical issues that placed legitimate limitations on the methods that could be used in early research. More problematic is a lack of progress in resolving

these issues since then. Most notably this includes the continuing focus on exploratory qualitative research despite the long-term availability of large-scale quantitative data, and the acceptance that young carers cannot be identified rather than develop methods to recruit them as a hard-to-reach population.

It is argued that, through not revisiting these challenges and expanding the methods used, the field has failed to build on the success of early studies, resulting in a lack of recent progress in impacting policy, legislation and provision. This argument underpins the approach used in this study to actively explore and utilise innovative methods.

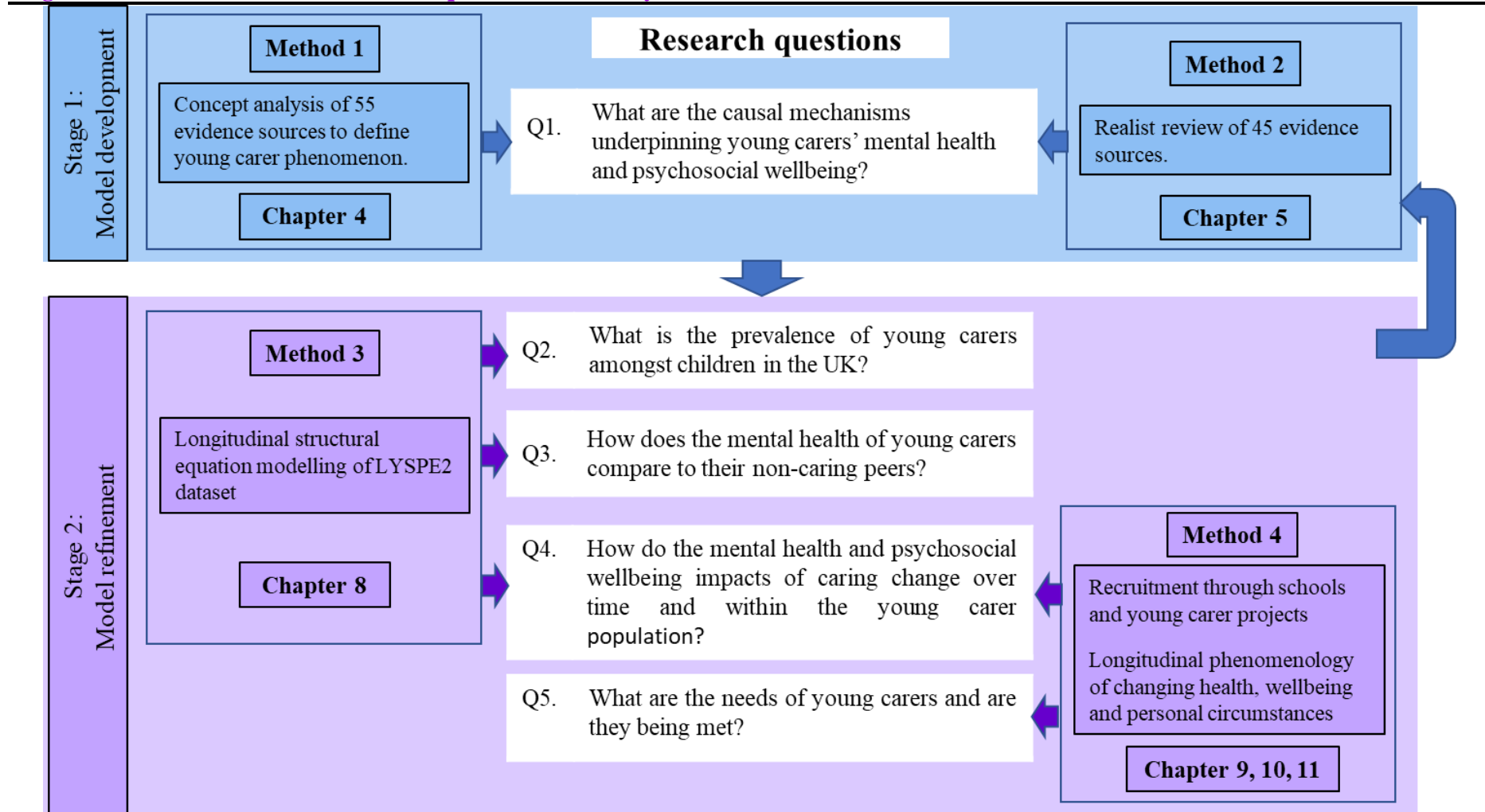
1.4.1 Study aims and questions

This study utilises a theoretically embedded mixed methods design with two stages concerning model development and refinement. The model development stage includes a realist synthesis of past research to increase clarity concerning how the health and wellbeing impacts of caring vary depending on the individual circumstances of the child. The initial model considers how the positive and negative impacts of caring interact and enables the identification of knowledge gaps and conflicting evidence. The model refinement stage seeks to resolve these gaps and conflicts. Based on the limitations of past research discussed in this chapter, innovative methods are utilised including structural equation modeling (SEM) of longitudinal data, and a school-based phenomenological study that aims to recruit young carers not known to services.

The research questions are as follows, and Figure 1.2 presents a schema summarising the methods used to investigate each question:

1. What are the causal mechanisms underpinning young carers' mental health and psychosocial wellbeing?
2. What is the prevalence of young carers amongst children in the UK?
3. How does the mental health of young carers compare to their non-caring peers?
4. How do the mental health and psychosocial wellbeing impacts of caring change over time and within the young carer population?
5. What are the needs of young carers and are they being met?

Figure 1.2 Schema of the five research questions and study methods



1.4.2 *Defining wellbeing*

The first and fourth research questions refer to the mental health and psychosocial wellbeing of young carers and the second term needs to be defined for the purpose of this study. Positive psychology (Seligman 2011) was considered as the basis of the definition, with wellbeing consisting of five elements (PERMA: Positive emotions, Engagement, positive Relationships, Meaning and Accomplishment).

Another potential basis for a definition of wellbeing was WEMWBS, the validated Warwick-Edinburgh Mental Wellbeing Scale (Tennant et al. 2007), and specifically the short 7-item version (SWEMWBS). WEMWBS treats wellbeing as a complex construct with components concerning subjective experience of happiness and life satisfaction, psychological functioning and self-realisation. WEMWBS was developed by an expert panel to have a focus on the positive aspects of mental health, contrasting with the mental health academic literature that tends to focus on mental illness.

While WEMWBS is a 14-item scale, the short 7-item version (SWEMWBS) has been tested and found to be suitable for studying mental wellbeing during adolescence (Melendez-Torres et al. 2019), a key period of change for individuals and therefore a major focus of research. SWEMWBS uses a World Health Organisation definition of mental wellbeing as ‘a state in which an individual can realize his or her own abilities, cope with the normal stresses of life, work productively and fruitfully, and is able to make a contribution to his or her community’. This studies utilises the SWEMWBS definition due to it being empirically validated and appropriate for studies of children.

1.5 **Guide to this thesis**

Chapter Two details the critical realist paradigm as the epistemological framework for the study. The decision to split the thesis into model development and refinement stages, with separate methods chapters for each part, is also justified.

Chapter Three introduces the realist approach of identifying key mechanisms in a system and the contextual factors that produce different outcomes. Realist syntheses are introduced as a specific literature review technique that analyses previous research to develop a model. In addition, the concept analysis technique is introduced as a tool for

defining a contested phenomenon. The chapter closes with the procedures for the two techniques.

Chapter Four reports the results of the concept analysis, based on the analysis of 55 research, policy and legislation documents. The analysis considers how the young carer term has evolved over time, in addition to common antecedents and consequences. The chapter ends with the young carer term being defined for the purpose of the study.

Chapter Five reports the results of the realist synthesis, based on 44 research studies. The initial model of young carers' mental health and psychosocial wellbeing is explained, with three domains concerning their *caring responsibilities*, the *support* that they receive, and the *young carer identity*. Knowledge gaps are considered, in particular concerning the underrepresentation of young carers not known to services in the model, and a lack of studies comparing young carers with children who do not have young carer responsibilities. These gaps informed the model refinement stage of the study.

Chapter Six is the beginning of the model refinement stage. The chapter discusses the merits of mixed methods research and introduces the theoretically embedded concurrent mixed methods design used in this study. The initial realist model and evidence gaps, as well as the limitations of past research, are used to justify the methods used to answer each research question.

Chapter Seven details the methods for the theory refinement stage of the thesis. Structural equation modeling (SEM) is introduced as a quantitative method for the longitudinal analysis of young carers health and wellbeing over time. The model also enables comparison of young carers to children without caring responsibilities, with a second model comparing higher-level young carers with all other respondents. The hypotheses are detailed, and the SEM model development explained.

The chapter also considers phenomenological techniques for the qualitative study of experiences, and details a longitudinal approach that assessed participants' health and wellbeing in the context of their changing circumstances. The procedure for the development of a school-based project to recruit young carers unknown to services is detailed.

Chapter Eight presents the results of the quantitative research. The findings improve understanding of how positive and negative impacts of caring interact together over time, with evidence that impacts of caring are initial marginal but become increasingly detrimental over time. For young carers with higher-level responsibilities, the short-term benefits and long-term negative effects were of a greater magnitude.

Chapter Nine is the first of three qualitative results chapters and concerns the impacts of caring responsibilities. The findings include the emergence of perception of control as central to whether young carers are able to develop a positive caring routine alongside other aspects of their lives. A number of factors that have the potential to threaten this control are identified. The chapter also considers the impacts of other adverse events in young carer families, including family substance misuse, bereavement and disability, and attempts to differentiate these impacts from those of caring.

Chapter Ten presents results in relation to the support potentially received from sources including family, friends, neighbours and services. The chapter differentiates between young carer families that are reluctant to be identified and those that disclose their status, whether to trusted friends, neighbours or services. The chapter also considers the success of services in identifying young carers who do not disclose their status, and participants' experiences of receiving support.

Chapter Eleven is the final results chapter and concerns the caring identity. Young carers have the potential to develop a positive or negative identity, depending on control of their caring responsibilities. This is moderated by their perception of support, recognition and their choice to be a young carer.

Chapter Twelve synthesises the results of the quantitative and qualitative research together. Original knowledge, most notably concerning control, the strengthening of previous research findings and the resolution of conflicting evidence informs refinements to the initial model.

Chapter Thirteen begins with a high-level summary of the study components and key findings. The descriptive model developed by Joseph et al. (2020) of a spectrum of young carers is developed considerably, with the differentiation of tiers by level of control and varying support needs. Recommendations for policy and practice include

the provision of appropriate support to all young carers including those that have largely manageable responsibilities, those with reduced control, and those with elevated needs due to particular aspects of their caring. Strengths and weakness of the study are considered with a focus on the benefits of revisiting past challenges and utilising innovative methods to resolve knowledge gaps.

Chapter Two

Epistemological framework

Chapter One concluded with the specification of five research questions concerning how the mental health and psychosocial impacts of caring differ depending on the individual circumstances of the young carer. This includes how young carer impacts change over time and in comparison with children who are not carers. A final question considers whether the support needs of the whole young carer population are being met.

This chapter details the ontological and epistemological assumptions that underpin all social sciences research and the epistemological framework for this study. The study utilises critical realism, and the paradigm is introduced and critiqued as a response to positivism and interpretivism. An explanation is also given for the decision to divide the study into model development and refinement stages, with this ensuring that the initial model was able to inform the methods selected for model refinement. A glossary of methodological terms is included in Appendix A.

2.1 Debates in ontology and epistemology

Social sciences have been in the midst of a paradigm debate for over 150 years, due to fundamentally different views of the world and how to best investigate it. All social sciences research paradigms are based on assumptions relating to these ontological and epistemological beliefs, and these paradigms inform subsequent decisions in the research design including the research strategy and method selection. At times this debate has been divisive due to a common belief that there should be a single ‘paradigmatic approach’ to all social sciences research (della Porta and Keating 2008). However, this is increasingly being replaced by a ‘hyper-pluralist’ attitude that is more inclusive, and a middle ground ‘search for commensurable knowledge’ where researchers have their own preferred methods but recognise the value of other approaches.

Ontology is defined in the Sage Encyclopaedia of Social Science Research Methods as ‘concerned with the nature of what exists. It is the study of theories of being, theories about what makes up reality’ (Blaikie 2004b, p. 767). While there are many ontological stances, Johnson et al. (1984) has conceptualised two main positions, namely materialism and idealism. The materialist perspective views social phenomena, including the people in it, as constrained by the natural laws of the world (Blaikie 2004b). We are therefore subject to the same limits as natural phenomena including animals and objects, leading to the acceptance that the methods and techniques of natural sciences can be applied in social sciences. In comparison, idealists recognise a fundamental difference due to the complex nature of human culture and the meaning and rules that we ascribe to objects. Negotiations over these meanings result in an additional social reality and, according to Johnson et al. (1984), idealists believe that natural science techniques are not equipped to investigate this social reality. This has led to the development of separate interpretive methods.

Epistemology is the ‘theory of knowledge, a theory of how humans come to have knowledge of the world around them’ (Blaikie 2004b, p. 310). This includes the study of what methods produce reliable results and how to assess the legitimacy of knowledge (Crotty 1998). Again Johnson et al. (1984) conceptualised two main types, nominalism and realism. Nominalists argue that the individual instances of a set of events or objects can be conveniently categorised together as a concept due to the features that they have in common (Blaikie 2004a). In considering them together, this concept is a generalisation about the world and therefore holds no additional meaning to be worth study. In contrast the realist position views the concepts as having additional explanatory power, with the researcher able to look beyond the individual observations and view the social reality underneath.

In conceptualising ontology and epistemology as each having two main positions, Johnson et al. (1984) developed a fourfold classification (Figure 2.1) as a basis for understanding the different approaches to sociological theory. The first classification, empiricism, reflects a materialist ontology and nominalist epistemology, with the world only observable through the senses. Subjectivism, incorporating idealism and nominalism, views the world as socially constructed and negotiated by the different actors, with the researcher aiming to replicate their different interpretations. Proponents

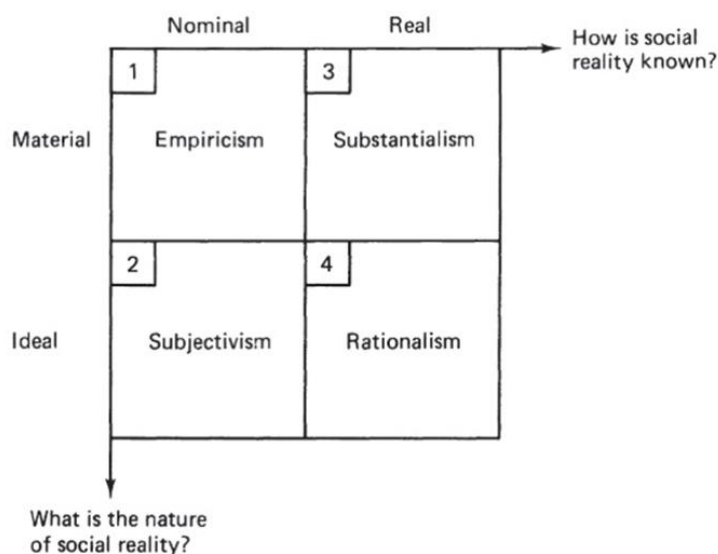
of substantialism, combining materialism and realism, accept the material view of the world but argue that knowledge changes over time and space. The final position, rationalism combines an idealist ontology with a realist epistemology. Rationalists views the world as external to the people in it, with research with people therefore of no value to understanding the world.

With the exception of rationalism, each combination of ontology and epistemology has resulted in a different paradigm for studying the social sciences (Johnson et al. 1984). Empiricism is the basis of positivism, subjectivism is the foundation for interpretivism, and substantialism informed the development of critical realism.

2.2 Paradigms

These considerations of social reality and the nature of knowledge continue to underpin social sciences research and the way that we investigate the world. However, researchers do not choose a paradigm based on their ontological and epistemological beliefs with them instead heavily influenced by the community that they are part of, and that community's use of particular techniques and approach to knowledge production. This section considers the context and stance of the researcher and how it potentially influenced the research.

Figure 2.1 Fourfold classification of sociological theory (Johnson et al. 1984)



2.2.1 *Context and stance*

Kuhn (2012) argued that the paradigm and methods utilised by a particular researcher often align with those of their scientific community. As a member the researcher is exposed to the world view of a generally like-minded group of individuals with similar preferences for particular concepts, beliefs and practices. Students in particular attend courses within the community, read recommended textbooks and access signposted training that serves to reinforce the community worldview. This can affect the problem selected for investigation, the specific questions that are asked and the methods used, as well as the paradigm that underpins the endeavour as a whole.

This studentship has been based in Cardiff University's public health team (DECIPHer: Centre for Development, Evaluation, Complexity and Implementation in Public Health Improvements) and children's social care team (CASCADE: Children's Social Care Research and Development Centre). Insert 2.1 contains a reflective account of the researcher's involvement in the centres, and how they potentially informed the use of the critical realism paradigm and the model development and refinement approach.

The reflection also considers the influence of DECIPHer and CASCADE as Mode-2 knowledge producers. The two modes theorised by Nowotny et al. (2001) concern different approaches to the production of scientific knowledge. Mode-1 is traditional 'pure' research, with the researcher having a high level of control of their research direction and potentially little concern over its application in society. As a result, science informs society in a predominantly one-way relationship. Mode-2 emerged in the 20th century as an alternative that is often found in research centres. It is the result of a closer two-way relationship between science and society based on communication and negotiation. Government, policy makers and the public have greater involvement in the identification of problems to be solved, and research aims to be socially robust by investigating them. As a result, solutions are identified for that context, and only then is application beyond the immediate setting considered.

While Nowotny and her colleagues argue that all knowledge production is becoming increasingly Mode-2 oriented due to government expectations and public accountability, research centres including CASCADE and DECIPHer actively pursue this mode while traditional producers of Mode-1 knowledge are reluctant to engage.

Insert 2.1 Reflection on scientific communities and exposure to paradigms

The studentship has been based in Cardiff University's public health centre. DECIPHer specialises in developing and evaluating complex interventions, and works closely with policy makers, practitioners and communities, to ensure that research results are translated into practical outcomes. Prior to the studentship I was also employed in the centre as the Youth Worker for ALPHA (Advice Leading to Public Health Advancement), the centre's Youth Advisory Group. Developing training and facilitation sessions with ALPHA required knowledge of the research centre and individual DECIPHer projects, and the role also enabled me to attend training on intervention development and evaluation.

I have also been affiliated with the children's social care centre. CASCADE conducts research on how to improve the well-being, safety and rights of children and their families, with a focus on how community services respond to social need in families. The centre advocates for the use of evidence to improve the outcomes of children, and regularly engages with policy makers, practitioners, and professionals as well as children and families.

Attending the DECIPHer training on intervention development enabled the development and successful application for a PhD studentship with a focus on theory development and refinement. As a student I have progressed these ideas further with the study considering young carer needs and the potential for future interventions. In addition, DECIPHer and CASCADE are producers of Mode-2 knowledge (Nowotny et al. 2001) as a result of working closely with stakeholders including children, communities, policy makers and practitioners. This ensures that research carried out by the centres is relevant to the public health and social care challenges currently faced, and that the findings are translated into practical outcomes that make a difference. As a result, it is likely that the use of a critical realist paradigm and the focus on problem-solving and potential future interventions partly reflect my involvement in DECIPHer and CASCADE.

However, while the research has been shaped by involvement in DECIPHer and CASCADE, my prior experiences working on the other side of the science-society divide resulted in a pre-existing interest in applied research and public engagement. This included approximately nine years working as a Participation Officer in a children's rights organisation, and the management of a local authority research and engagement team that ensured the views of the public were informing decision-making. Working in these roles enabled me to see the potential for applied research to make a genuine impact on people's lives, and these views attracted me to DECIPHer and CASCADE where I was able to develop them further.

2.2.2 *Critical Realism*

Critical realism was developed in the mid-late 20th century as a response to the 'inadequate philosophies of science and society' (Bhaskar 2010, pp. 1-2). Bhaskar was particularly critical of positivist philosophy for claiming to reduce knowledge to what is known for certain when that certainty is actually the subjective perspective of the researcher. Bhaskar also disagreed with the positivist framing of society as a closed system and claimed that the observation of many isolated events described moments rather than the structure of society. This structure is central to critical realism.

Bhaskar also criticised the interpretivist approach for failing to provide a viable alternative to positivism. He welcomed the interpretivist idea of the researcher as part of the society that they are studying but argued that the new approach did not go far enough in terms of recognising how knowledge changes over time and through space.

In developing critical realism Bhaskar returned to the question of the difference between natural and social sciences. He was supportive of the ontological position that natural science methodologies can be applied in social sciences but argued this from an anti-positivist position. As a result, critical realism is epistemologically realist with the assumption that the world is socially constructed and complex due to the large number of structures that interact together to produce phenomena and social change.

The realist researcher is interested in the interdependent relationship between social structure and human agency. Society governs behaviour through provision of social rules, laws and resources while human beings predominantly reinforce these societal norms while occasionally enabling transformation. The result of this interdependence and co-evolution of society and the individuals in it is knowledge that constantly changes over time and space.

Criticisms and further development of critical realism

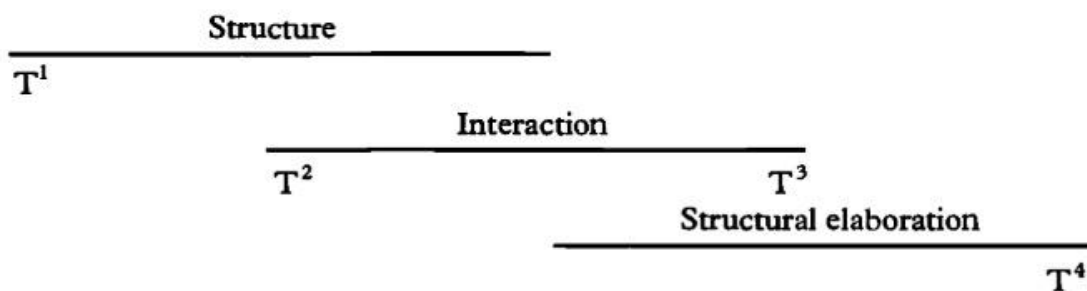
Bhaskar's ideas on the relationship between structure and agency attracted criticisms from within and outside the critical realism. Writing from a hermeneutic perspective King (1999) criticised Bhaskar's 'contradiction-ridden social theory' (p. 269) as containing two antinomies. The first concerns society as being dependent on individuals but also independent of them, and King argued that this threatens to reify society as a real thing existing independently of the individuals. He also criticised Bhaskar's idea of social action by individuals as both unintentional and intentional when they reinforce and transform society respectively. Benton (1998) also argued that Bhaskar had failed to fully transcend the traditional opposition between positivism and interpretivism. Instead, critical realism made concessions to interpretivism and social reality as existing through the actions of individuals.

From within the critical realist paradigm Archer (1995) complemented Bhaskar's theory but argued he had failed to fully consider the relationship between structure and agency. This relationship, termed by Archer as the 'vexatious fact of society' (p. 1) is the central problem of sociology and underpins how researchers study the world, and she proposed the morphogenetic cycle (Figure 2.2) as a better way to explain this relationship.

Archer argued that neither of the dominant ontologies managed to adequately explain this relationship, with the materialist ontology stressing the individual as being dependent on society and therefore 'inert', while the reverse was true of the idealist approach. Archer proposed instead the presence of a temporally stratified analytical dualism with structure and agency existing on separate strata and therefore at different times. The temporal nature of the relationship enables an interplay with each able to shape the other.

The resulting morphogenetic approach has three stages concerning structure, interaction and social elaboration. The first stage, structure predates and conditions interaction with individuals but cannot determine their response. In the interaction stage the response of individuals is often influenced by other factors including their life situation, opportunities and available resources. The final social elaboration stage concerns the effect of the overall interaction with society either reproduced as before (morphostasis) or transformed through human agency (morphogenesis). As the morphogenetic approach is cyclical the resulting social elaboration conditions the next generation.

Figure 2.2 The morphogenetic sequence (Archer 1995)



2.2.3 *Retroductive research strategy*

Critical realist research is underpinned by a retroductive research strategy (Blaikie 2000) that seeks to prove the existence of non-observable mechanisms through witnessing change in observable phenomena. There are initial similarities to the deductive research strategy with the two approaches initially observing regularities, but a number of key differences exist. Most notably, the deductive approach hypothesises a theory and attempts to assess it by collecting data and testing the relationship between specific variables. In contrast, the retroductive strategy proposes an initial model through hypothesising the mechanisms that underpin the wider phenomena. Data collection enables the assessment of the whole model by testing the individual mechanisms. In addition, the retroductive strategy seeks to identify the conditions needed for the mechanisms to produce the outcomes. The strategy is iterative with model testing always resulting in tentative knowledge that can be refined through additional research.

2.3 **Evidence based policy and realist evaluations**

This chapter has introduced the dominant ontologies, epistemologies and paradigms in social sciences research, and explained how critical realism underpins the study. Following on from that, evaluation research is considered as a way to explore systems and differentiate between successful and ineffective social programs. Multiple methods for evaluation research are considered and realist evaluation is selected for use in this study.

2.3.1 *Evaluation research*

Evaluation research developed in the aftermath of World War Two when substantial levels of public expenditure were accompanied by an increasing focus on government decision making and the effective use of finances (Rossi et al. 2004; Weiss 2007). Evaluation research promised ‘research-driven policy making’ (Pawson and Tilley 1997) and assesses interventions against the yardstick of their original objectives and whether they improve the lives of people and wider society (Weiss 1972).

Evaluations are ideally undertaken by external evaluators who share the findings with decision makers to inform whether an intervention should be expanded, modified or closed. However, Weiss (1972) argued that the reality is considerably more problematic and described the application of academic methods in the action context of real-world organisations as ‘intrinsically inhospitable’ (p. vii), largely due to the potential for conflict between the external evaluators and internal practitioners. Weiss also highlighted a lack of influence of the evaluators on decision-making, and the tendency of evaluations to identify negligible benefits or negative impacts. Initially these challenges led to an increasing disillusionment concerning the potential to enable genuine social change, but over time evaluation research has moved away from influencing decision-making, towards reducing uncertainties and highlighting the potential outcomes of different decisions.

Attempts to solve these stubborn challenges resulted in multiple approaches to evaluation research. The original evaluation approach was conducted as a scientific approach with a treatment group having access to an intervention while a control group did not. This was followed by two approaches that were aligned to positivism and interpretivism. The first, pragmatic evaluation, identifies the key stakeholders and involves them in the assessment of the evaluation (Patton 2015). The second constructivist approach works with each stakeholder group to develop a construction, and the researcher then negotiates a consensus (Guba and Lincoln 1989). Further approaches include pluralist evaluation which was developed as a middle ground between the pragmatic and constructivist approach (Rossi et al. 2004), with all stakeholder groups identified and careful consideration of which groups to involve and why.

An additional approach, realist evaluation, was developed by Pawson and Tilley (1997) and based on the principles of critical realism. Similarly to how critical realism was developed as an alternative to positivism and interpretivism, realist evaluation is an alternative to pragmatic and constructivist evaluation methods. Pawson and Tilley stressed the need to return to the idea of researchers as ‘evaluation pioneers’ focusing on knowledge progression rather than epistemological debate. The realist approach emphasises the importance of context as providing the conditions for an intervention to

succeed or fail. This was in contrast to the original experimental approach that Pawson and Tilley criticised for focusing on the intervention at the expense of context.

2.3.2 *The principles of realist evaluation*

Researchers are interested in cause and effect, and why events are causally linked. Mechanisms are one way to explain these relationships, and realist evaluations seek to identify the causal mechanisms under the surface of the social world. These pre-existing mechanisms are not directly observable but cause transformations in the social world and its participants that can be witnessed. Interventions are developed with the intention to target and trigger particular mechanisms with the intention of producing desired social change.

We understand how an intervention works through the use of CMO configurations (Figure 2.3), diagrammatic representations of the relationship between the central mechanism and the context and outcome components. Multiple CMO configurations represent the whole system, and a realist evaluation seeks to understand how each configuration works to understand the system as a whole. The individual elements in a CMO configuration are as follows:

- The **mechanism** is the central component of each configuration. It pre-exists in the social system and there is the potential for a transformation if the mechanism is triggered by a particular change in context.
- The **context** for each configuration encompasses multiple conditional factors relating to the people in the intervention, how they interact with the space and with each other. The context enables the development of societal rules and values over time, but a favourable contextual change can trigger the mechanism.
- **Outcomes** are the product of the context and mechanism together. All mechanisms produce outcomes, and if the mechanism is triggered it causes change in the outcomes produced.
- **Interventions** set out to engineer change in a system that produces negative outcomes for the population, or more often a specific group. Specific mechanisms are targeted by changing the context, and if correctly theorised, the

change triggers the mechanism to enable the desired social change. However, there is always the potential for unexpected outcomes including negative effects.

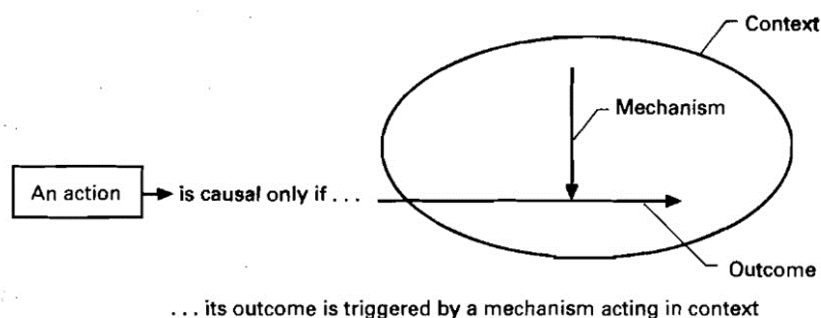
Pawson and Tilley (1997) argue that CMO configurations can be theoretically modelled in any type of intervention. Once modelled, this can then be applied to evaluate specific interventions to assess whether the intended mechanisms are being triggered and causing the desired social changes. The results of the evaluation can subsequently inform the closure or modifications of current interventions or result in the development of new interventions targeting different mechanism.

Realist evaluation quickly became popular and led to the development of RAMESES (Realist and Meta-narrative Evidence Syntheses – Evolving Standards), a Delphi panel of realist experts interested in ensuring high quality evaluations. The panel produced a protocol (Greenhalgh et al. 2015) with the aims of ensuring quality and consistency in studies, building capacity, and providing support with common challenges, as well as publication standards for the reporting of realist syntheses to ensure that readers had the relevant information to assess the quality of research (Wong et al. 2013).

Further advances in realist evaluations

Having considered the main principles of realist evaluations as laid out by Pawson and Tilley, three additional advances are considered; the embedding of CMO configurations; the potential for realist evaluations of pre-existing mechanisms and context in society; and the potential for realist randomised controlled trials (RCTs).

Figure 2.3 Causation in CMO configurations (Pawson and Tilley 1997)



In evaluating participatory health interventions, Jagosh et al. (2012, 2014) identified the potential for the same piece of evidence to inform different components of multiple CMO configurations. This has the potential to cause overlapping or ‘embedded configurations’ where ‘an outcome of one CMO can become context in a subsequent CMO’ (p. 136). On the basis that an intervention successfully targeted the mechanism in the first configuration, the positive outcome from this triggered configuration can also be the contextual change that triggers the mechanism in a subsequent embedded configuration.

Progress has also been made in the use of realist evaluations outside of interventions, with De Souza (2013) arguing for the need to move the focus of investigation away from interventions and towards the pre-existing social system instead. As the contextual factors and mechanism components already exist, they interact to produce the social system that is problematic for certain individuals and groups. De Souza argued that it is just as important to seek to understand the pre-existing social system to inform the development of new interventions, as it is to evaluate the success of existing interventions.

While Pawson and Tilley were initially critical of other evaluation research approaches there have been attempts to reconcile the realist approach with experimental RCTs. Experimental evaluations traditionally aim to remove the effects of context that is central to the realist approach, and Porter and O’Halloran (2012) and Bonell et al. (2012) accepted that RCTs struggle with the complexity of healthcare interventions due to the differing outcomes on the basis of social context. However, they disputed the realist charge that there is no merit in studying the overall success of an intervention, as opposed to who it works for and when. At the same time, they identified strengths in the realist approach that could enhance experimental evaluations. Bonell proposed realist RCTs underpinned by causal mechanisms to inform the development and evaluation of trials, and also suggested trials with multiple arms to test intervention components in different contexts.

Despite previous opposition to experimental evaluation, Pawson (2019) has increasingly focused on how to improve pragmatic RCTs, trials that focus less on premeditative controls and more on real-world application. With pragmatic RCTs struggling to incorporate previous learning into new studies, Pawson argued that previous RCTs

should inform the development of program theories, to ensure that relevant knowledge is passed on.

2.4 The case for a split methodology

This chapter has detailed the development of an epistemological framework that includes the selection of the critical realist paradigm and retroductive research strategy. In using this framework, the intention is to develop an initial model of young carers' mental health and psychosocial wellbeing that can be refined through further research. The optimal way to achieve this is to divide the research into two components with the first fully completed before the methods for the second is planned.

Standard practice is to detail the design procedure in full before the commencement of the study. However, this does vary for instance when the findings of a preliminary research element are expected to inform future stages (Blaikie 2000). This division is particularly common in retroductive research where flexibility is needed to ensure that the data collection in the second stage can resolve the evidence gaps found in the first.

In the case of this research there is a need to conceptualise the young carer system, and designing the whole study at this stage has the potential to limit model refinement. Instead, the research is divided into model development and model refinement stages, with the initial model directly informing the refinement stage, and gaps in the model informing the utilisation of particular methods.

2.5 Chapter summary

This chapter has considered the ontological and epistemological assumptions that underpin research, and how the use of paradigms, techniques and approaches are often informed by the scientific community the research is based in. The epistemological framework for the study was detailed with this including use of the critical realism paradigm, retroductive research strategy and a realist evaluation approach.

Having detailed the decision to split the methods into two components, Chapter Three begins the model development stage by introducing the concept analysis method as a technique for defining the young carer term, and the realist synthesis method for developing the initial model. The chapter also details the procedures used for each of the techniques.

Chapter Three

Model development methods and procedures

Having detailed the epistemological framework and the decision to split the thesis in Chapter Two, this chapter introduces the concept analysis and realist synthesis methods that were used in the model development stage of the research. Procedures for the two techniques are then detailed, with the results of the concept analysis and realist synthesis presented in Chapter Four and Chapter Five respectively.

3.1 Methods

The concept analysis technique is introduced first as a method for exploring how a contested term has evolved over time, thus enabling the development of a definition for this study. This is followed by consideration of different approaches to evidence-based reviews. Having considered the strengths and weaknesses of systematic reviews, the decision to utilise the realist synthesis technique to develop a realist model is explained.

3.1.1 *Concept analysis*

Chapter One identified a number of key challenges in young carers research. One of the most prominent is the challenge of conceptualising the phenomenon, resulting in the lack of a universal definition in research. The need to theoretically conceptualise and define young carers was highlighted and the concept analysis technique enables this through the study of how the concept has evolved in previous research.

Walker and Avant (1983, 2014) first developed concept analysis as a technique for refining and clarifying ambiguous or contested concepts in the field of nursing, in order to support the understanding of practice and improve care standards. In viewing the concept under investigation as rarely changing over time or in relation to contextual

factors, rigid conditions could be set for the identification of the concept. These could then be used to assess whether cases were instances of the concept of interest, borderline or illegitimate.

Rodgers (1989) highlighted issues with viewing concepts as static and proposed an alternative evolutionary cycle of concept analysis (Figure 3.1). This places a greater focus on how the attributes of a concept can change over time and potentially lose definition through use, interaction and application. As a result, rigid conditions cannot be set and cases are not considered as legitimate or illegitimate. Instead, the technique tracks the evolution of the concept over time and identifies related concepts that are connected to the original concept of interest but not the same. The completed concept analysis can support the definition of the concept for a research study.

3.1.2 Evidence-based reviews

Chapter One highlighted the need for increased clarity concerning young carers and why the impacts of caring vary depending on the individual circumstances of the child, care receiver and their family. The strengths and weaknesses of systematic reviews are initially considered as a method for reviewing previous research evidence, before focusing on the benefits of the realist synthesis technique in developing a model that explains a complex system.

Systematic reviews

Systematic reviews are used in evaluation research to assess the success of an individual intervention type. The method is rigorous in the search of literature, and process-driven and objective in the consideration of relevant intervention studies to limit systematic errors (Petticrew and Roberts 2006). A key benefit is the reduction of large amounts of evidence into robust and reliable summaries that can inform decision-making and, as a result, they have become popular with policy makers who have limited time to read the increasing amounts of primary research.

Figure 3.1 The evolutionary cycle of concept analysis (Rodgers 1989)

1. Identify and name the concept of interest.
 2. Identify surrogate terms and relevant uses of the concept.
 3. Identify and select an appropriate realm (sample) for data collection.
 4. Identify the attributes of the concept.
 5. Identify the references, antecedents, and consequences of the concept, if possible.
 6. Identify concepts that are related to the concept of interest.
 7. Identify a model case of the concept.
-

While realist researchers share the central objective of using previous research to inform decision making, Pawson (2006) had numerous criticisms of the method. First, he questioned the success of systematic reviews in leading to societal change and the assumption that the conditions of a successful intervention can be replicated elsewhere. Second, he rejected the assumption of a hierarchy of evidence that ranked randomised controlled trials (RCTs) as producing the strongest evidence. Third, Pawson disagreed with the extraction process where a range of data including theories, context and comparable data are lost. These data were vital to the realist approach of assessing what works for who and when. Fourth, and also relating to this key realist aim, he criticised the aggregative focus of systematic reviews as identifying net effect. Pawson argued instead for a synthesis that compares studies by viewing their results in the light of programme variation.

Realist syntheses

The realist synthesis approach was developed by Pawson (2006) as an alternative to systematic reviews and is a process-intensive method for the development of the central question and search for studies. Differences to systematic reviews include the acceptance that all studies, irrespective of method used, have the potential to contribute fragments of evidence to different elements of the theory. In addition, evidence is synthesised by comparing the context of different studies, rather than accumulated. This enables the development of a realist model that identifies key mechanisms, the contextual factors that have the potential to trigger them, and the resulting outputs. In

line with the realist evaluation approach, the end result is a model that considers ‘what works for whom in what circumstances and what respects’ (Pawson 2006, pp. 74).

The epistemological framework, as detailed in Chapter Two, considered research by de Souza (2013) concerning the potential for realist evaluation to be extended beyond interventions and into society. De Souza proposed the elaboration of CMO (Context-Mechanism-Outcome) configurations to include the pre-existing contextual factors that exist as a result of social structures. These contextual factors have the potential to trigger mechanisms and produce outcomes for individuals. On the basis that a standard realist synthesis reviews previous intervention research to develop a model of mechanisms for that intervention type, a realist synthesis can also assess the pre-existing mechanisms that produce differing outcomes for individuals in a social system.

Considering systematic reviews and realist syntheses together, the latter is more appropriate to this specific study. Chapter One considered the heterogeneity of the young carer population and the increasing specificity of research, and there is a real need to increase clarity for the whole population. The comparative and context-focused nature of realist syntheses is better suited to reviewing this past research, and the resulting model of young carers’ mental health and psychosocial wellbeing enables consideration of the whole system. This includes why the impacts of caring vary depending on the individual circumstances of the child, the person that they care for, and their wider family.

3.2 Concept analysis procedure

The first part of this chapter has introduced the methods that enabled the development of the model. The procedures are now detailed, beginning with the concept analysis that defined the young carer phenomenon for this study. That definition is then central to the procedure for the realist synthesis.

Rodger’s evolutionary cycle was applied to ‘young carers’ as the concept of interest. ‘Child’, ‘teenage’ and ‘adolescent’ were identified as surrogate terms for ‘young’ with ‘caregiver’ an alternative to ‘carer’. In addition, with the intention to identify studies that defined the phenomenon, the search also included ‘definition’ as a term. Sources in

three databases (International Bibliography of the Social Sciences, Scopus, Sociological Abstracts) plus the Web of Science citation index were searched for these terms in the title, abstract or full paper. Full paper screening enabled the identification of sources that included an explicit definition of young carers.

Evidence sources in the dataset were analysed in Nvivo 11 using line-by-line coding. This enabled the identification of content relevant to attributes of the young carer concept. The abstract, introduction, literature review and methods of studies were also analysed to identify antecedents that could cause the young carer phenomenon and consequences that could result from it.

Chapter Four presents the results of the concept analysis, including a flow diagram of the search and screening process and a definition of young carers for this study. However, as the definition is key to the realist synthesis procedure that follows next, the definition is presented in Insert 3.1.

3.3 Realist synthesis procedure

The concept analysis process leads directly into the realist synthesis procedure. The procedure and reporting were guided by the RAMESES (Realist and Meta-Narrative Evidence Syntheses – Evolving Standards) guidance and publication standards (Wong et al. 2014), with the search strategy, screening process, analysis and model development detailed below. Deviations from the guidance are explicitly stated and explained.

Table 3.1 Concept analysis search strategy

	Term	Surrogate terms
Field 1	Young carers	Child/Adolescent/Teenage; Caregiver
Field 2	Definition	-

Insert 3.1 Young carer definition

‘Children and young persons under 18 who provide, or intend to provide, care, assistance or support to another family member (or members) due to an illness or disability, mental health or substance misuse issue. They assume a level of responsibility which may, depending on the support that is in place both within and from outside the family, have an impact on their lives’.

3.3.1 Initial model building

The concept analysis had identified antecedents and consequences as causes and outcomes of the young carer phenomenon respectively. With these equating to the realist components of contextual factors and outcomes, the antecedents and consequences were utilised for the initial model building (Appendix B).

3.3.2 Search strategy development

The young carer definition enabled the development of inclusion and exclusion criteria (Table 3.2). The criteria supported the development of a complex search strategy to identify studies relating to young carers' mental health and psychosocial wellbeing. The strategy utilised the SPICE (Setting, Perspective, Intervention, Comparison and Exploration) framework (Booth 2006) to focus the search. As the synthesis was not limited to particular settings or comparative studies these fields were left blank.

The researcher actively sought to identify disability studies research but this complicated the search process due to the different terminology used, for example 'children of disabled people' in place of 'young carers'. In using these terms, it was recognised that not all children of disabled people are young carers, and that young carers may be supporting other family members as well as parents. This increased the potential for the inclusion of irrelevant studies and omission of key papers, resulting in the decision to develop separate search strands for the different terminologies by field. Table 3.3 includes the resulting SPICE framework for the two strands.

Surrogate terms were identified for each of the fields. Concerning the 'young carers' term, surrogates included 'caregivers' for 'carers', and 'teenage' and 'adolescent' for 'young'. Surrogates for 'children of disabled people' included 'children of disabled parents' and 'children of impaired parents'. 'Mental health' and 'psychosocial health' were the core terms for the Intervention field, with this expanded to include 'emotional health', and with 'wellbeing' a surrogate term for health. 'Development' was the core term for the Exploration field, with 'child welfare', 'child health' and 'childhood development' included as surrogates. Terminology around 'child abuse' and 'child neglect' was included to ensure that previous studies concerning children caring as a form of neglect or abuse were identified.

Table 3.2 Inclusion and exclusion criteria

	Criteria for inclusion of paper	Criteria for exclusion of paper
Child age	<ul style="list-style-type: none"> All participants are children/young people between the ages of 4 and 18 years old. Alternatively, a significant proportion should be aged 4-18 with separate analysis of this age group. 	<ul style="list-style-type: none"> Children under the age of 36 months, including 'babies' and 'toddlers' (also 'prenatal', 'paranatal' or 'post-partum') at the time of study. These studies concern parents caring for their children, or problems during pregnancy and birth. Retrospective studies with adults looking back to when they were young carers Adults over 18, including where carer is the 'adult child' of the person they care for. Participants are not children (e.g., parent, professional carer, clinician) Child taking on responsibility as a regular part of growing up (i.e., chores)
Young carer status	<ul style="list-style-type: none"> Child is taking on extra responsibility due to caring for someone. This can include sibling care (caring for an able-bodied sibling due to the care receiver's disability). The caring relationship may be fully inverted where the child cares for the adult, or partially inverted meaning there is a two-way caring relationship. The physical abuse, emotional abuse, neglect or parentification of children, due to the child having inappropriate caring tasks 	<ul style="list-style-type: none"> The caring relationship is not inverted at all. I.e., the adult is caring for the child The child has a disabled person in their family but no caring responsibilities. Sexual abuse, or violence
Relationship	<ul style="list-style-type: none"> Care receiver(s) is a member of the family, and usually living in the same home 	<ul style="list-style-type: none"> Child is caring for a friend of the family Child is a young parent The child is no longer in the family home (i.e., this includes being in the care system)

Care receiver illness	<ul style="list-style-type: none"> The care receiver has a chronic illness or disability. This can include mental health issues or a substance misuse problem 	<ul style="list-style-type: none"> Child is taking on responsibility for other reason than illness/disability (including being a young parent, being a language broker, parental absence or divorce, parental incarceration, babysitting)
Outcome	<ul style="list-style-type: none"> The mental health of the young person including negative impacts (e.g., depressions, anxiety, conduct disorder) and benefits (improved relationships). Their psychosocial health including negative impacts (e.g., sleep and eating disorders, risky behaviour, adjustment and personality disorders including ADHD) and benefits (life skills, resilience). Outcomes should be a result of their environment (i.e., their family situation and caring role). 	<ul style="list-style-type: none"> Mental health effects relating to genetics or 'nature' Outcomes relating to physical health (including developmental and congenital disorders) Health effects solely from pre-birth and first 3 years of life (e.g., FASD)
Research design	<ul style="list-style-type: none"> Empirical studies including qualitative, quantitative and mixed methods will be included. Articles, book chapters 	
Article language	<ul style="list-style-type: none"> All articles in the English language 	<ul style="list-style-type: none"> Books, book reviews, commentaries, grey literature Articles not in the English language

Table 3.3 SPICE framework for the search strategy

Field	Young carers search	Disability studies search
Setting	None	None
Perspective	Young carers	Children of disabled people
Intervention	Mental and psychosocial health	Mental and psychosocial health
Comparison	None	None
Exploration	Development	Development

Literature search

The search was carried out in seven electronic databases (PsycINFO, MEDLINE, EMBASE, ASSIA, Sociological Abstracts, IBSS and JSTOR) plus the Web of Science citation index. With each database having different functions in relation to the use of MeSH (Medical Subject Headings), subject headings, Boolean operators and general word searches, the search strategy guided the development of the individual searches.

Each search was built incrementally at term, field and whole system levels. Terms were initially searched individually to assess whether the surrogate terms identified additional results. Terms that offered no additional value or reduced the accuracy of the results were removed. Additional MeSH and subject heading terms identified in particular databases were included, for example including ‘caregiver burden’ in the PsycINFO and EMBASE database searches.

The realist synthesis search was carried out in June 2018. Appendix C include full details and results of the search for each database.

3.3.3 *Article screening process*

Following deduplication, the remaining studies were screened against the inclusion criteria at title, abstract and full paper levels. Articles were single screened at title level. While this is not standard RAMESES practice, the decision was made due to the size of the dataset and the title screening concentrated on the removal of studies that obviously concerned other topics rather than young carers. As titles contained limited information, all studies of uncertain relevance were progressed to abstract screening.

Abstracts were double screened against the inclusion criteria by the researcher and a second screener using Rayyan QCRI software. The use of Rayyan ensured that the procedure was blinded with the screeners unaware of each other's decisions. Periodic meetings enabled the resolution of conflicting decisions.

With reference to the full paper screening, articles were sourced through Cardiff University library, either as paper or electronic versions. Where this was not possible inter-library loans, Research Gate and personal communications with authors were partially successful, but a small number of articles could not be sourced. The researcher screened the remaining studies at full text level, with snowballing of papers to check for studies that were not included in the search results. Full papers were then second screened with conflicting decisions again resolved through discussion.

While standard RAMESES practice is to include all studies progressed through full paper screening in the synthesis, this was not possible due to the large number of studies. Instead, each evidence source was assessed and prioritised using the realist principles of relevance to the model development and whether the methods were rigorous. Studies were divided into primary, secondary and surplus sets with the primary and secondary papers included in the synthesis. Surplus papers with lower model development potential were removed.

3.3.4 Analysis and synthesis

Analysis and synthesis were completed in Nvivo 11, with the antecedents and consequences identified in the concept analysis (Appendix B) utilised as initial building blocks for the theory. In line with the realist approach that all information has the potential to inform the model, all studies were assessed using line-by-line coding. The model-building process was incremental with primary papers analysed in turn to identify key evidence and develop initial concepts. As the analysis continued these concepts became increasingly detailed configuration components and then whole CMO-configurations.

Analysis of the secondary papers enabled further strengthening and modification of the configurations. Consideration was also given to embedding (Jagosh et al. 2014) where

a mechanism in one configuration is informed by the same evidence as a contextual factor in a subsequent embedded configuration. These embedded configurations coalesced into the three thematically similar domains that are presented in Chapter Five.

3.4 Chapter summary

Chapter Three has initiated the model development stage of this study through the introduction and the detailing of the procedures for the concept analysis and realist synthesis methods. Chapter Four presents the result of the concept analysis and concludes with a definition of young carers for the purpose of the project, while Chapter Five reports the results of the realist synthesis and the resulting model of young carers' mental health and psychosocial wellbeing.

Chapter Four

Concept analysis results

Chapter Three introduced the methods used to develop the model for this study. This included a concept analysis to define the ‘young carer’ phenomenon due to it being a contested term, and a realist synthesis to identify CMO configurations and the individual context, mechanism and outcome components. This chapter presents the results of the concept analysis with the synthesis findings reported in Chapter Five.

The results of the concept analysis are presented as a narrative of how the term has evolved through the dataset studies. Four attributes (age, caring status, the relationship of the care receiver to the young carer, and the care receiver needs) are identified, in addition to antecedents and common consequences of the young carer concept.

The chapter ends with the identification of each attribute and an overall definition that enables differentiation between the evolution of the young carer concept and development of related but different concepts. Particular consideration is given to the fourth attribute concerning the increasing expansion of the care receiver’s needs beyond those relating to illness and disability.

4.1 Introducing the concept analysis dataset

Chapter Three detailed the concept analysis procedure and the resulting literature search identified 86 results. Following full-paper screening to identify sources that explicitly defined the term, 55 articles were included in the concept analysis. The flow diagram for the model development (Figure 4.1) includes the search and screening process for the concept analysis, as well as the realist synthesis which are reported in Chapter Five.

Table 4.1 includes the details of the 55 evidence sources. The date of publication ranged from two 1993 to 2018. Forty-seven were academic sources, including 43 journal articles, three books and Becker’s definition of young carers in the Blackwell Encyclopaedia of Social Work (2000). These academic sources had 35 different first authors.

Figure 4.1 Flow diagram of the concept analysis and research synthesis procedures

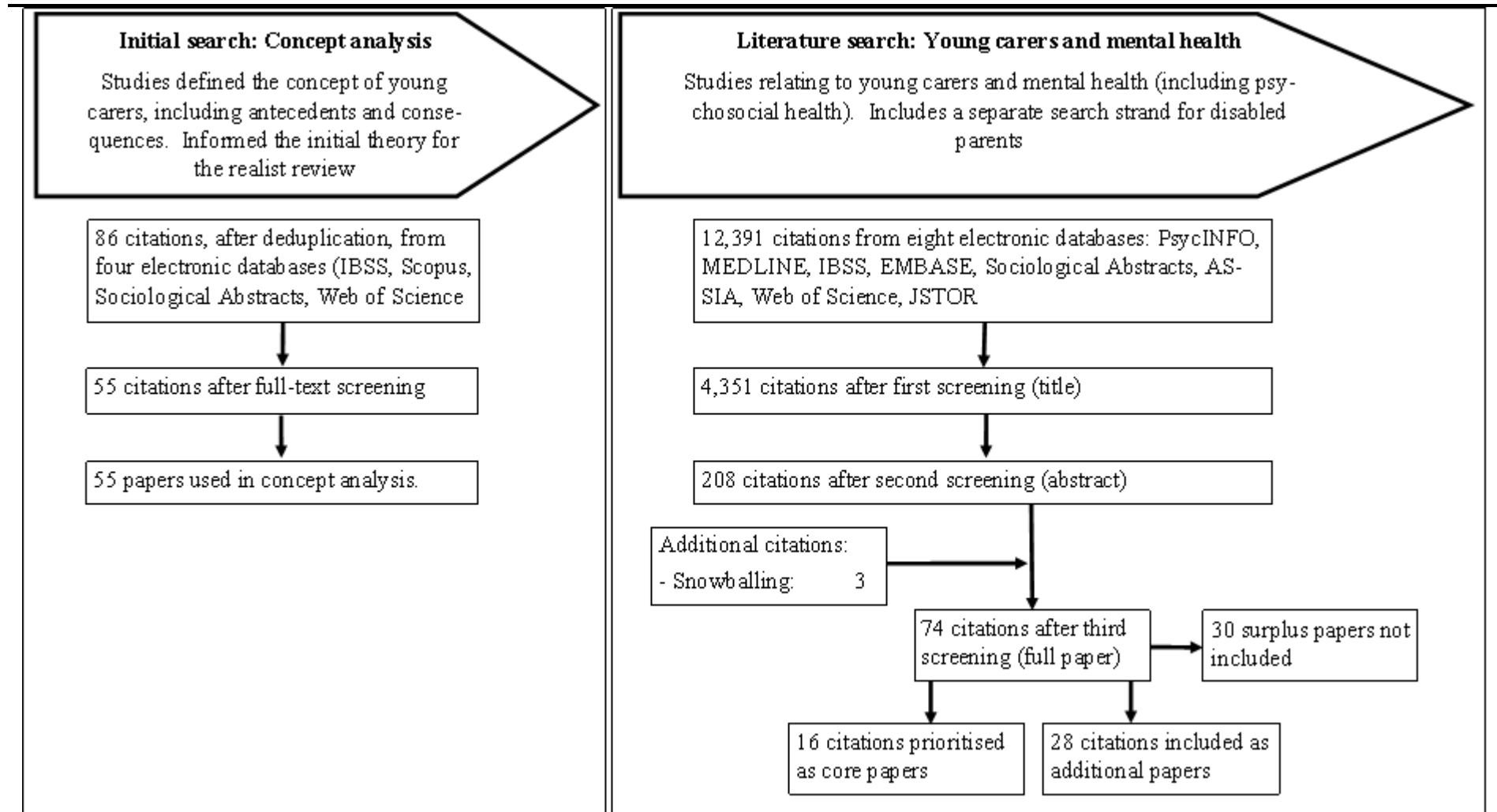


Table 4.1 Concept analysis evidence sources

Author	Source type	Year	Author	Source type	Year
Aldridge & Becker	Journal	1993a	Pakenham et al	Journal	2007
Aldridge & Becker	Journal	1993b	Warren	Journal	2007
Jenkins & Wingate	Journal	1994	Schlarrman et al.	Journal	2008
Carers (Recognition and Services) Act Practice Guide	Policy	1995	Shifren	Journal	2008
Department of Health	Policy research	1996	Cline et al.	Journal	2009
Office of National Statistics	Policy research	1996	Sahoo & Suar	Journal	2009
Dearden & Becker	Journal	1997	O'Dell et al.	Journal	2010
Becker et al.	Book	1998	Rose & Cohen	Journal	2010
Aldridge & Becker	Journal	1999	Svanberg et al.	Journal	2010
National Strategy for Carers	Policy	1999	Barry	Journal	2011
Becker	Encyclopaedia	2000	Moore et al.	Journal	2011
Bibby & Becker	Book	2000	Kennan et al.	Journal	2012
Dearden & Becker	Book	2000	McAndrew et al.	Journal	2012
Olsen	Journal	2000	Purcal et al.	Journal	2012
Banks et al.	Journal	2001	Shifren & Chong	Journal	2012
Banks et al.	Journal	2002	Ali et al.	Journal	2013
Earley & Cushway	Journal	2002	Andreouli et al.	Journal	2013
Newman	Journal	2002	Cassidy & Giles	Journal	2013
Underdown	Journal	2002	Hamilton & Adamson	Journal	2013
Thomas et al.	Journal	2003	Carers Strategy for Wales	Policy	2013
Eley	Journal	2004	Kavanaugh	Journal	2014
Butler & Astbury	Journal	2005	Care Act	Legislation	2014
National Alliance for Caregiving	Report	2005	Children and Families Act	Legislation	2014
Aldridge	Journal	2006	Stamatopoulos	Journal	2015
Early et al.	Journal	2006	Assaf et al.	Journal	2016
Pakenham et al	Journal	2006	Cunningham et al.	Journal	2017
Becker	Journal	2007	Aldridge	Journal	2018
Moore & McArthur	Journal	2007			

Two sources were pieces of policy research produced by the UK Government's Department of Health (1996) and the Office of National Statistics (1996) respectively, with a further report by an alliance of American care organisations (National Alliance for Caregiving 2005). Two were pieces of UK legislation (Care Act 2014; Children and Families Act 2014), with the final three UK or Welsh policy documents (Carers (Recognition and Services) Act Practice Guide 1995; National Strategy for Carers 1999; The Carers Strategy for Wales 2013).

4.2 Defining young carers as an evolving phenomenon

Four attributes (age, carer status, care receiver's relationship to the young carer, and care receiver needs) were identified. Due to the 'young carer' term itself containing two attributes, all 55 sources defined age and carer status to at least a minimum level. Many, but not all, defined the care receiver relationship and their needs. Each attribute is considered in turn, with an evidence statement followed by a narrative of evolution. In-text citations are ordered chronologically to demonstrate evolution.

4.2.1 *Age or life stage*

Insert 4.1 Evidence statement 1: Age

The age at which a child can be a young carer. This was numerically defined with minimum and/or maximum age limits in some studies, or alternatively specified as a life stage.

While every source defined the age attribute (Insert 4.1), the detail varied substantially. Twenty-two sources did not specify a numerical age, instead defining the phenomenon as happening during childhood, a stage of life that varies in different cultures. Ten studies (Dearden and Becker 1997; Aldridge and Becker 1999; Olsen 2000; Banks et al. 2002; Early et al. 2006; Pakenham et al. 2006; Warren 2007; Schlarmann et al. 2008; Shifren 2008; Shifren and Chong 2012) and the National Strategy for Carers (1999) simply referred to 'young carers', with a further 11 identifying them as children or

young people (Department of Health 1996; Newman 2002; Thomas et al. 2003; Aldridge 2006; Cline et al. 2009; Rose and Cohen 2010; Barry 2011; Kennan et al. 2012; Andreouli et al. 2013; Cassidy and Giles 2013; Kavanaugh 2014).

Thirty-two sources attributed a maximum numerical age. In the earliest studies Aldridge and Becker (1993a, 1993b) defined young carers as under 18, with this adopted by a further 20 studies (Jenkins and Wingate 1994; Department of Health 1996; Becker et al. 1998; Becker 2000; Bibby and Becker 2000; Banks et al. 2001; Earley and Cushway 2002; Underdown 2002; Dearden 2004; Eley 2004; Butler and Astbury 2005; Becker 2007; Moore and McArthur 2007; O'Dell et al. 2010; Svanberg et al. 2010; Moore et al. 2011; McAndrew et al. 2012; Andreouli et al. 2013; Assaf et al. 2016; Aldridge 2018). This is also the age specified in policy and legislation including the Carers (Recognition and Services) Act Practice Guide (1995), The Carers Strategy for Wales (2013), the Care Act (2014) and the Children and Families Act (2014). Two sources (National Alliance for Caregiving 2005; Sahoo and Suar 2009) included 18 year-olds as young carers.

An alternative has resulted from an increasing interest in carers during transition to adulthood. Within the dataset a higher age limit of 25 was first referenced by Dearden and Becker (2000), followed by Pakenham et al. (2007), Ali et al. (2013) and Cunningham et al. (2017). However, this population has increasingly been recognised as 'young adult carers', a separate but related category (Purcal et al. 2012; Hamilton and Adamson 2013; Stamatopoulos 2015). The Carers Strategy for Wales (2013) explicitly recognises young carers (under 18) and young adult carers (18 to 25) as separate populations needing support for different challenges.

Cunningham et al. (2017) is the only source to specify a minimum age limit (over 10). This was asserted as the definition in Australia based on a report (Cass et al. 2010) that is not included in the dataset. However, this is incorrect: while the research participants were over the age of ten, Cass did not define this as the minimum age of all young carers.

4.2.2 *Carer status and assessing levels of care*

Insert 4.2 Evidence statement 2: Carer status

Whether an individual is providing support to another person. While some sources did not specify a minimum threshold, others identified carers as those providing higher levels of support, on the basis of quantity, type of responsibilities or impact.

The second attribute concerns care status (Insert 4.2). Similarly to the age attribute, this was defined in every source. Early studies defined young carers as surpassing a minimum threshold that was initially based on the level of responsibilities. Aldridge and Becker (1993a, 1993b) identified ‘primary carers’ as the main carer in a family, and while this terminology was used in other sources (Jenkins and Wingate 1994; Banks et al. 2001; Eley 2004), nine instead referenced ‘substantial’ or ‘significant’ care (Banks et al. 2001; Earley and Cushway 2002; Underdown 2002; O’Dell et al. 2010; Svanberg et al. 2010; Cassidy and Giles 2013; Hamilton and Adamson 2013; Stamatopoulos 2015), including the Carers (Recognition and Services) Act Practice Guide (1995). An additional eight expanded substantial care to include those who take on responsibilities that would normally be expected of an adult (Office of National Statistics 1996; Becker 2000, 2007; Bibby and Becker 2000; Eley 2004; Early et al. 2006; Sahoo and Suar 2009; Assaf et al. 2016).

An alternative focus developed concerning types of caring. Twelve evidence sources, beginning with research by the Department of Health (1996) referred to different caring tasks (Becker et al. 1998; Banks et al. 2002; National Alliance for Caregiving 2005; Pakenham et al. 2006; Svanberg et al. 2010; Purcal et al. 2012; Shifren and Chong 2012; Andreouli et al. 2013; Cassidy and Giles 2013; Kavanaugh 2014; Cunningham et al. 2017) including personal care, companionship, domestic responsibilities and looking after able-bodied siblings. Four studies differentiated between these types by distinguishing between appropriate responsibilities and those that were deemed inappropriate (e.g., toileting, administering medication and emotional support) for children (Office of National Statistics 1996; Earley and Cushway 2002; Early et al. 2006; McAndrew et al. 2012).

Several studies have attempted to combine these foci on quantity and type of care through consideration of impact. According to this impact approach, young carers are those who are impacted by their caring role (Aldridge and Becker 1999; National Strategy for Carers 1999; Bibby and Becker 2000) or whose lives are restricted by the role that they take on (Dearden and Becker 1997; Becker et al. 1998; Earley and Cushway 2002; Thomas et al. 2003).

However, research, policy and legislation have increasingly moved away from differentiating young carers as those with greater responsibilities. Olsen (2000) was the first of 14 studies (Newman 2002; Butler and Astbury 2005; Aldridge 2006, 2018; Pakenham et al. 2006; Warren 2007; Schlarmann et al. 2008; Shifren 2008; Rose and Cohen 2010; Moore et al. 2011; Barry 2011; Kennan et al. 2012; McAndrew et al. 2012) not to define a minimum threshold, with this also reflected in the Carers Strategy for Wales (2013) and the UK Care Act (2014). This serves to recognise that, while researchers have been predominantly interested in the experiences of those with higher-level responsibilities who potentially need greater support, they are part of a larger population of young carers.

A final evolution in the carer attribute concerns responsibilities as being unpaid. First appearing in research by the National Alliance for Caregiving (2005) in the USA, this was referenced in nine sources (Becker 2007; Sahoo and Suar 2009; Svanberg et al. 2010; Purcal et al. 2012; Andreouli et al. 2013; Hamilton and Adamson 2013; Children and Families Act 2014; Stamatopoulos 2015). However, based on further consideration of the National Alliance for Caregiving report, the use of ‘unpaid care’ is an alternative term to ‘informal care’ and reflects the support provided by family members as opposed to professional carers. The language is particularly common in international research and the increasing use reflects young carers research as an increasingly global field.

4.2.3 *Care receiver relationship to child*

Having focused on the evolution of the age and carer status attributes which feature in all evidence sources, the relationship of the care receiver to the child (Insert 4.3), and the needs of the care receiver are now considered.

Insert 4.3 Evidence statement 3: Care receiver relationship to child
The care receiver and the child are in the same family, with the care receiver often the parent but potentially any relative including grandparent or sibling. Some sources also specify that the child and the care receiver live in the same household.

Forty-one sources specified the care receiver in terms of their relationship to the child. Thirty-seven sources, beginning with Aldridge and Becker (1993a) defined them as an unspecified relative (Jenkins and Wingate 1994; Office of National Statistics 1996; Dearden and Becker 1997, 2000; Becker et al. 1998; Aldridge and Becker 1999; Becker 2000, 2007; Bibby and Becker 2000; Olsen 2000; Banks et al. 2001; Newman 2002; Underdown 2002; Thomas et al. 2003; Early et al. 2006; Pakenham et al. 2006, 2007; Moore and McArthur 2007; Warren 2007; Shifren 2008; Cline et al. 2009; Sahoo and Suar 2009; O'Dell et al. 2010; Rose and Cohen 2010; Barry 2011; Moore et al. 2011; Kennan et al. 2012; Purcal et al. 2012; Andreouli et al. 2013; Hamilton and Adamson 2013; Kavanaugh 2014; Stamatopoulos 2015; Assaf et al. 2016; Aldridge 2018). The UK Government's National Strategy for Carers (1999) and the Welsh Government's Carers Strategy for Wales (2013) also did not specify beyond a relative. There are, however, exceptions with Aldridge and Becker (1993b) limiting the care receiver to an adult, and Aldridge (2006) defining them as specifically the carer's parent.

Thirteen sources specified that the care receiver and child should be living in the same household (Jenkins and Wingate 1994; Aldridge and Becker 1993a, 1993b; Dearden and Becker 2000; Banks et al. 2001, 2002; Thomas et al. 2003; National Alliance for Caregiving 2005; Sahoo and Suar, 2009; Andreouli et al. 2013; Assaf et al. 2016; Aldridge 2018). This included the National Strategy for Carers (1999).

4.2.4 *Reason for care provision*

Insert 4.4 Evidence statement 4: Care receiver needs
The needs of the care receiver are most often due to an illness or disability that partially impacts their ability to look after themselves or other people in their family. Sources have increasingly explicitly stated the inclusion of mental health and substance misuse issues, and other expansions include language brokering, divorce, neglect and abuse.

The final attribute is the needs of the care receiver (Insert 4.4). Thirty-nine sources considered the care receiver needs, which has seen substantial evolution in comparison to the other attributes. Aldridge and Becker (1993a, 1993b) originally defined the needs of the care receiver as resulting from an illness or disability. This is specified in an additional 16 evidence sources (Dearden and Becker 2000; Olsen 2000; Banks et al. 2001; Newman 2002; Thomas et al. 2003; Early et al. 2006; Moore and McArthur 2007; Pakenham et al. 2007; Warren 2007; Schlarmann et al. 2008; O'Dell et al. 2010; Rose and Cohen 2010; Barry 2011; Ali et al. 2013; Andreouli et al. 2013; Aldridge 2018), with a further six studies expanding this to explicitly include old age and frailty (Aldridge and Becker 1993b; Becker et al. 1998; National Alliance for Caregiving 2005; Sahoo and Suar 2009; Stamatopoulos 2015; Assaf et al. 2016).

One of the key areas of debate concerning definition relates to the inclusion of young people who care for people with substance misuse and mental health issues. Dearden and Becker (1997) was the first of 19 sources (Becker et al. 1998; Aldridge and Becker 1999; National Strategy for Carers 1999; Becker 2000, 2007; Bibby and Becker 2000; Banks et al. 2002; National Alliance for Caregiving 2005; Aldridge 2006; Pakenham et al. 2006; Sahoo and Suar 2009; McAndrew et al. 2012; Purcal et al. 2012; Ali et al. 2013; Hamilton and Adamson 2013; Stamatopoulos 2015; Assaf et al. 2016; Cunningham et al. 2017) to incorporate care receivers with mental health issues in the definition of young carers. This includes Aldridge (2006) who specifically studied children with caring responsibilities for parents with mental health issues.

In contrast, substance misuse was referenced in an additional 11 study definitions (Becker et al. 1998; Pakenham et al. 2006; Cline et al. 2009; Sahoo and Suar 2009; Moore et al. 2011; McAndrew et al. 2012; Purcal et al. 2012; Hamilton and Adamson 2013; Stamatopoulos 2015; Assaf et al. 2016; Cunningham et al. 2017), with Moore et al. (2011) conducting research with this population alone. The National Strategy for Carers (1999) again included care receivers with substance misuse issues in their definition of young carers.

The dataset also included studies that expanded the reason for the care receiver requiring support further. Stamatopoulos (2015) included children caring as a result of parent or family absence, stating that it was a recent socio-demographic change that should be incorporated. Thomas et al. (2003) included children who were taking on

responsibilities because their parents lacked the skills to care for them. In researching young carers and language brokers together, Cline et al. (2009) recognised the similarities of these groups in taking on responsibilities beyond that of other children, though he also identified differences in terms of the communities that they are part of and the support that they receive. Lastly in conducting a literature review of young carers and parentification (therefore including disability but also marital conflict, divorce and sexual abuse), Earley and Cushway (2002) found a limited overlap between the two areas.

4.3 Antecedents to the young carer phenomenon

Having detailed how the four attributes of the young carer phenomenon have evolved over time, the concept analysis also identified antecedents that can be a precursor to children becoming carers. Three groups of antecedents are detailed: the presence of a family illness or disability; social conditions; and family circumstances.

4.3.1 *Family illness and disability*

With care receiver need an attribute for the phenomenon, family illness or disability is an antecedent. Aldridge and Becker (1999) was the first source in the dataset to recognise this and stated that ‘the ‘trigger’ for children undertaking care responsibilities is the onset or presence of parental ill-health or disability’ (p. 304). An additional five sources referenced how the nature of the illness can affect the care receiver’s independence, needs and parenting capacity (Warren 2007) and affect the caring responsibilities of the child (Becker 2000, 2007; Hamilton and Adamson 2013; Kavanaugh 2014).

Many evidence sources referenced research prior to the young carers field concerning the parenting practices of disabled people and their suitability to be parents. However, with the exception of Thomas et al. (2003) and (Aldridge 2006) equating mental health and substance misuse issues with a parental deficiency, there was little evidence of this thinking in young carers research.

4.3.2 Social conditions and the need for professional support

The second antecedent group relates to social conditions for disabled people and their families. Dearden and Becker (1997) identified community care legislation as increasing the number of disabled people in the community and the increased expectation on families to provide support. This was referenced by an additional seven evidence sources (Bibby and Becker 2000; Dearden and Becker 2000; Banks et al. 2001; Thomas et al. 2003; Eley 2004; Becker 2007; Purcal et al. 2012) that also recognised the impacts of reduced state provision for these families.

The evidence also highlights a change in the perception of what form professional support should take in order to reduce caring by children. While Aldridge and Becker (1993b) was the first of 12 studies (Becker et al. 1998; Aldridge and Becker 1999; Becker 2000; Dearden and Becker 2000; Thomas et al. 2003; Eley 2004; Warren 2007; Sahoo and Suar 2009; Hamilton and Adamson 2013; Kavanaugh 2014; Aldridge 2018) to recognise that professional care for the disabled person will reduce responsibilities within the family, there has also been an increasing recognition that supporting disabled people increases their independence and autonomy. This reduces their needs and also support them as parents (Aldridge and Becker 1999; Banks et al. 2002; Aldridge 2006, 2018; Becker 2007; O'Dell et al. 2010).

4.3.3 Family circumstances

Family structure was a key antecedent with children less likely to become carers when there were other family members present (Becker 2000, 2007; Banks et al. 2002; Hamilton and Adamson 2013), including relatives from outside the household (Aldridge and Becker 1993a, 1999). In contrast, the lack of other adults (Becker et al. 1998) and particularly the presence of lone parent families (Office of National Statistics 1996; National Strategy for Carers 1999; Bibby and Becker 2000; Banks et al. 2002; Aldridge 2006, 2018; Shifren 2008; Sahoo and Suar 2009; Barry 2011; McAndrew et al. 2012; Purcal et al. 2012; Shifren and Chong 2012) increased this likelihood.

The availability of adult family members to care can be limited by poverty and low income. This was identified by Aldridge and Becker (1993a, 1993b) and has featured in

16 evidence sources (Office of National Statistics 1996; Dearden and Becker 1997, 2000; Becker 2000, 2007; Bibby and Becker 2000; Olsen 2000; Banks et al. 2001; Butler and Astbury 2005; Warren 2007; Sahoo and Suar 2009; Barry 2011; Purcal et al. 2012; Aldridge 2018). This resulted in family members needing to work (Thomas et al. 2003; Kavanaugh 2014), but also families being unable to afford professional carer support (Aldridge and Becker 1993a; Dearden and Becker 2000; Olsen 2000; Becker 2007; Sahoo and Suar 2009; Barry 2011; Hamilton and Adamson 2013).

Lastly, other family members may be present and available but children are more likely to become young carers if they are unwilling to provide support (Aldridge and Becker 1993a, 1993b, 1999; Office of National Statistics 1996; Becker et al. 1998; Olsen 2000; Banks et al. 2001, 2002; Moore and McArthur 2007; Assaf et al. 2016). Becker et al. (1998), Warren (2007) and Rose and Cohen (2010) all considered family dynamics and power relations, and found that children were less able to refuse to provide care compared to other family members.

4.4 Consequences of caring

This concept analysis has considered the four attributes of the phenomenon and the three antecedent groups that have the potential to lead to a child becoming a carer. The final element is the consequences of caring reported in the dataset. Four groups of consequences are considered in the chronological order of the evidence sources: fear of intervention and stigma; restricted lives; health impacts; and psychosocial impacts.

4.4.1 *Fear of intervention and stigma*

Aldridge and Becker (1993a, 1993b) identified a fear among families of state intervention as a consequence of the phenomenon. This fear has been referenced by an additional 15 studies (Jenkins and Wingate 1994; Dearden and Becker 1997; Becker et al. 1998; Banks et al. 2002; Underdown 2002; Early et al. 2006; Pakenham et al. 2006; Moore and McArthur 2007; Cline et al. 2009; Sahoo and Suar 2009; O'Dell et al. 2010; Rose and Cohen 2010; Barry 2011; Kennan et al. 2012; Cunningham et al. 2017) and by

the Carers (Recognition and Services) Act Practice Guide (1995), with families viewing authorities as more likely to take young carers into care than provide them with support.

A second fear concerns stigma, either due to the care receiver's disability or the child's carer status. This was identified in early research (Aldridge and Becker 1993a) and became increasingly prominent over time (Becker et al. 1998; Banks et al. 2002; Underdown 2002; Thomas et al. 2003; Butler and Astbury 2005; Pakenham et al. 2006; Moore and McArthur 2007; Cline et al. 2009; Sahoo and Suar 2009; Barry 2011; McAndrew et al. 2012). Together this fear of state intervention and stigma have created a reluctance in the family for the young carer to be identified.

4.4.2 Restricted lives and a loss of childhood

Aldridge and Becker (1993a, 1993b) referred to young carers as experiencing a 'loss of childhood'. While this has been adopted in seven subsequent sources (Jenkins and Wingate 1994; Dearden and Becker 1997, 2000; Banks et al. 2001; Schlarmann et al. 2008; Cline et al. 2009; O'Dell et al. 2010), ten have instead focused on caring as restricting their lives (Office of National Statistics 1996; Dearden and Becker 1997; Becker et al. 1998; Aldridge and Becker 1999; Becker 2000, 2007; Banks et al. 2001; Butler and Astbury 2005; Pakenham et al. 2006; Cline et al. 2009).

Research has increasingly detailed these restrictions with a report by the Office of National Statistics (1996) the first of 21 evidence sources (Becker et al. 1998; Becker 2000; Bibby and Becker 2000; Banks et al. 2001; Newman 2002; Thomas et al. 2003; Eley 2004; Butler and Astbury 2005; Early et al. 2006; Pakenham et al. 2006, 2007; Schlarmann et al. 2008; Cline et al. 2009; Sahoo and Suar 2009; O'Dell et al. 2010; Rose and Cohen 2010; McAndrew et al. 2012; Purcal et al. 2012; Hamilton and Adamson 2013) including the National Strategy for Carers (1999) to identify a lack of spare time. In addition, 26 studies highlighted the isolation of young carers due to a loss of friendships and the potential for bullying (Dearden and Becker 1997; National Strategy for Carers 1999; Becker 2000; Banks et al. 2001, 2002; Underdown 2002; Eley 2004; Butler and Astbury 2005; Aldridge 2006; Early et al. 2006; Pakenham et al. 2006, 2007; Schlarmann et al. 2008; Shifren 2008; Cline et al. 2009; Moore et al. 2009; Sahoo and Suar 2009; O'Dell et al. 2010; Rose and Cohen 2010; Barry 2011; McAndrew et al.

2012; Shifren and Chong 2012; Kavanaugh 2014; Stamatopoulos 2015; Cunningham et al. 2017).

Restrictions to education were also evidenced (Bibby and Becker 2000; Newman 2002; Purcal et al. 2012). This was initially identified by the Office of National Statistics (1996) in relation to school attendance and the accessing of additional educational opportunities, and subsequently referenced in an additional 14 sources (Becker et al. 1998; Aldridge and Becker 1999; Becker 2000; Dearden and Becker 2000; Banks et al. 2002; Thomas et al. 2003; Eley 2004; Butler and Astbury 2005; Early et al. 2006; Schlarmann et al. 2008; Sahoo and Suar 2009; McAndrew et al. 2012; Stamatopoulos 2015; Cunningham et al. 2017). This has been extended with 14 sources focusing on low attainment and an early school leaving age (Aldridge and Becker 1999; National Strategy for Carers 1999; Becker 2000, 2007; Dearden and Becker 2000; Banks et al. 2002; Eley 2004; Moore and McArthur 2007; Sahoo and Suar 2009; Barry 2011; Shifren and Chong 2012; Ali et al. 2013; Kavanaugh 2014; Stamatopoulos 2015).

4.4.3 Health impacts

The final two sets of consequences are comparatively recent and concern health and psychosocial impacts. Bibby and Becker (2000) identified mental health impacts including stress and depression. These impacts have become common reference points and feature in an additional 12 sources (Dearden and Becker 2000; Banks et al. 2001; Thomas et al. 2003; Pakenham et al. 2006, 2007; Sahoo and Suar 2009; Rose and Cohen 2010; Barry 2011; Shifren and Chong 2012; Kavanaugh 2014; Stamatopoulos 2015; Cunningham et al. 2017). Additional mental health consequences in the dataset include tiredness and fatigue (Banks et al. 2001, 2002; Thomas et al. 2003; Schlarmann et al. 2008; Sahoo and Suar 2009; Rose and Cohen 2010; Stamatopoulos 2015) and frustration (Thomas et al. 2003; Pakenham et al. 2006; Rose and Cohen 2010).

Impacts on physical health, often attributed to manual support of the care receiver, were identified by Dearden and Becker (1997) and subsequently referenced in an additional 12 sources (Becker et al. 1998; Bibby and Becker 2000; Dearden and Becker 2000; Banks et al. 2001; Newman 2002; Thomas et al. 2003; Butler and Astbury 2005; Moore

and McArthur 2007; Sahoo and Suar 2009; Purcal et al. 2012; Ali et al. 2013; Stamatopoulos 2015).

4.4.4 *Psychosocial impacts*

The final set of consequences concern psychosocial impacts and, while the other consequences were predominantly negative these were more positive. Bibby and Becker (2000) was the first of nine evidence sources to reference the development of caring skills and domestic skills (Dearden and Becker 2000; Thomas et al. 2003; Becker 2007; Moore and McArthur 2007; Pakenham et al. 2007; Rose and Cohen 2010; Moore et al. 2011; Cassidy and Giles 2013).

Bibby and Becker (2000) were also the first of 12 studies to identify increased maturity, independence and empathy (Dearden and Becker 2000; Banks et al. 2001; Thomas et al. 2003; Pakenham et al. 2007; Becker 2007; Moore and McArthur 2007; Sahoo and Suar 2009; Rose and Cohen 2010; Svanberg et al. 2010; Moore et al. 2011; Cassidy and Giles 2013). The development of these life skills potentially explains the improved relationships within the family reported by 13 sources (Aldridge and Becker 1993b; National Strategy for Carers 1999; Dearden and Becker 2000; Banks et al. 2001; Thomas et al. 2003; Becker 2007; Moore and McArthur 2007; Schlarmann et al. 2008; Sahoo and Suar 2009; Rose and Cohen 2010; Barry 2011; Moore et al. 2011; Kavanaugh 2014), though sources also reported rifts and isolation within a minority of families (Aldridge and Becker 1993a; National Strategy for Carers 1999; Moore and McArthur 2007).

Finally, there is evidence of the development of coping strategies. Becker (2007) and Cassidy and Giles (2013) identified beneficial strategies that resulted in increased resilience, but there is also evidence of negative coping strategies concerning risky behaviour, self-harm and substance misuse (Banks et al. 2001; Sahoo and Suar 2009; Stamatopoulos 2015).

4.5 Identifying an acceptable range, and defining the young carer phenomenon

The analysis of 55 evidence sources in this concept analysis has resulted in the identification of four attributes for the young carer phenomenon. These are age, their caring status, the relationship of the care receiver to the child, and the needs of the care receiver. In addition, the identification of three antecedent groups and four sets of consequences has helped build a picture of the lives of young carers.

The final part of the concept analysis is to define the young carer phenomenon for the purpose of this research study. The definition is justified by differentiating between genuine evolutions of the young carer concept and the development of related concepts.

Age

The first attribute enables a demonstration of how a concept can become ambiguous over time, as well as the value of the concept analysis approach in resolving this. Concerning the age attribute, the majority of studies defined young carers as under 18 and with no minimum age. While several studies expanded this to consider carers during transition to adulthood (up to the age of 24), there is already a recognition that they are a separate subgroup of young adult carers. In identifying young adult carers as a related concept the similarities are acknowledged, but it is also accepted that there are substantial differences. Considering them together risks confusing their respective experiences and challenges, while separating them enables specific investigation and potentially different solutions.

Carer status

Early studies focused on children who passed a certain threshold of caring responsibilities, initially on the basis of quantity of care, but later also type of responsibilities or impact. However, the concept analysis identified an increasing focus in research, policy and legislation on the inclusion of all children with caring responsibilities irrespective of level. In accepting this broader definition, it is recognised that young carer researchers traditionally seek to investigate the lives of

those with greater responsibilities in order to assess how to support them. However, there is merit in investigating the lives and experiences of the whole population to help understand how the impacts vary and the point at which caring becomes problematic.

Relationship of the care receiver to the child

With the exception of deviations in individual studies that referenced the care receiver as a parent or an adult, sources identified the care receiver as any family member. Evolution in the attribute concerned the limiting of the care receiver to being in the same household, therefore excluding young carers with responsibilities for family members who lived separately. However, with the acceptance that the care receiver and young carer should be related, there appeared to be no justification for this further limitation.

The needs of the care receiver

The final attribute, the care receiver's needs is the most complex. This is due to considerable evolution from the initial intention to focus on illness and disability, with subsequent debate over the inclusion of substance misuse and mental health issues as types of illness, but more recent extensions concerning parentification, divorce, abuse and language brokering. The original attribute and each of the evolutions are considered using the same approach demonstrated with the age attribute, where young carers and young adult carers were compared in terms of their different experiences and needs.

Considering the original intention of the care receiver need attribute, it sought to identify individuals who were at least partially unable to care for themselves or other family members due to an illness or disability. This reflects the fact that not every disabled person is a care receiver, and that they would not necessarily be fully dependent, but at some level those receiving care struggle to manage alone. Therefore, while the nature of care receivers' illnesses and disabilities are extremely diverse, they share a need for support on a medical basis. In providing this support young carers have experiences in common.

In accepting the diverse nature of the care receiver's illnesses and disabilities, the attempt to incorporate substance misuse and mental health issues diversifies the attribute further. However, the central core of the original intention still applies to them: there is a medical necessity for support due to the family member with mental health or substance misuse issues being at least partially unable for them to care for themselves or provide care for others. In addition, there is also potential for overlaps in the caring responsibilities, the impacts of these responsibilities and the interventions that they would benefit from.

Further expansion concerns the inclusion of language brokering, parental absence, neglect, abuse and divorce, and their incorporation is more problematic. The medical need for support that underpins care receivers' illnesses, disabilities, poor mental health or substance misuse issues is absent. As a result, the child's responsibilities and therefore the impacts and possible solutions are different.

Considering each in turn, language brokering is not a medical necessity but a social challenge of integrating family members in a society where people speak a different language. With the possible exception of children who translate for people with hearing impairments where there is a greater overlap, the experiences of young carers are likely very different from language brokers. This has been admitted by Cline et al. (2009) who recognised that the needs and the required interventions for the respective groups are different, and there is little value in considering potential interventions for young carers based on the experiences of language brokers, or vice-versa.

Turning to parental absence and divorce together, the expectation of children to look after themselves and siblings because parents are not present is again the result of a social problem. There may be overlaps in terms of some of the responsibilities taken on but, in a field oriented towards solutions, interventions for the two groups are likely very different. While there is a need to study the impacts of parental absence and divorce of families (Stamatopoulos 2015), this should not be as part of the young carer population.

Final consideration is given to neglect and sexual abuse. More than any of the other recent extensions considered there is little in common between the experiences of young carers and those of neglected and abused children. There is also little in common

between disabled people and abusive partners, with interventions grounded in positive support for the first group and criminal investigation for the second.

Study definition

On the basis of the four attributes the following definition is adopted for this study Insert 4.5, with the exact wording achieved through adapting Becker's definition in the Blackwell Encyclopaedia of Social Work (Becker 2000):

Insert 4.5 Definition of young carers for study
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Children and young persons under 18 who provide, or intend to provide, care, assistance or support to another family member (or members) due to an illness or disability, mental health or substance misuse issue. They assume a level of responsibility which may, depending on the support that is in place both within and from outside the family, have an impact on their lives.

4.6 Chapter summary

This chapter has reported the results of a concept analysis to explore how the young carer phenomenon has evolved over a 25-year period. The analysis of 55 studies identified four attributes (age, carer status, familial relationship of the care receiver to the child, and care receiver need). The evolution of each was considered, enabling the development of a definition for this study.

The results of the concept analysis and subsequent definition are integral to the realist synthesis and the development of the model. The definition informs the search strategy, the development of inclusion criteria and the screening of the papers. In addition, the antecedents and consequences enable the initial theorising and model development process. The next chapter presents the results of the realist synthesis and the initial model of young carer mental health and psychosocial wellbeing.

Chapter Five

Realist synthesis results

This chapter completes the first research stage, the development of an initial model of young carers' mental health and psychosocial wellbeing. Chapter Three detailed the realist synthesis procedure for the model development including the search, screening and analysis of previous research.

This chapter includes the results of the screening process, a summary of the primary and secondary papers that were included in the realist synthesis and brief consideration of the dataset. A high-level organising construct of the model is introduced consisting of three domains: *caregiving responsibilities*; *support*; and *identity*. Each domain, and the multiple CMO (Context-Mechanism-Outcome) configurations contained within, is considered in turn, with a focus on how contextual factors trigger mechanisms to produce differing outcomes for children depending on their individual circumstances.

The chapter concludes with a discussion on the strengths of the model and the potential to inform future interventions. Limitations are also considered in terms of the variable amounts of evidence informing each CMO configuration and the need to strengthen sections of the model. The need for further research with young carers who are not known to services, and for studies comparing young carers with children without caring responsibilities is highlighted, and this informs the second research component.

5.1 Search and screening results

Chapter Four included a flow diagram of the model development stage of the research. This includes the realist synthesis, with details of the papers that were excluded and progressed at the different stages. The realist literature search identified 15,518 results which were reduced to 12,391 unique results following deduplication. Having followed the procedure detailed in Chapter Three, the papers were screened at title ($n = 12,391$), abstract ($n = 4,351$) and full paper level ($n = 201$). Of the 72 papers that were progressed through the full paper review and prioritised by relevance and rigor, 16 were

identified as primary papers and analysed first to initially develop key concepts and configurations. Table 5.1 details the authors, publication year, country, participant recruitment source and method of data collection and analysis. Analysis of 28 secondary papers (Table 5.2) enabled the strengthening and modification of the configurations and model. The remaining 28 surplus papers were not analysed but are included in Appendix D.

5.1.1 Dataset properties

The final dataset included 44 studies, seven of which were also sources included in the concept analysis (Aldridge 2006; Aldridge and Becker 1993a; Cassidy and Giles 2013; Early et al. 2006; Kavanaugh 2014; Moore et al. 2011; Thomas et al. 2003). The papers had 40 different lead authors and spanned from 1993 (Aldridge and Becker) to 2018 (Kallander et al.; Tseliou et al). Seventeen of the studies were based in Europe including the UK (n=15), with 11 American and ten African studies.

The main sources of recruitment were services for the care receiver (n=12), mainstream education, health and social care services (n=12) and carer projects (n=11), while other studies continued research with participants recruited for previous research (n=5), worked with secondary data (n=4), or recruited through advertisements (n=3). One study did not disclose recruitment information.

The dataset included 18 qualitative, 18 quantitative and seven mixed methods studies with one study a literature review. Of the studies with qualitative components, interviews were the chosen method in 20 studies (Aldridge 2006; Aldridge and Becker 1993b; Bifulco et al. 2014; Bolas et al. 2007; Cree 2003; Doutre et al. 2013; Kain 2009; Kavanaugh 2013, 2014; Lane et al. 2015; McMahon and Luthar 2007; Moore et al. 2011; Olang'o et al. 2012; Olsen and Clarke 2003; Robson et al. 2006; Sahoo and Suar 2010; Skovdal 2011; Skovdal et al. 2009; Stein et al. 1999; Thomas et al. 2003), and focus groups in seven (Nichols et al. 2013; Olang'o et al. 2012; Robson et al. 2006; Skovdal 2011; Skovdal et al. 2009; Thomas et al. 2003; Williams et al. 2009). Case study (Gelman and Greer 2011; Skovdal and Ogutu 2009), ethnography (Andersen 2012; Hwang and Charnley 2010) and observational approaches (Olang'o et al. 2012; Trondsen 2012) were each utilised in two studies.

Table 5.1 Primary papers included in the realist synthesis

	Authors	Year	Country	Recruitment	Method	Data collection / Analysis
1	Kavanaugh	2013	USA	Care receiver services	Mixed	Interviews / Thematic analysis; Structural equation modeling
2	Olang'o et al.	2012	Kenya	Community services; Health services	Qualitative	Interviews; Focus groups; Observations / Content analysis
3	Moore et al.	2011	Australia	Advertisements; Services	Qualitative	Interviews / Thematic analysis
4	Skovdal	2011	Kenya	Community services	Qualitative	Photovoice; Essay writing; Interviews; Focus groups / Thematic network analysis
5	Early et al.	2006	UK	Carer projects	Quantitative	Questionnaire; Measure development
6	Nagl-Cupal et al.	2014	Austria	Schools	Mixed	Questionnaire / Cross-sectional descriptive analysis
7	Aldridge & Becker	1993b	UK	Community services; Health services; Social services	Qualitative	Interviews
8	Aldridge	2006	UK	Care receiver services	Qualitative	Interviews
9	Pakenham & Cox	2012	Australia	Care receiver services	Quantitative	Questionnaire / Longitudinal inferential analysis
10	Bolas et al.	2007	UK	Carer projects	Qualitative	Interviews / Interpretative phenomenological analysis
11	de Roos et al.	2017	Netherlands	Survey participants	Quantitative	Secondary data / Cross-sectional inferential analysis
12	Cree	2003	UK	Carer projects	Mixed	Questionnaire; Interviews / Descriptive statistics; Thematic analysis
13	Robson et al.	2006	Lesotho, Tanzania, Zimbabwe	Schools; Social services; Survey participants	Mixed	Focus groups; Interviews; Questionnaire / Descriptive analysis
14	Skovdal et al.	2009	Kenya	Community	Qualitative	Photovoice; Interviews; Focus groups / Thematic analysis
15	Lane et al.	2015	South Africa	Community; Schools	Mixed	Interviews / Descriptive analysis; Thematic analysis
16	Andersen	2012	Kenya	Health services	Qualitative	Ethnography

Table 5.2 Secondary papers included in the realist synthesis

	Authors	Year	Country	Recruitment	Method	Data collection / Analysis
17	Assaf et al.	2016	USA	Carer projects	Quantitative	Secondary data / Descriptive analysis
18	Bauman et al.	2007	USA, Zimbabwe	Previous research	Quantitative	Questionnaire / Cross-sectional analysis
19	Bifulco et al.	2014	UK	Care receiver services	Mixed	Interviews / Inferential analysis
20	Cassidy & Giles	2013	UK	Carer projects	Quantitative	Questionnaire / Measure development
21	Champion et al.	2009	USA	Advertisements; Previous research	Quantitative	Questionnaire / Cross-sectional inferential analysis
22	Coles et al.	2007	Australia	Care receiver services	Quantitative	Intervention evaluation; Questionnaire / Inferential analysis
23	Doutre et al.	2013	UK	Carer projects	Qualitative	Photovoice; Interviews / Interpretative phenomenological analysis
24	Fraser & Pakenham	2009	Australia	Parents; Schools; Youth services	Quantitative	Questionnaire / Inferential analysis
25	Gelman & Greer	2011	USA	Carer projects	Qualitative	Case study
26	Hwang & Charmley	2010	Korea	Care receiver services; Carer projects	Qualitative	Ethnography / Thematic analysis
27	Joseph et al.	2009	UK	Carer projects	Quantitative	Questionnaire; Measure development
28	Kain	2009	USA	Carer projects	Qualitative	Interviews / Grounded theory
29	Kallander et al.	2018	Norway / UK	Care receiver services	Quantitative	Questionnaire; Cross-sectional inferential analysis
30	Kavanaugh	2014	USA	Care receiver services	Quantitative	Interviews / Inferential analysis
31	Khafi et al	2014	USA	Previous research	Quantitative	Questionnaire / Longitudinal and cross-sectional analysis

32	Lloyd	2013	UK (Northern Ireland)	Survey participants	Quantitative	Secondary data / Cross- sectional inferential analysis
33	McMahon & Luthar	2007	USA	Advertisements	Quantitative	Interviews / Inferential analysis
34	Martin	2006	Zimbabwe	Health services	Qualitative	Secondary data analysis
35	Nichols et al.	2013	Canada	Previous research	Qualitative	Focus groups / Thematic analysis
36	Olsen & Clarke	2003	UK	Care receiver services	Mixed	Questionnaires; interviews / Descriptive statistics
37	Sahoo & Suar	2010	India	Care receiver services	Qualitative	Interviews / Cross-sectional content analysis
38	Sharer	2015	South Africa	Previous research	Quantitative	Secondary data / Inferential analysis
39	Skovdal & Ogutu	2009	Kenya	Not disclosed	Qualitative	Case studies; Photovoice / Thematic analysis
40	Stein et al.	1999	USA	Care receiver services	Quantitative	Interviews / Structural equation modeling
41	Thomas et al.	2003	UK	Carer projects; Community services; Health services; Schools; Social services	Qualitative	Focus groups; Interviews
42	Trondsen	2012	Norway / UK	Health services	Qualitative	Observations / Framework analysis
43	Tseliou et al.	2018	UK (Northern Ireland)	Survey participants	Quantitative	Secondary data / Cross- sectional inferential analysis
44	Williams et al.	2009	USA, Canada	Care receiver services	Qualitative	Focus groups / Content analysis

The 25 studies with quantitative components included six that utilised descriptive analysis (Assaf 2015; Bauman et al. 2007; Cree 2003; Lane et al. 2015; Olsen and Clarke 2003; Robson et al. 2006), and eight with inferential statistics (Bifulco et al. 2014; Champion et al. 2009; Coles et al. 2007; Fraser and Pakenham 2009; Kallander et al. 2018; Kavanaugh 2014; McMahon and Luthar 2007; Sharer 2015). Four utilised cross-sectional methods comparing young carers with non-caring peers (de Roos et al. 2017; Lloyd 2013; Nagl-Cupal et al. 2014; Tseliou et al. 2018) and two studied longitudinal change (Khafi et al. 2014; Pakenham and Cox 2012). Three studies developed measures for caregiving level or magnitude of impact (Cassidy and Giles 2013; Early et al. 2006; Joseph et al. 2009), and two utilised structural equation modeling (Kavanaugh 2013; Stein et al. 1999).

5.2 A realist model of young carers' mental health and psychosocial wellbeing

Having detailed the characteristics of the final dataset, this section outlines the resulting model. A high-level overview and organising construct precedes detailed consideration of the complex model in full.

The realist model contains 17 CMO configurations in three domains concerning caregiving responsibilities, identity and support. The *caregiving responsibilities* domain concerns the impact of the caring tasks which varied with the circumstances of young carers, care receivers and wider families. The *support* domain focuses on the assistance provided to young carers by different levels of society including family members, friends, neighbours, schools, health services and young carer projects. The *identity* domain considers the development of a caring identity within the wider identity.

The organising construct (Figure 5.1) demonstrates how the three domains interact with each other. *Caring responsibilities* lead to the development of a caring *identity* which, if positive, can help to mitigate the negative effects of caring and increase benefits. *Support* is a moderator for the effects of responsibilities, and positive assistance can mitigate negative impacts and enables benefits. However, poor quality support can

exacerbate the negative impacts. The quality of support also affects perception of caring and whether they value the role.

The three domains are considered in turn, starting with *caregiving responsibilities*, followed by *support* and *identity*. Appendix E contains a guide detailing each CMO configuration component, with excerpts from studies to demonstrate links between components.

5.2.1 *Caregiving responsibilities domain*

The *Caregiving responsibilities* domain (Figure 5.2) contains six CMO configurations relating to the responsibilities of the young carer and the person that they care for.

Figure 5.1 Organising construct

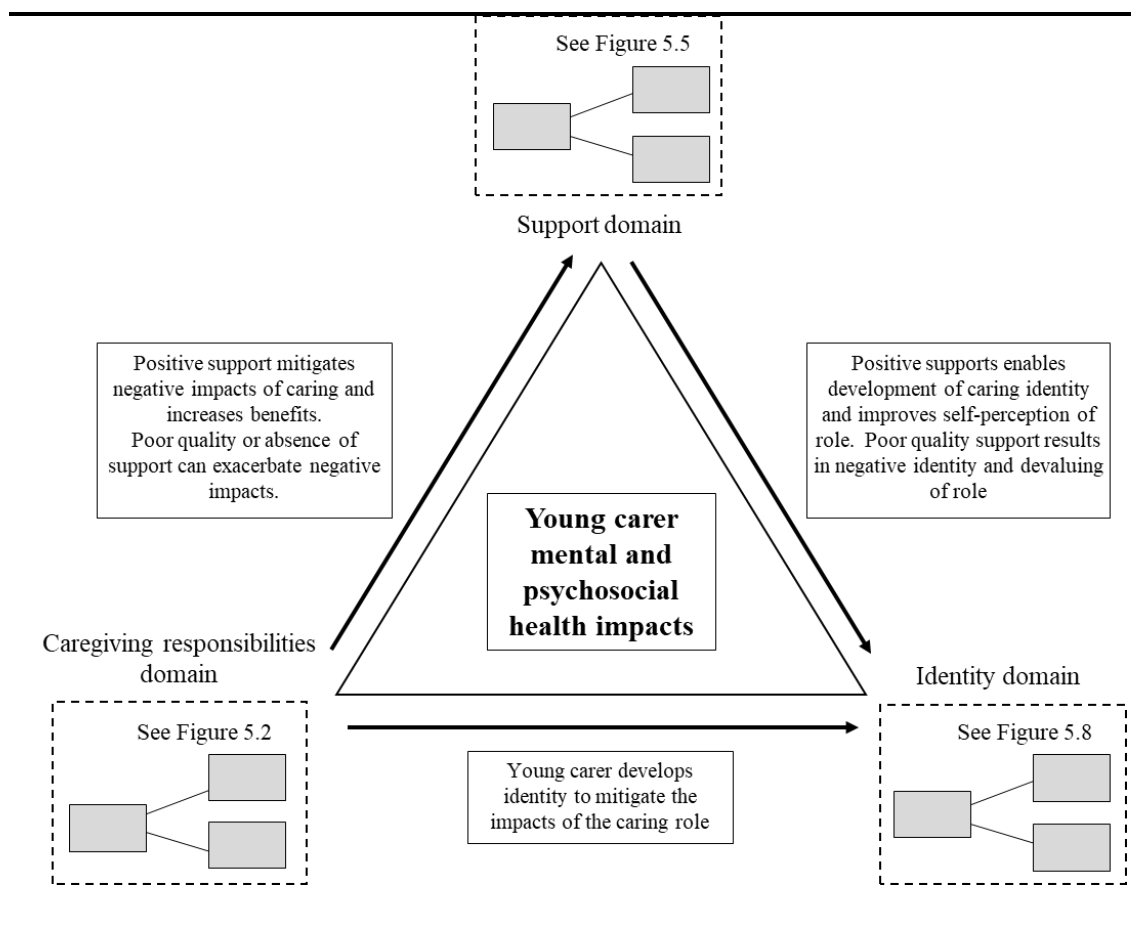
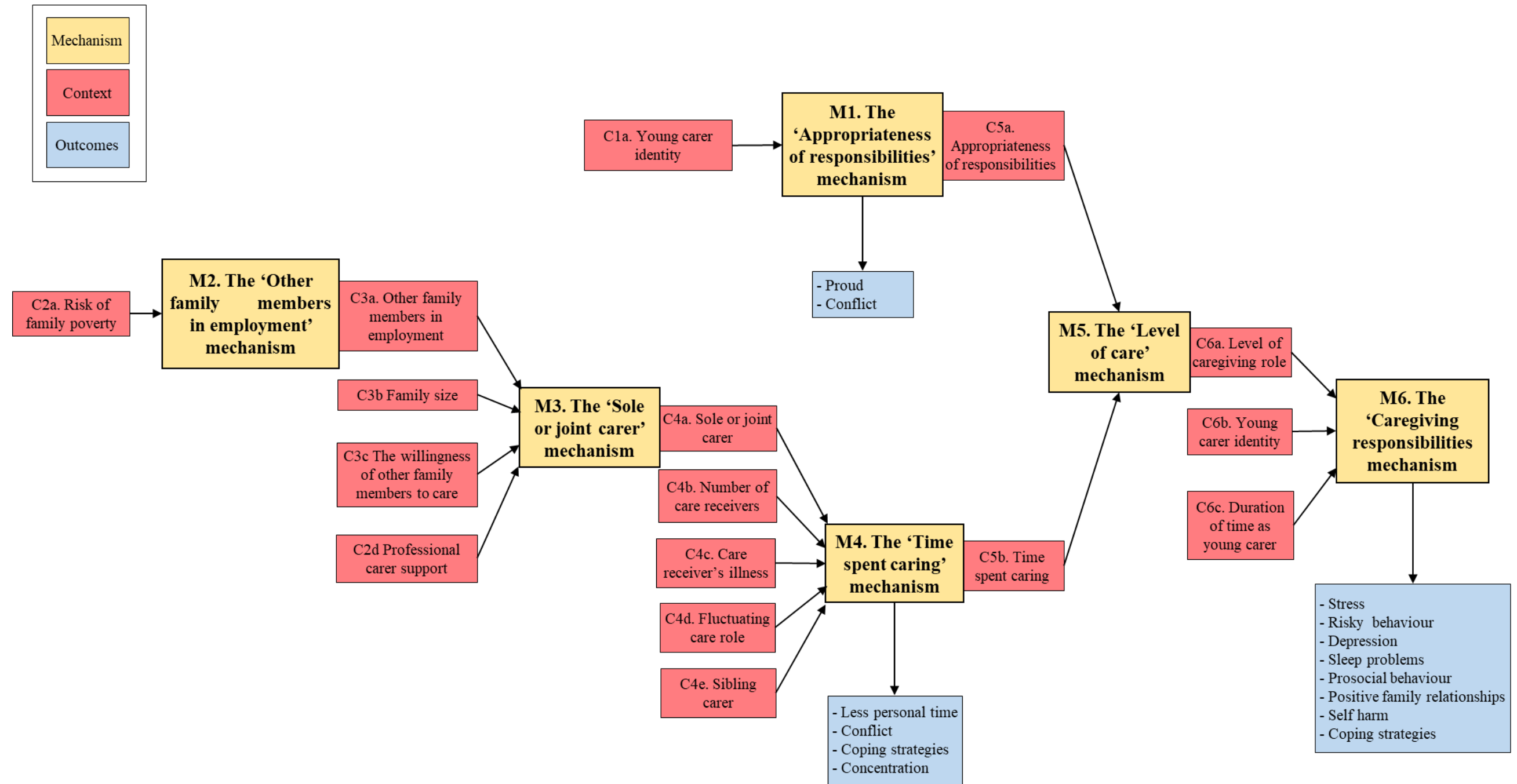


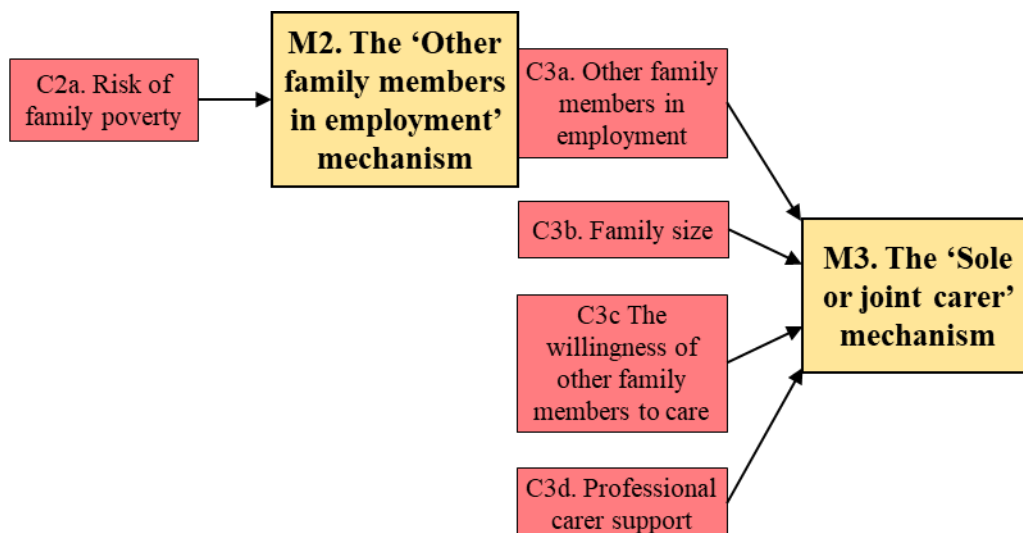
Figure 5.2 Caregiving responsibilities domain



The first configuration is informed by nine of the 44 studies and concerns the **Appropriateness of responsibilities** [CMO¹]. Specific tasks are identified as potentially inappropriate including toileting and bathing, dressing, administering medication, emotional care and physical support (Aldridge 2006; Aldridge and Becker 1993b; Kavanaugh 2014; Lane et al. 2015; Martin 2006; Pakenham and Cox 2012). This mechanism can potentially be triggered by the single contextual factor of the *young carer identity* [C^{1a}], specifically their age and development (Aldridge 2006; Bifulco et al. 2014; Lane et al. 2015; Martin 2006). Andersen (2012) suggested that intimate caring tasks can cause conflict, while Nichols et al. (2013) found evidence that young carers are proud of managing these difficult responsibilities.

The **Other family members in employment** configuration [CMO²] is informed by Gelman and Greer (2011) and Lane et al. (2015) and concerns the financial need for family members to work. The *risk of family poverty* is the single contextual factor [C^{2a}] that triggers the mechanism. This is an embedded configuration (Figure 5.3) as need for employment is also a contextual factor for the subsequent sole or joint carer configuration.

Figure 5.3 Example of an embedded configuration, with the 'Other family members in employment' mechanism [M²] also a contextual factor [C^{3a}] for the 'Sole or joint carer' mechanism [M³].

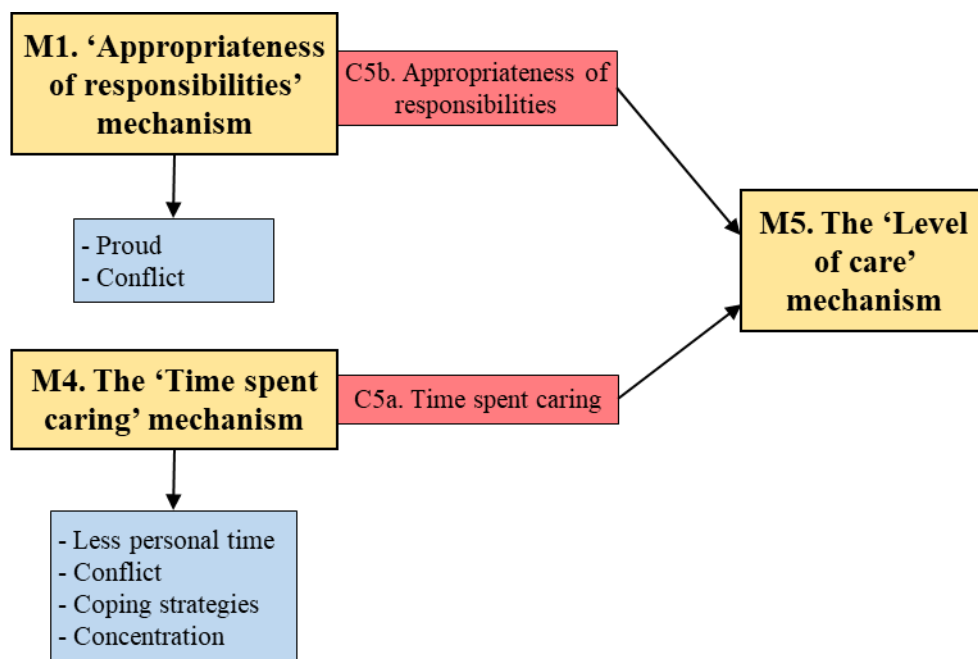


The **Sole or joint carer** configuration [CMO³] concerns the presence of other carers and contains evidence from nine studies. In addition to *other family members in employment* [C^{3a}], the configuration has three factors relating to the *family size* [C^{3b}] with the young carer potentially the only person in the home with the care receiver (McMahon and Luthar 2007; Moore et al. 2011; Olang'o et al. 2012; Olsen and Clarke 2003; Skovdal 2011; Skovdal and Ogutu 2009), the *willingness of other family members to care* [(Aldridge and Becker 1993b; Lane et al. 2015; Olsen and Clarke 2003) C^{3c}], and the provision of *professional carer support* [(Aldridge and Becker 1993b; Kallander et al. 2018; Lane et al. 2015; Olang'o et al. 2012; Olsen and Clarke 2003) C^{3d}].

Again, the *sole or joint carer* configuration is an embedded contextual factor [C^{4a}] in the subsequent **Time spent caring** configuration [CMO⁴] due to the presence of other carers reducing the responsibilities of the young carer (Aldridge and Becker 1993b; Kallander et al. 2018; Lane et al. 2015; Moore et al. 2011; Skovdal 2011; Skovdal and Ogutu 2009). The configuration is evidenced from 16 studies and has four additional contextual factors including the *number of care receivers* [(Skovdal 2011; Skovdal and Ogutu 2009) C^{4b}], the nature and severity of the *care receiver's illness* [(Andersen 2012; Assaf et al. 2016; Bauman et al. 2007; Gelman and Greer 2011; Joseph et al. 2009; Kallander et al. 2018; Kavanaugh 2013; Moore et al. 2011) C^{4c}] and the *fluctuating care role* over time [(Andersen 2012; Champion et al. 2009; Moore et al. 2011; Skovdal 2011; Skovdal and Ogutu 2009) C^{4d}]. Being a *sibling carer* for a non-disabled brother or sister due to another family member's illness is the final factor [(Andersen 2012; Lane et al. 2015; Moore et al. 2011; Sahoo and Suar 2010) C^{4e}]. Outcomes for the mechanism include a lack of time for other activities (Kallander et al. 2018; Sahoo and Suar 2010), the development of positive and negative coping strategies (Early et al. 2006), conflict (Kavanaugh 2013, 2014) and concentration problems (Lane et al. 2015).

The **Level of care** configuration [CMO⁵] is informed by six studies and is key to consideration of assessment. The two contextual factors are embedded configurations (Figure 5.4) that have been already detailed; *appropriateness of responsibilities* [(Lane et al. 2015) C^{5a}] and *time spent caring* [(Aldridge and Becker 1993b; Champion et al. 2009; Joseph et al. 2009; Kallander et al. 2018; Lane et al. 2015; Moore et al. 2011) C^{5b}].

Figure 5.4 The 'Level of care' mechanism has two contextual factors that are also embedded configurations: appropriateness of responsibilities [M¹; C^{5a}] and time spent caring [M⁴; C^{5b}].



Caregiving responsibilities is the final configuration [CMO⁶] and considers why caregiving impacts young people differently. The configuration is sourced from 11 studies and has three contextual factors. The first, *level of care* [(Lane et al. 2015) C^{6a}] is an embedded configuration. *Young carer identity* [C^{6b}] is key with evidence that female young carers are more likely to have emotional health issues including depression (Sharer 2015), risky behaviour, stress and self-harm (Cree 2003), and to develop negative coping strategies (Fraser and Pakenham 2009). In comparison males may develop more positive family relationships but also have higher emotional stress (McMahon and Luthar 2007), though this opposes findings by Stein et al. (1999). There is evidence that older young carers have increased problems with sleep, substance misuse, self-harm, stress (Cree 2003), risky behaviour and conduct problems (Stein et al. 1999). Minority ethnic young carers experience greater stress (Cree 2003) but also improved family relationships in comparison with other young carers (Khafi et al. 2014).

The final contextual factor, *duration of time as a young carer* [C^{6c}] can result in issues (Doutre et al. 2013) including poor concentration (Cree 2003). In addition, there was

conflicting evidence over how the impacts vary over time. While Cree (2003) had found evidence that stress is highest for middle-term carers, Aldridge (2006) warned of the negative impacts of inappropriate long-term care. Comparison studies identified poor mental health (Lloyd 2013; Tseliou et al. 2018) and greater involvement in risky behaviour (Cree 2003) among young carers in comparison to non-caring children.

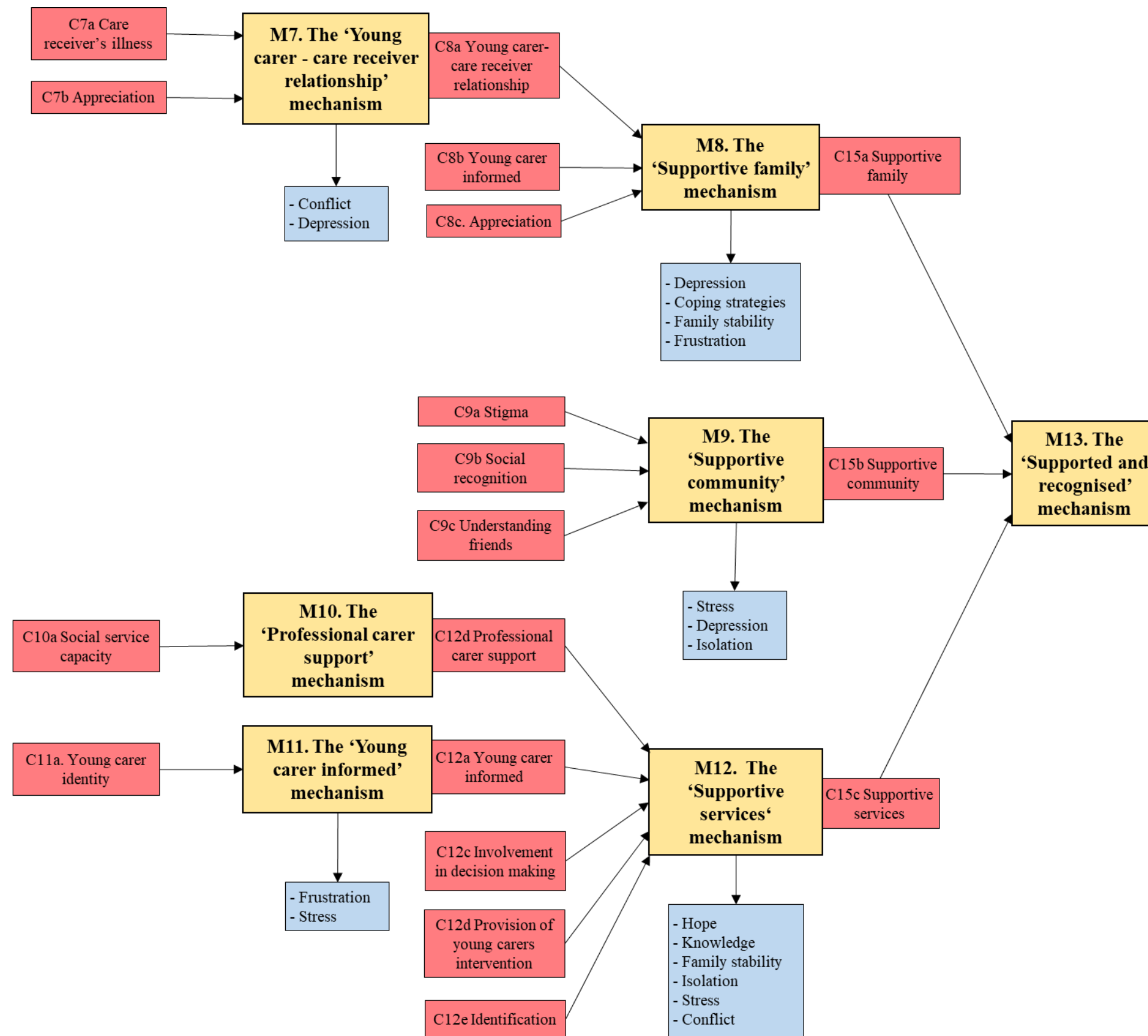
5.2.2 *Support domain*

The second domain considers the *support* that is available to young carers from differing levels of society including their families, friends, neighbours, services and young carer project support. The presence of high-quality support has the potential to improve their outcomes, while either poor-quality support or an absence of assistance can be detrimental. The domain includes seven configurations (Figure 5.5).

The **young carer – care receiver relationship** configuration [CMO⁷] is informed by eight studies and has two contextual factors. Symptoms relating to the severity of the *care receiver's illness* [C^{7a}] have the potential to affect their behaviour and relationship with the young carer (Aldridge and Becker 1993b; Bolas et al. 2007; Martin 2006; Nichols et al. 2013), potentially resulting in conflict (Kavanaugh 2014). The relationship is also affected by *the appreciation* of the young carer by the care receiver (Kain 2009; Martin 2006) C^{7b}), with the potential for depression (Bauman et al. 2007) when young carers do not feel fully appreciated (Kavanaugh 2013, 2014).

The **Supportive family** configuration [CMO⁸] is based on nine studies and has three contextual factors including the *young carer – care receiver relationship* configuration as an embedded configuration [(Kavanaugh 2013; Martin 2006; Nichols et al. 2013; Trondsen 2012) C^{8a}]. The *young carer informed* about the illness [C^{8b}] by family is important (Kain 2009; Nichols et al. 2013; Robson et al. 2006; Trondsen 2012) but Martin (2006) suggests that families are reluctant to tell the young person despite the evidence that this reduces frustration and enables the development of coping strategies. *Appreciation* within the family [C^{8c}] was also important (Kain 2009) with this increasing family stability (Nichols et al. 2013). Bauman et al. (2007), Kavanaugh (2013, 2014) and Sharer (2015) linked a lack of appreciation within the family with decreased depression.

Figure 5.5 Support domain



The **Supportive community** configuration [CMO⁹] refers to the support made available from friends and neighbours and contains data from 12 studies. The first of three contextual factors, *stigma* [C^{9a}] is due to particular illnesses being viewed as undesirable, for example AIDS (Bolas et al. 2007; Martin 2006; Olang'o et al. 2012; Skovdal and Ogutu 2009) or substance misuse (Moore et al. 2011), and can result in isolation from the community. In contrast, *social recognition* [C^{9b}] of the young carer can increase community support and reduce isolation (Andersen 2012; Skovdal et al. 2009; Skovdal and Ogutu 2009). The presence of *understanding friends* [C^{9c}] is the final contextual factor with friendships reducing the stress and depression caused by the caregiving itself (Kain 2009; Kavanaugh 2013; Nichols et al. 2013; Sharer 2015; Skovdal et al. 2009; Williams et al. 2009).

The **Professional carer support** configuration [CMO¹⁰] concerns the provision of formal support for the care receiver from outside the family. It is informed by four studies and has one contextual factor with *social services capacity* [C^{10a}] limiting the number of families who receive support (Aldridge 2006; Aldridge and Becker 1993b; Andersen 2012; Olang'o et al. 2012).

The **Young carer informed** configuration [CMO¹¹] relates to the provision of information from social care and health professionals that help the carer in their role. The configuration is evidenced by four sources and has a single contextual factor. *Young carer identity* [CMO^{11a}] concerns the appropriate age for young carers to receive information that may be distressing (Aldridge and Becker 1993b; Martin 2006; Nichols et al. 2013; Trondsen 2012). Trondsen (2012) found that a lack of information or training can cause stress and increase frustration.

Both *professional carer support* [(Aldridge 2006; Aldridge and Becker 1993b) C^{12a}] and *informed young carer* [(Aldridge and Becker 1993b; Martin 2006; Nichols et al. 2013) C^{12b}] are embedded contextual factors in the **Supportive services** configuration [CMO¹²] (Figure 5.6). The configuration concerns whether education, health, social services and young carer projects meet the needs of young carers and is informed by 11 sources. The configuration includes three further contextual factors, with evidence that young carers have rare *involvement in decision making* [(Andersen 2012; Martin 2006; Robson et al. 2006; Thomas et al. 2003) C^{12c}]. The *provision of young carers projects* [C^{12d}] are valued by service users as a place to meet other young carers and receive

support (Aldridge 2006; Kavanaugh 2013; Moore et al. 2011; Thomas et al. 2003) and benefits of these projects including reduced isolation and stress, increased knowledge of the illness and family stability (Coles et al. 2007). There is also evidence that the lack of *identification* [C^{12e}] by services increases isolation (Aldridge 2006; Aldridge and Becker 1993b; Thomas et al. 2003), with negative school experiences increasing conflict. In contrast positive experiences increase hope and improve mental health (Andersen 2012; Skovdal et al. 2009).

The final **Supported and recognised** configuration [CMO¹³] has three contextual factors and is based on eight sources (Aldridge 2006; Kain 2009; Kavanaugh 2013; Martin 2006; Nichols et al. 2013; Robson et al. 2006; Sharer 2015; Skovdal et al. 2009). Each contextual factor is an embedded configuration (Figure 5.7) concerning support from different levels of society, namely *family* [C^{13a}], *community* [C^{13b}], and *services* [C^{13c}].

Figure 5.6 The 'Supportive services' mechanism [CMO¹²] has five contextual factors. Two of these factors are embedded configurations: Professional carer support [C^{12a}; M¹⁰] and informed young carer [C^{12b}; M¹¹]

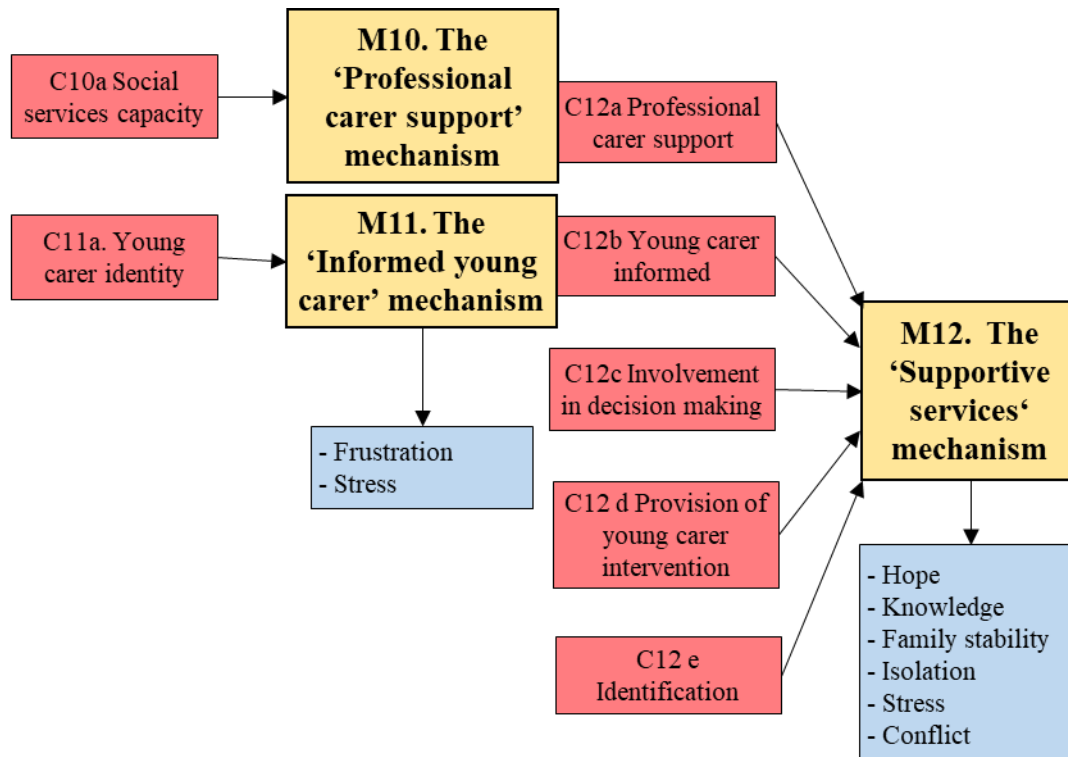
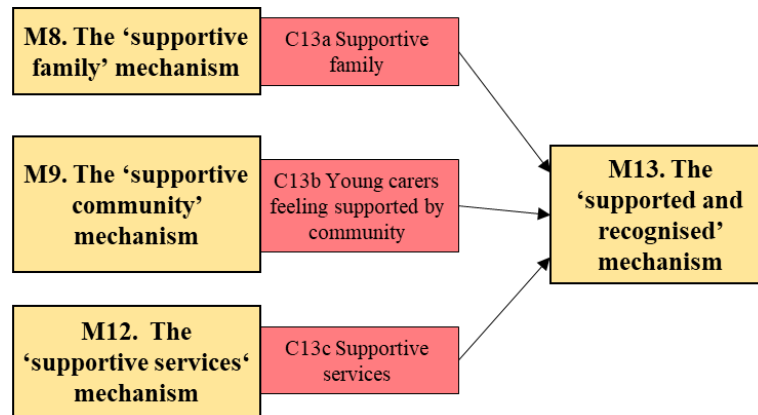


Figure 5.7 All three contextual factors for the 'Supported and recognised' mechanism [M¹³] are embedded configurations: 'Supportive family' [C^{13a}; M8], 'supportive community' [C^{13b}; M⁹], and 'Supportive services' [C^{13c}; M¹²]

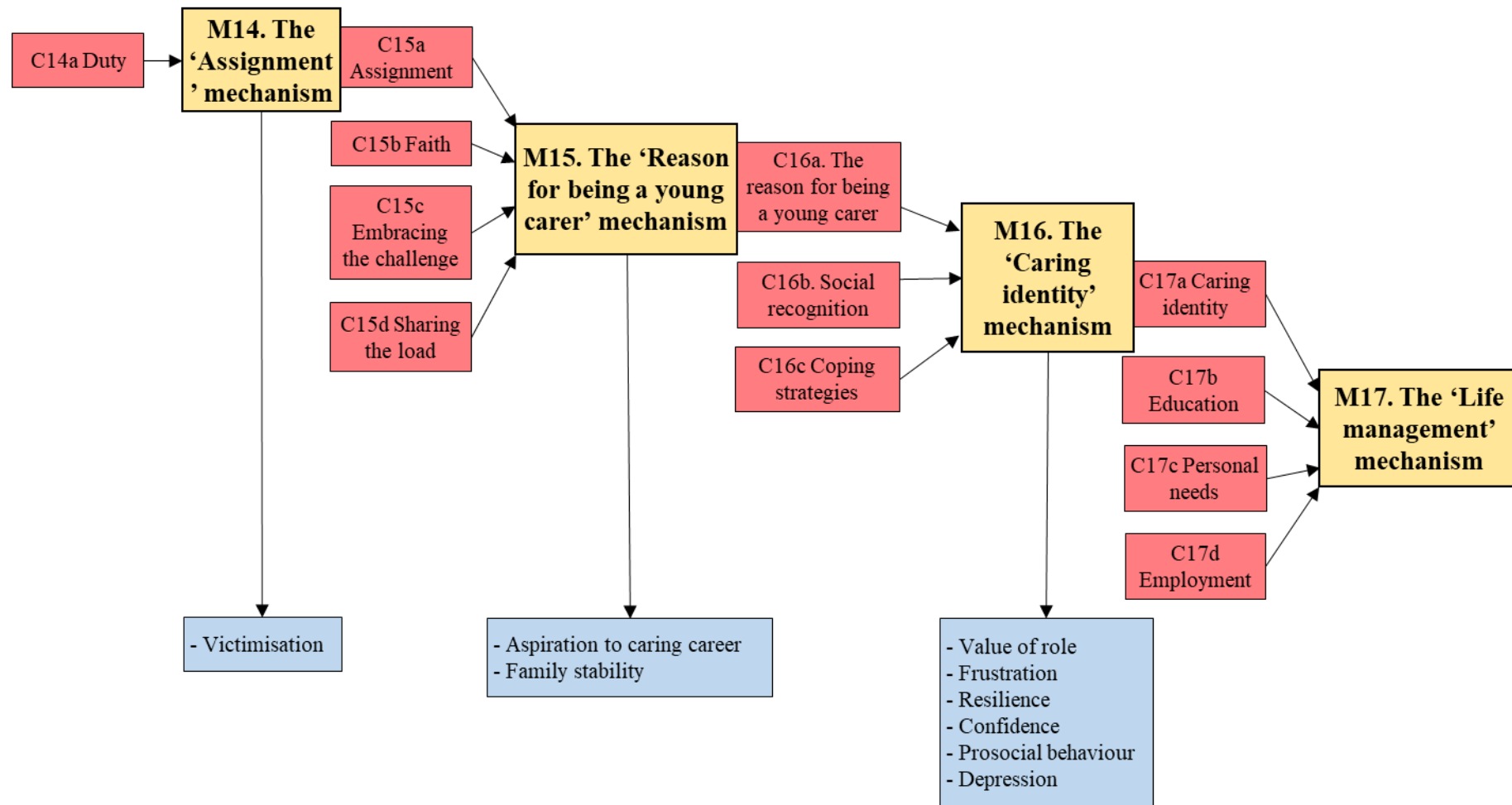


5.2.3 *Identity domain*

Up to this point the model has considered the impacts of *caregiving responsibilities*; and the *support* that can moderate these impacts. The final domain concerns the development of a caring *identity* and is a series of four configurations, each of which is embedded in the next configuration (Figure 5.8). Depending on the nature of the caring role and whether support is positive or negative, this identity enables the young carer to balance their caring responsibilities with other aspects of their life.

The first configuration, **Assignment** [CMO¹⁴] concerns how particular young people can be selected to be a carer by their family, and is evidenced by nine studies. A single contextual factor, *duty* [C^{14a}] predominantly reflects African (Andersen 2012; Lane et al. 2015; Olang'o et al. 2012; Robson et al. 2006; Skovdal 2011; Skovdal and Ogutu 2009; Skovdal et al. 2009) and South Korean cultures (Hwang and Charnley 2010) where children are raised to have a duty towards elderly or unwell relatives. In place of cultural duty Aldridge and Becker (1993) evidenced familial duty in the UK. Identity is central to this duty and there is evidence from multiple studies that gender is key, with females more likely to be selected as young carers (Olang'o et al. 2012; Robson et al. 2006; Skovdal 2011; Skovdal et al. 2009), though male young carers in Korea reflect the honour attached to the role (Hwang and Charnley 2010). Andersen (2012), Hwang and Charnley (2010) and Skovdal et al. (2009) also evidenced age as important with older young people becoming carers. Skovdal et al. (2009) and Skovdal and Ogutu (2009) found that assigned young carers can feel victimised in the role.

Figure 5.8 Identity domain



Assignment is embedded as one [(Skovdal 2011; Skovdal et al. 2009; Skovdal and Ogutu 2009) C^{15a}] of four contextual factors for the next configuration, **Reasons a young person becomes a young carer** [CMO¹⁵]. Ten studies inform this configuration with the remaining contextual factors including religious *faith* [(Andersen 2012; Skovdal 2011; Skovdal and Ogutu 2009) C^{15b}], *embracing the challenge* for young people who were interested in caring and potentially a caring career [(Kain 2009; Robson et al. 2006) C^{15c}], and *sharing the load* which can help to improve family stability and recognition of the young carer [(Bolas et al. 2007; Kain 2009; Nagl-Cupal et al. 2014; Olsen and Clarke 2003; Skovdal 2011; Trondsen 2012) C^{15d}].

The **Caring identity** configuration [CMO¹⁶] concerns whether the young person values the role and views their caring as a positive part of who they are. The configuration is based on eight studies with the *reason for becoming a young carer* embedded as one of three contextual factors [(Andersen 2012; Bolas et al. 2007; Skovdal 2011; Skovdal and Ogutu 2009) C^{16a}]. *Social recognition* of their role [(Andersen 2012; Bolas et al. 2007; Cassidy and Giles 2013; Skovdal 2011; Skovdal et al. 2009; Skovdal and Ogutu 2009) C^{16b}] is also key, as are *coping strategies* [C^{16c}]. These coping strategies can lead to positive adjustment including valuing the role (Skovdal 2011; Skovdal et al. 2009), resilience (Cassidy and Giles 2013), confidence and prosocial behaviour (Fraser and Pakenham 2009). However negative avoidance coping strategies causes the young carers' focus to be redirected away from caregiving, leading to poor adjustment, depression (Early et al. 2006; Fraser and Pakenham 2009) and frustration (Bolas et al. 2007).

The **Life management** configuration [CMO¹⁷] is sourced from nine studies and has four contextual factors. This includes the previous configuration, *caring identity* [(Andersen 2012; Cassidy and Giles 2013; Skovdal et al. 2009) C^{17a}] as an embedded contextual factor. Together with *education* [C^{17b}], *personal needs* [C^{17c}] and *employment* [C^{17d}], this factor demonstrates a complex and fluctuating balance that young carers attempt to manage (Cassidy and Giles 2013). Caring is often their top focus, leading to the de-prioritisation of school (Andersen 2012; Bauman et al. 2007; Kain 2009; Kavanaugh 2013; Olsen and Clarke 2003; Robson et al. 2006; Skovdal et al. 2009; Thomas et al. 2003) and their personal and social needs (Kain 2009; Kavanaugh 2013; Olsen and Clarke 2003; Skovdal et al. 2009). There is also evidence of young

carers working to raise income for their family as another part of this balance (Andersen 2012; Olsen and Clarke 2003; Skovdal et al. 2009).

5.3 Discussion

This chapter has detailed the development of a model of young carers' mental health and psychosocial wellbeing, based on the analysis of 44 studies. The model included three domains concerning the *caregiving responsibilities* of young carers, the presence or absence of *support* and the development of a *caregiving identity*.

The remainder of this chapter considers the strengths and limitations of the realist synthesis method and the resulting model. Particular attention is given to the potential for the model to inform intervention development, but also the need for refinement of configurations that are informed by comparatively less and sometimes conflicting evidence.

5.3.1 Assessing the realist synthesis approach

The procedure for the realist synthesis and model development was guided by the RAMESES (Realist and Meta-narrative Evidence Syntheses – Evolving Standards) (Wong et al. 2013). The synthesis adapted the traditional approach of assessing the success of interventions in triggering mechanisms (Pawson and Tilley 1997) to instead study the pre-existing mechanisms and context that exist as a result of societal structures (de Souza 2013). This enabled the study of mechanisms and contextual factors in the social system and gave considerable clarity to the findings of previous research concerning how the caring role impacts children differently.

The model has a high level of embedding. When evaluating existing interventions and developing models with similar embedding, Jagosh et al. (2012) argued that a program could be modified to trigger the first mechanism in the chain. If the triggered mechanism provides the expected positive outcome, that outcome can become a positive contextual change for the next embedded configuration and potentially trigger that mechanism as well. Therefore, if correctly modelled, the targeting of a single

mechanism at the beginning of the chain can result in multiple mechanisms being triggered and wider system change.

The model in this study is different to a standard realist synthesis but Jagosh's argument can be extended. As the young carers model is of the pre-existing mechanisms and contextual factors of society it has potential to inform the development of new interventions. These interventions could target pre-existing mechanisms and trigger them to provide positive change, but carefully planned interventions could again trigger chains of multiple configurations.

For example, the *support* domain (Figure 5.5) includes a chain of three CMO configurations: The **Professional carer support** mechanism [CMO¹⁰]; the **Supportive services** mechanism [CMO¹²]; and the **Supported and recognised** mechanism [CMO¹³]. The **Professional carer support** mechanism has *social services capacity* [C^{10a}] as a contextual factor, and if an intervention is developed that increases this capacity, the mechanism can be triggered, resulting in greater availability of professional carers. As *professional carer support* is a contextual factor [C^{12a}] for the next **Supportive services** mechanism this increased availability can trigger the second mechanism and improve overall services. Finally, the improved *supportive services* contextual factor [C^{13c}] can trigger the final **Supported and recognised** mechanism [CMO¹³], ensuring that young carers feel increasingly supported.

5.3.2 *The need for further refinement*

Despite being a large synthesis of 44 studies and developing a model that could inform future interventions, there is also a need for further research. In assessing the individual CMO configurations it is possible to differentiate between parts of the model that are informed by higher and lower amounts of evidence, and CMO configurations based on less evidence are clearly in need of refinement. In contrast, configurations informed by larger amounts of evidence can be viewed as comparatively reliable but, in line with the retroductive strategy that underpins the study and recognises knowledge as always tentative, should still be tested through further investigation. As a result there is a dual need to refine particular configuration while testing the wider model.

The most reliable parts of the model are the **Time spent caring** configuration [CMO⁴] and the **Supportive community** configuration [CMO⁹] as they are informed by 16 and 12 sources respectively. This reflects their status as focal points of research. In contrast, the **Professional carer support** configuration [CMO¹¹] and the **Young carer informed** configuration [CMO¹²] are informed by four evidence sources each, and the **Other family members in employment** configuration [CMO²] by two. In addition to fewer sources, the amount of evidence in each source is also less.

This impacts on confidence as configurations based on less evidence may be incorrect or have additional contextual factors or outcomes that were not identified. If a configuration, or part of a configuration, is based on evidence from a larger number of sources, it is more likely that conflicting results in an individual study can be resolved, but this is more challenging when the evidence is limited. For example, while the **Caregiving responsibilities** configuration [CMO⁶] is well-evidenced, the contextual factor *duration of time as young carer* is based on two studies, and the evidence conflicted over whether the impacts of caregiving responsibilities [CMO⁶] grow over time (Aldridge 2006) or peak for middle range carers (Cree 2003). This points towards a need for further study, preferably using methods that track the impacts of caring over a prolonged period of time.

Furthermore, the model reflects a lack of studies concerning the mental health and psychosocial wellbeing of young carers in comparison to children without caring responsibilities. The **Caregiving responsibilities** mechanism [CMO⁶] includes a range of outcomes including stress, risky behaviour, sleep problems and depression but these qualitative findings need refining with large-scale quantitative studies of children with and without caring responsibilities. This will enable evidence on the relative health and wellbeing of young carers in comparison to the wider population.

The absence of unidentified young carers.

A particular area of concern is the almost complete absence of identification in the model despite this being a key topic in research. Limitations considered in Chapter One included the lack of available quantitative data and the reluctance of young carers and their families to be identified. The result has been a focus on qualitative research with

project users, rather than with young carers that are not known to services. These unidentified young carers are therefore largely unrepresented in the model.

They are also underrepresented in the model framework with the exception of *Identification* [C^{12e}] as a contextual factor for the **Supportive Services** configuration (CMO¹²). This is due to a lack of evidence on the difference that identification makes to the health and wellbeing of young carers, or in-depth consideration of why young carers do not disclose their status. The absence from the model implies that the lives of unidentified and identified young carers are largely similar when, in reality, it is likely that identification is a contextual factor for multiple configurations, and identification also a key mechanism. Research with this population in particular is a priority for the refinement of the model.

5.4 Chapter summary

This chapter completes the model development stage of the thesis. Having defined the young carer phenomenon for the purpose of this study in Chapter Four, the realist synthesis enabled the development of a model of young carers' mental health and psychosocial wellbeing. The model includes three interlinking domains relating to *caring responsibilities*, *support* and the *caring identity*.

The model highlighted the potential for the development of interventions to improve the outcomes for young carers. In particular the embedded nature of the model demonstrated the potential for interventions to target a particular configuration and trigger a chain of mechanisms. At the same time there is also a need to test the whole model while refining sections of the model that are based on limited or conflicting data. In particular there is a need for research with young carers who are not known to services, investigation of duration of care, and comparison of young carers to non-caring peers.

The second stage of this thesis focuses on the development of a mixed methods approach to test the model and refine these sections. Chapter Six considers the merits and challenges of mixed methods research, and Chapter Seven details methods for a longitudinal data study comparing the mental health of young carers with non-caring

children over time, and a school-based phenomenology that aimed to recruit young carers unknown to services.

Chapter Six

Justification for mixed methods research

The first stage of this thesis concerned the development of a model for the mental health and psychosocial wellbeing of young carers. That concluded in Chapter Five with a discussion on the need to test the whole model but to also refine specific sections due to a lack of evidence or conflicting findings. It was also argued that these weaknesses are at least partly due to the limitations in young carers research that were discussed in Chapter One, in particular the lack of research with young carers unknown to services, and the lack of large-scale quantitative research analysing the impacts of caring over time or in comparison with peers.

This chapter argues that a mixed methods research design is needed to resolve these challenges, and the maturation of mixed methods research into an increasingly rigorous third methodological approach is considered. Having already developed a realist model as a theoretical basis, the approach for this study is introduced as a theoretically embedded concurrent mixed methods design. Each research question is considered individually with the model enabling justification of the appropriate method to use.

6.1 Mixed methods research as the third research community

While combining qualitative and quantitative methods was not novel, the current mixed methods approach was developed in the late 20th century. Creswell and Creswell (2018) and Bergman (2008a) reported three main eras of mixed methods research, with the pre-1980s approach concerned with the use of triangulation to resolve the bias and weaknesses of the respective qualitative and quantitative methods. The second era began during the 1990s with a greater focus on the integration of findings from the separate methods and how each technique can help to explain the other, and the current era concerns the focus on improving rigor in mixed methods research.

6.1.1 Development of mixed methods research

Mixed methods research can be considered alongside the traditional qualitative and quantitative approaches. Chapter Two of this thesis detailed the epistemological framework for this study and, in doing so, considered ontology, epistemology and paradigms. The traditional research fields are divided with quantitative methods adhering with positivist values, and qualitative techniques with constructivism or interpretivism. A key part of the divide between the approaches is the incompatibility thesis (Teddlie and Tashakkori 2009) and the inappropriateness of combining methods with fundamentally different theoretical underpinnings.

Mixed methods research enables researchers to move beyond these constraints and utilise the most appropriate methods for the specific research question (Creswell et al. 2008). The approach is underpinned by pragmatism and the compatibility thesis (Teddlie and Tashakkori 2009) that states that methods with differing theoretical positions can be used to study different aspects of complex phenomena. Mixed methods research also progressed theoretically by critiquing the traditional view of a dichotomy of quantitative or qualitative approaches, instead arguing that research is a continuum with the respective qualitative, quantitative and mixed methods fields overlapping. On this basis no approach is superior with research quality instead based on the justification of a suitable method (or methods), and the chosen method being implemented to a high standard.

6.1.2 The challenge of rigor

However, this improved theoretical basis also led to concerns over quality and, despite the increasing popularity of mixed methods research, Bergman (2008a, 2008b) has highlighted the need to increase rigor. In particular Bergman and Biesta (2010) highlighted the limitations of pragmatism as the underpinning theory, with it enabling a toolkit approach to combining any techniques often with poor rigor and little justification of the chosen method.

Bryman (2008) evidenced this lack of rigor in a review of mixed methods studies, finding that few researchers gave a methodological justification for the selection of mixed methods rather than purely qualitative or quantitative studies. In addition, when

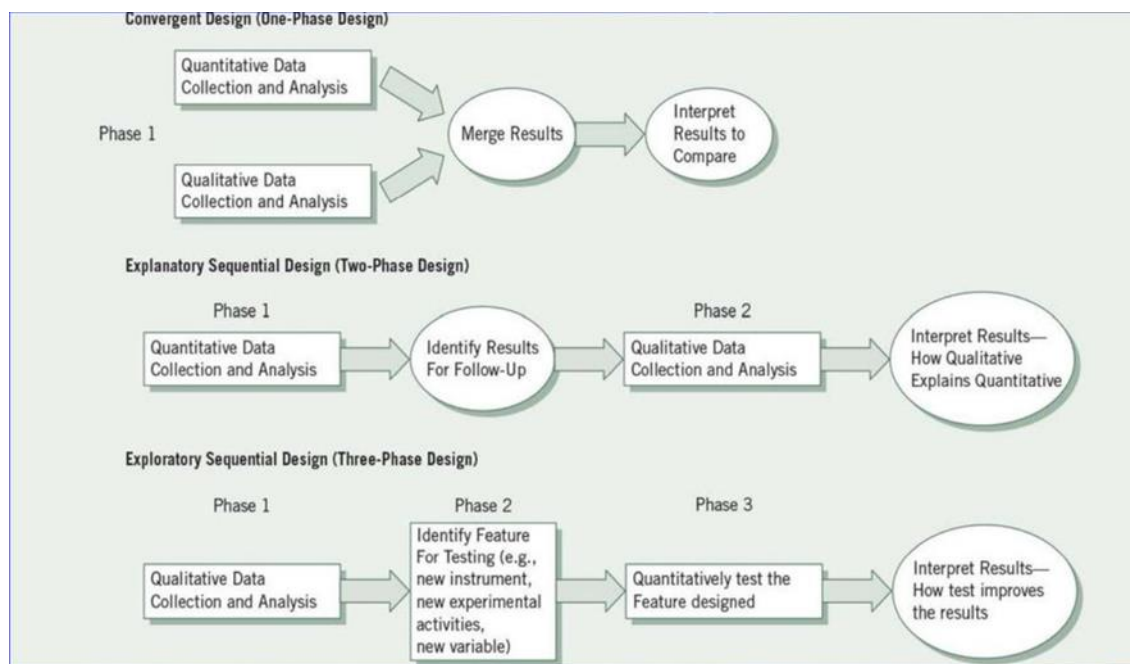
justifications were made these claims often did not reflect the methods that were used. Creswell et al. (2008) offered further evidence of low rigor due to poor quality integration of the qualitative and quantitative findings, contradictory evidence between the approaches and one method creating a bias for the other. This led to the focus on increasing rigor through the development of research typologies and a focus on the genuine integration of findings.

The development of research typologies

Attempts to improve justification of methods led to the development of research design typologies that mapped out different procedures and provided potential methodological paths. The most prominent is the Method Strand Matrix (Teddlie and Tashakkori 2006, 2009) that identified four distinct types of mixed methods design. The first, concurrent design, concerns the qualitative and quantitative phases of the research being run independently but at the same time, while the fully integrated approach is similar but with the qualitative and quantitative phases informing each other throughout the process. The sequential design features one phase of the research, either qualitative or quantitative, being run first with the findings influencing the design of the second phase. The fourth and final conversion approach is substantially different due to the data type from one phase being converted to the data format of the other phase, enabling joint analysis of the results.

Creswell and Creswell (2018) also considered core design types (Figure 6.1). Similarly to Teddlie and Tashakkori (2006), they included the concurrent approach, and also differentiated between the explanatory sequential design where initial quantitative research is explained through the qualitative phase, and exploratory sequential design where qualitative findings are tested through quantitative research. Creswell and Creswell also suggested the potential for core designs to be embedded in more complex studies including research which states a theory at the outset, in order to justify the research design. Pawson (2008) has also supported the theoretical grounding of mixed methods research to enable the investigation of multi-faceted phenomena.

Figure 6.1 Core mixed methods design types (Creswell and Creswell 2018)



Integrating the qualitative and quantitative findings.

This increasing rigor also includes consideration of how to integrate the separate findings of qualitative and quantitative research together. Except for the conversion approach which converts one set of data to the same format as the other (Teddle and Tashakkori 2006), all mixed methods research ensures that the components remain separate during the planning, implementation, data collection and analysis to reduce potential bias. Integration of the inferences from each method is then vital to maximising understanding of the phenomenon, with Yin (2006) arguing that studies that do not integrate the individual components fully should not be viewed as genuine mixed methods research.

Integration of the components was previously challenging due to the different approaches in qualitative and quantitative research to assessing quality. Quantitative research traditionally uses the concept of validity and whether the research measured what it set out to measure (Onwuegbuzie and Johnson 2006), but this term is rejected in qualitative research due to the connotations of validity measuring a single objective truth. Authenticity (Onwuegbuzie and Johnson 2006), or credibility (Teddle and

Tashakkori 2006) instead reflects whether qualitative research captures the true experience of the research participants. In attempting to find a joint term Onwuegbuzie and Johnson suggested legitimization to represent the aim of mixed methods research to build on complementary strengths of the qualitative and quantitative components while resolving weaknesses.

Hammersley (2008) identified two main tools for the integration of findings. Triangulation, the original focus of mixed methods research, enables the checking of the findings for each method using the results of the other. Hammersley, Teddlie and Tashakkori (2006) and Blaikie (2000) argue that, despite the acceptance that two different methods based on different philosophical assumptions can produce different findings, triangulation is still of value in helping to understand complex and multifaceted phenomena. The second tool, complementarity enables the use of different methods to answer different questions, with Hammersley (2008) comparing this to a jigsaw with separate methods providing different pieces. These two tools are not mutually exclusive with studies able to employ triangulation and complementarity.

6.2 Justifying a mixed methods approach for this study

This chapter has highlighted the past challenges of mixed methods research, particularly in relation to the philosophical basis of the research and the lack of justification for the selection of specific methods in many studies. However, progress has been made with the development of common design typologies that have supported the justification of methods, as well as tools for the integration of qualitative and quantitative findings.

The remainder of this chapter concerns the justification of the methods used in the model refinement stage of this study. Based on Teddlie and Tashakkori's Methods Strand Matrix (2006) and the extension by Creswell and Creswell (2018), a complex concurrent mixed methods design is used. The design is complex due to the research questions and methods in this stage being theoretically informed by the realist model developed in the first part of the study.

Each of the five research questions, and justification of the methods used to investigate them, are detailed below. Intention to integrate the results, most often through complementarity but also triangulation, is also considered. The schema in Chapter One summarises the research questions and methods.

Q1. What are the causal mechanisms underpinning young carers' mental health and psychosocial wellbeing?

The model development stage answered this question through the identification of mechanisms concerning how the mental health and psychosocial wellbeing of young carers vary depending on their individual circumstances. However, the integrated findings of the mixed methods research enable refinement of the model in Chapter Twelve.

Q2. What is the prevalence of young carers amongst children in the UK?

Chapter One detailed previous attempts to estimate the prevalence in the UK with alternative, and often flawed, methods used due to the absence of large-scale quantitative data. The estimates varied substantially but with confidential child cohort studies increasingly including young carer status questions, there is potential to utilise this quantitative data to produce more reliable estimates of prevalence.

Q3. How does the mental health of young carers compare to their non-caring peers?

This is also a quantitative question and the need for further study was highlighted in the realist model due to a lack of previous research. Similarly to the second question concerning prevalence, the inclusion of the carer status question in cohort studies enables identification of young carers and comparison to children without caring responsibilities.

Q4. How do the mental health and psychosocial wellbeing impacts of caring change over time and within the young carer population?

Both quantitative and qualitative methods are utilised to answer this question, enabling triangulation of the results. The lack of past quantitative data has limited the potential for longitudinal study but multiple waves of data concerning young carer status and mental health are now available. In addition, many cohort studies include an indicator for the measurement of quantity of care, enabling differentiation between young carers with standard and higher levels of responsibilities.

The qualitative method, a year-long longitudinal phenomenology, considers the wider circumstances of young carers beyond the limited indicators in the quantitative study. This includes a focus on the impact of receiving *support* and the development of a caring *identity*, in line with the two domains in the realist model.

Q5. What are the needs of young carers and are they being met?

The final question is answered through the qualitative research. This is an extension of whether they receive support and, for those that do, the quality of that support. As the phenomenology is aimed at young carers unknown to services as well as those who were accessing support, the method set out to strengthen their representation in the refined model.

6.3 Chapter summary

This model refinement stage of the research began with consideration of the mixed methods research designs. The chapter considered the theoretical basis for combining qualitative and quantitative methods, and the progress made in increasing rigor through the development of typologies and focus on integration of findings.

Based on these typologies, a theoretically embedded concurrent mixed methods research design was selected. The initial realist model enabled the justification of the methods used to answer each of the research questions, in order to test, refine and

resolve knowledge gaps in the model. Chapter Seven introduces structural equation modeling (SEM) as the quantitative method and longitudinal phenomenology as the qualitative method. The respective procedures are then detailed.

Chapter Seven

Model refinement methods

The previous chapter justified the use of a mixed methods approach to refine the realist model of young carers' mental health and psychosocial wellbeing. The use of particular methods to tackle each question was specified to maximise the potential that the data collected from the components can be integrated together to resolve the evidence gaps in the model.

This chapter introduces the methods used to refine the model. Structural equation modeling (SEM) is outlined first with a summary of the basic steps common to the quantitative approach, key criticisms and attempts to resolve them. The qualitative method, phenomenology, is then discussed, with a focus on Husserl and Heidegger's initial development, but also Gadamer's hermeneutic focus.

The procedures are then detailed in turn, beginning with the decisions made in developing the SEM model and the selection of the Longitudinal Study of Young People in England: What Next (LSYPE) cohort study for analysis. The phenomenological procedure details the development of a process for recruiting young carers that are unknown to services, as well as the interview development, data collection and analysis.

7.1 Model refinement methods

7.1.1 *Structural equation modeling*

Structural equation modeling is the collective name for a group of techniques that were initially developed in separate disciplines (Bentler 1980; Matsueda 2012; Tarka 2018); factor analysis was developed in psychology by Spearman as a way of studying unobservable latent variables through sets of observable indicators; path analysis was created by the geneticist Wright to analyse multiple linear regressions simultaneously and better enable causal explanation; and Haavelmo is largely credited with the focus on unidirectional influence between different variables in econometrics. These were later

incorporated together in the 1970s, united by the central aim of moving beyond the rule-based framework of traditional statistical procedures (Rodgers 2010; Tarka 2018). Joreskog is credited as the developer of the LISREL, the first computer to successfully run a SEM model (Matsueda 2012; Tarka 2018).

SEM was developed and initially used predominantly by statisticians. This was partly due to the computationally demanding nature of the technique but advances in SEM software and computing have increased access. As a result, it has become one of the most popular methods across academia due to its increasing versatility and complexity in modeling cross-sectional, longitudinal and multigroup data (Biesanz 2012; Tarka 2018). This led to criticism over use of the method without adequate statistical knowledge, particularly concerning the inappropriate analysis of categorical data relating to attitudes, abilities and behaviour (Edwards et al. 2015). These criticisms and the work to resolve them are considered after introducing the basic steps of SEM.

The basic steps of SEM

Despite the versatility of SEM, it is still recognised that there are a number of basic steps to developing and testing any model (Hoyle 2012; Kline 2016), with the complexity of the technique due to the individual decisions taken as part of each step. Figure 7.1 demonstrates the six steps laid out by Kline. The process is not linear as the outcome of each stage potentially leads to progression, returning to a previous stage or the process being aborted altogether. Each stage is briefly considered below.

The first step, specification, is the visual representation of the study hypotheses, based on theoretical knowledge of the research area. All decisions in subsequent steps are based on the assumption that these hypotheses are correct.

The identification step concerns the theoretical fit of the data to the hypotheses, and the visual representation is translated into a statistical model for analysis. The statistical model includes observed variables and latent variables, with observed variables corresponding with collected data. Latent variables, also known as factors, are hypothetical constructs that cannot be observed directly and are instead represented by a

collection of observable indicators. Factor loading considers the extent to which the indicators together accurately represent the latent variable.

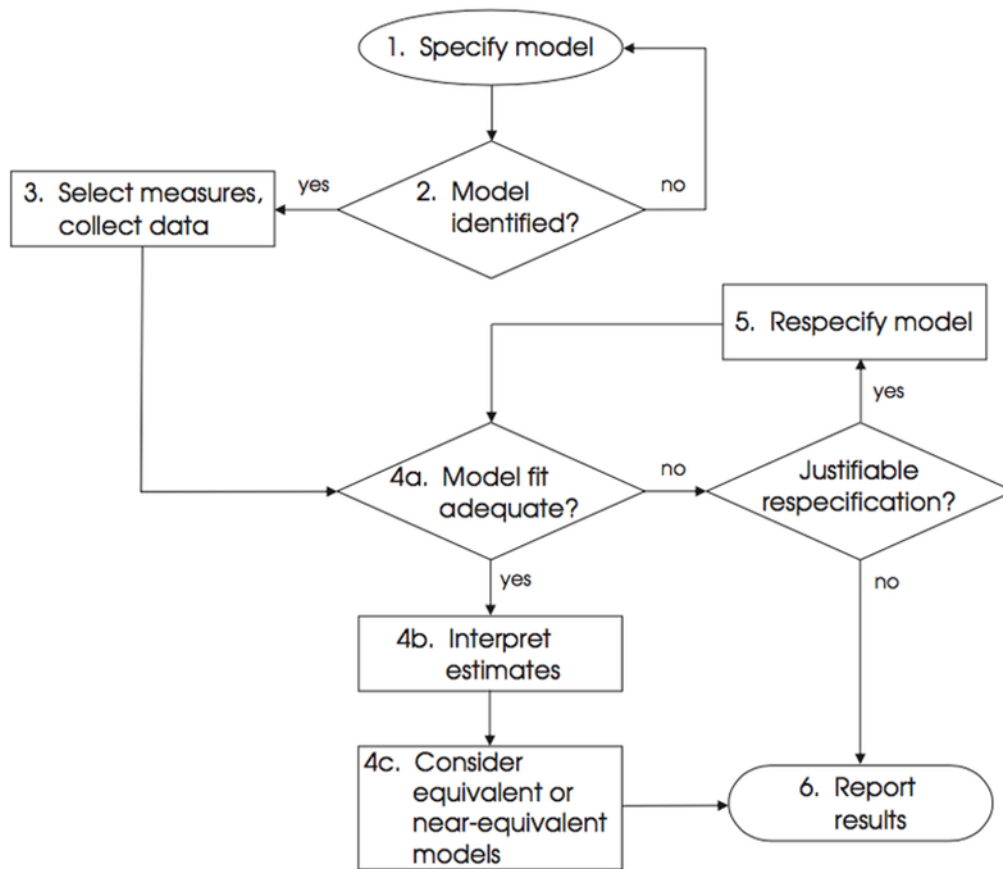
Every observed or latent variable is represented in the model, and parameters denote the hypothesised relationships between pairs of variables. There are three types of parameters that must be specified by the researcher. Fixed parameters are set to a specific value by the researcher, while constrained parameters are partially restricted. The third type, free parameters, are estimated by the SEM software, and successful identification relies on the SEM software being able to produce a unique estimate for every free parameter. Higher complexity models, including models with a larger proportion of free parameters are less likely to be identified, with unidentified models returning to the first stage for respecification.

Step three concerns the selection of measures, and this stage either informs the survey data collection or alternatively influences the selection of a secondary dataset. Irrespective of this choice the data is cleaned, tested for normality, and assessed for missing data. The results of the assessment inform the action taken in future stages to minimise the impact of any limitations in the data.

While the identification stage concerns theoretical fit, the estimation stage considers how well the model fits the data. Models with a good fit can be accepted and the results interpreted. However, if the fit is poor respecification needs to be justified, and if justification is not possible the modeling is accepted as unsuccessful and aborted.

In practice there are three possible approaches to identification, and this influence the decision to respecify or abort models with poor fit (Hoyle 2012). The confirmatory approach specifies a single *a priori* model in advance which, when estimated, is either accepted as giving an adequate account of the data or seen as flawed and aborted. This approach is rare in practice as the initial model is rarely successful. The alternative models approach is similar but the researcher develops additional *a priori* models. If the preferred model is not identified an alternative model with good fit can be selected. The third, generative, approach has key differences with respecification acceptable when models have been estimated as having poor fit. Generative models are therefore not *a priori* but have the advantage of enabling substantive researchers to develop a successful model.

Figure 7.1 The six basic steps of structural equation modeling (Kline 2016)



The sixth and final stage concerns the reporting of results and analysis of how well the model fits the data.

Criticism of SEM

Two criticisms are considered concerning the method itself but also how the technique has been applied in social sciences. Considering the SEM method, critics have highlighted the complexity of the world and queried whether the technique is able to model this to even an adequate level. Cartwright (1999, 2000) highlighted how research often views the world as a well-ordered and rational system when it is actually a ‘dappled world, a world rich in different things, with different natures, behaving in different ways’ (p. 1). Freedman (1987) argued that these attempts to model the world have been affected by an increasing focus on statistics and technology at the expense of theory. Theory, based on the knowledge of the researcher, should form the basis for the

model but the increasingly popular generative approach to specification concedes these theoretical assumptions in order to improve model fit. Freedman also highlighted the issue of omitted variables, indicators that are known to be influential but not represented in models, and he questioned the acceptance in SEM that a model can never be perfect without considering the magnitude of the imperfections.

In responding to these criticisms Heckman (2005) and Pearl (2011, 2012) conceded that, while theoretical assumptions were at the centre of SEM when initially developed, this focus has been lost in substantive research. They suggested different reasons for this loss, with Heckman attributing it to a failure in literature to fully explain and stress the importance of researchers accurately following instructions for model development. Pearl (2012) meanwhile argued that many SEM researchers omit causal assumptions from models due to criticisms from statisticians that causal interpretation using data analysis alone was not possible. However, Pearl argued that causal assumptions were not only possible when the theoretical knowledge was combined with data but vital, with the alternative to specify models in one of many random arrangements of relationships between variables (Pearl 2011).

The second criticism is of particular relevance to social sciences. SEM was initially developed for use with continuous data and therefore dependent on linear regression to examine relationships between continuous observed and latent variables (Tarka 2018). However, the technique has been increasingly used in social sciences to analyse attitudes, beliefs and experiences, with this data often categorical (Edwards et al. 2015). With categorical data containing non-linear relationships, this can impact analysis and potentially cause misspecification.

This led to developments in SEM for the analysis of binary, ordinal and categorical data (Matsueda 2012; Muthén 1984), echoing a trend in the wider field of statistics over the last fifty years (Agresti 2013). There has also been a focus on improving SEM software for this purpose and, in addition to the expansion of already existing software including SPSS, R and Stata, Mplus has been developed as specialist SEM software for categorical data analysis (Muthén and Muthén 2017). As a result, categorical data analysis is increasingly recognised as a mature area of quantitative research.

In considering the use of SEM for this specific study, simple regression analysis is a possible alternative but, as considered in Chapter One, Joseph et al (2020) highlighted the need for a greater theoretical focus and more complex methods in young carers research, particularly concerning quantitative approaches. The realist model of young carers' mental health and psychosocial wellbeing presented in Chapter Five provided the theoretical knowledge that is key to informing SEM modelling. In addition, the model highlighted a lack of research comparing the lives of young carers to children without caring responsibilities over time, and few quantitative modelling methods match the versatility of SEM to analyse both cross-sectional and longitudinal data together.

7.1.2 Phenomenology

Having introduced the quantitative method used in this mixed methods study, the background to phenomenology is now considered. Phenomenology was developed in the 20th century, due to the realisation that the original aim of philosophy had been lost (Glendinning 2007; Langdrige 2007), replaced by an increasing emphasis on quantitative research underpinned by the positivist idea of the world having a single objective truth. Three key figures in phenomenology are introduced: Husserl who developed phenomenological philosophy and the transcendental approach; Heidegger who pursued an alternative existential phenomenology; and Gadamer who extended their work through a focus on hermeneutics and understanding.

The origins of phenomenology

In developing phenomenology Husserl was concerned with the lifeworld, the landscape where humans experience the physical world (Kaufer and Chemero 2015). This lifeworld contains noema, the meaning that we attach to an object at the time of experiencing it, and noesis, the underlying essence of the object that is developed upon reflection (Moustakas 1994). Husserl was particularly interested in describing these essences.

Husserl was also interested in the ‘horizon’ that limits our personal perception of an object. This limited perception is due to our views, beliefs and attitudes of the world (Lohmar 2012; Yoshimi 2016), but the horizon is also dynamic, susceptible to change as a result of current and future experiences. Husserl recognised the key problem that researchers have a horizon that threatens their unbiased description of the participant’s experiences (Kaufer and Chemero 2015), and resolving this problem became the key concern of phenomenology. Husserl argued that transcendence enabled epoché, or the ‘bracketing’ of the researcher’s context, and therefore removal of their preconceived views and bias.

Transcendental phenomenologists continue the work of Husserl, including Moustakas (1994) who detailed his use of bracketing to become aware of the world as seen by others, and to identify and remove distorted thoughts. He also advocated use of Transcendental Phenomenological Reduction and Imaginative Variation to consider phenomena from multiple angles and different perspectives. Moustakas argued that, with the exception of strongly held views and beliefs shaped by major life events or trauma, these tools enable the suspension of researcher context and removal of bias.

However, many disagree that true transcendence is possible, and Heidegger theorised an existential turn (Langdridge 2007) that accepted the researcher as part of the world and therefore never fully able to view it as an external observer. Instead, Heidegger viewed phenomenology as hermeneutical with the researcher actively interpreting the world in the context of their own history and experiences (Figal and Espinet 2012). He also focused on self-understanding and dasein that helps explain how our past experiences inform our present understanding of the world. Researchers with a greater understanding of themselves are more able to consider and remove their assumptions and judgements, therefore focusing on the experiences of the participant.

The hermeneutic turn, and enabling the fusion of horizons

Gadamer advanced the work of Husserl and Heidegger through a greater focus on hermeneutics and the potential for conversation to resolve multiple perspectives and increase understanding (Grondin 2002, 2003). Gadamer (2004) focused on Husserl’s concept of horizon as a person’s perception of the world, with this horizon changing as

a result of new experiences. He extended Husserl's thinking by arguing that conversation can enable this change, with an interview between a researcher and a participant not just the sharing of two different horizons but an opportunity for each to consider the experiences of the other alongside their own. The resulting 'fusion of horizons' is the development of a shared understanding, though this only occurs when researcher and participant are fully engaged in an open and respectful two-way process of speaking and listening.

Fleming et al. (2003) argued that Gadamer offered considerable insight on how to seek understanding of experiences without detailing a method, and developed a five-step process (Figure 7.2). The first step entails the development of a research question concerned with developing a deep understanding of a phenomenon, and the second involves the identification of preunderstandings concerning the phenomenon, potentially informed by the opinion of researchers with expertise in the area.

The third step is the gaining of knowledge from dialogue with participants. It follows Gadamer's ideas concerning the importance of open dialogue to ensure a fusion of horizons and the development of genuine understanding. Step four is the gaining of understanding from dialogue with the text, and Fleming highlighted two particular aspects of this stage. First, the researcher should return to participants to share and discuss further the researcher's understanding of their experiences. Second, the dialogue should be analysed on multiple levels with each whole transcript studied for a fundamental meaning, and then each sentence or sections analysed for themes and considered alongside the transcript-level meaning. The final stage establishes trustworthiness through explanation of procedural decisions and the use of quotes to back up findings. This five-step method underpins the phenomenological procedure detailed in this chapter.

Figure 7.2 Five steps of a Gadamerian-based research method (Fleming et al 2003)

1. Deciding upon a research question.
 2. Identify preunderstandings.
 3. Gaining understanding through dialogue with participants.
 4. Gaining understanding through dialogue with text.
 5. Establish trustworthiness.
-

More specific research has focused on how researchers can understand a phenomenon from the perspective of others, and specifically how to enable the fusion of horizons. A key part concerns participant control during the conversation, and the semi-structured or unstructured interviews often used in phenomenological research give participants different levels of control (Langdridge 2007; Moustakas 1994). There is however a balance and unstructured interviews include a minimal number of questions by the researcher to maximise this control, sometimes at the expense of data quality. In comparison, researchers utilising traditional semi-structured interviews pose particular questions to maximise response usefulness, but this reduces control.

However, semi-structured interviews are changing and while researchers still identify potential questions in advance they also decide if and when to ask each question depending on the individual participant. This enables a more natural conversation with the participant able to direct the conversation into unplanned areas. In addition to ensuring a higher level of participant control, these deviations have the additional benefit of increasing the potential for innovative ideas and findings.

Research has highlighted the benefits of putting participants at ease and Van Manen (2016) highlighted the need for interviews to be held in informal spaces that are familiar to the participant. Moustakas (1994) and Langdridge (2007) emphasised the need for informal conversation at the outset to relax the participant and build a positive rapport. This rapport often increases over time and Langdridge also highlighted the benefits of multiple meetings that allow for the postponement of sensitive questions until later meetings when rapport is increased.

Other benefits of multiple meetings have been considered, and Van Manen (2016) argued that the research focus can change during the different stages. While the first meeting potentially focuses on data collection, the subsequent interviews can be increasingly interpretive with the participant helping the researcher understand their experience. Subsequent meetings also enable the revisiting of past topics to increase clarity. This can be particularly important when the original conversation deviated away from the expectations of the researcher, as additional questions can be identified for further exploration. Overall, this relaxed approach to planning deviation, natural conversation and rapport-building all help the fusion of horizons.

The benefits of longitudinal analysis

While Langdrige, Moustakas and Van Manen focused on the benefits of multiple interviews in terms of building a positive relationship with participants and potentially improving the quality of the collected, Bartolini (1993) highlighted the analytical benefits. He noted how the majority of qualitative studies focus on comparison between cases rather than change within individual cases over time, or alternatively consider change retrospectively from a single timepoint. In contrast, genuine longitudinal qualitative research is rare, and Bartolini advocated for true studies of temporal variance that actively study cases at multiple time points, enabling analysis in terms of the presence or absence of specified contextual properties.

The need to incorporate time as well as space into research design has also been highlighted by Pennings et al. (2006). They highlighted how qualitative research often treats temporal variance as if it is spatial by aggregating information at the individual time points and then analysing the data as if it is cross-sectional. Instead, meetings with multiple participants at multiple timepoints should enable cross-sectional study between cases and longitudinal study of the individuals. One final advantage of longitudinal study suggested by Pennings was improved causal relationships. Similar to Bartolini's recommendation of analysing the presence or absence of particular contextual factors at multiple timepoints, the method enables the study of how change in measured contextual factors can potentially be causally linked to future change in a dependent variable.

In considering which method to use for the qualitative component of the model refinement stage, there were two approaches that both seemed suitable. A realist evaluation, continuing the approach that enabled the development of the model of young carers' mental health and psychosocial wellbeing in Chapter Five, would have enabled in-depth consideration of participating young carers and how differing contextual factor affected their management of the caring role and resulted in varying outcomes. However, as with the decision to utilise SEM in the quantitative component, the realist model highlighted the need for a longitudinal focus and Gadamer's genetic phenomenology enabled a greater focus on how new experiences and changing circumstances affected perception of the caring role over time. In addition, the use of hermeneutics offered a means to achieve a shared understanding of participant lives.

7.2 Structural equation modeling procedure

Having introduced the two techniques, the procedure for the SEM component is now detailed. The process for this study is largely based on the basic steps (Kline 2016) summarised earlier in this chapter, but with one major difference. As this study used previously collected secondary data, the dataset was selected at the beginning of the process with the available indicators informing the model procedure.

7.2.1 *Using secondary data*

The decision to utilise secondary data was due to a number of practical reasons. Gaps in the realist model reported in Chapter Five included a lack of research on the impacts of caring over time, and the quantitative research aimed to investigate the impacts of long-term caring over a minimum of two years. The development of a longitudinal survey was not possible due to the limited study length, as well the resources required. In addition, Chapter One considered the reluctance of young carers to disclose their status, and this would likely hamper efforts to get a sufficient and representative sample of young carers within a population-level response.

In comparison, cohort studies enable access to the self-completed and confidential responses of thousands of children, with collected indicators including young carer status and mental health. There are however also disadvantages to using secondary data with the researcher having little control over the indicators that are collected, the specific wording of questions, and when the data is collected. This therefore limits the indicators that can be included in SEM, resulting in omitted variables.

Dataset selection

The UK Data Archive data catalogue was used to identify potential cohort studies for consideration on the basis that they included a young carer status variable and multiple indicators that together could represent a mental health factor. In addition, the respondent was the child themselves with confidentiality processes in place to reduce response bias. Four cohort studies met these criteria:

- The Longitudinal Study of Young People in England: What Next (LSYPE1): A cohort of children aged 13 in 2004. Seven annual waves were collected and published until 2011 (University College London 2020);
- The Longitudinal Study of Young People in England: Our Future (LSYPE2): A cohort study of children aged 13 in 2013. Seven annual waves have been collected to date though three had been published at the time of data collection (Kantar Public 2020);
- The School Health Research Network (SHRN): A school-oriented cohort study for pupils in secondary schools across Wales. Four bi-annual waves were completed between 2013 and 2019 (Hewitt et al. 2019);
- The Millennium Cohort Study (MCS): A birth cohort study of children born in 2000/2001. Seven waves have been completed to date since 2001, with the child responding in waves four to seven (University of London 2020).

The studies were assessed for the inclusion of multiple waves of young carer status and mental health indicators at the time of data collection in 2020 (Table 7.1). The Millennium Cohort Study (University of London 2020) and the School Health Research Network (Hewitt 2020) were excluded as the young carer status indicator was included in a single data wave. The Longitudinal Study of Young People in England: Our Future was also excluded because only one wave included the mental health indicators (Table 7.2) required to assess change in outcomes.

The Longitudinal Study of Young People in England: What Next (LSYPE1) is the oldest of the four cohort studies but was the only one to include the required indicators in multiple waves. All seven waves include a young carer status question, though the wording changes substantially from Wave Four onwards. Waves Two, Four and Seven collected data on mental health.

The Longitudinal Study of Young People in England: What Next

LSYPE1 was developed by the Department for Education to underpin youth policy development and appraisal (University College London 2020). The study collected data on family background, personal characteristics, attitudes, experiences and behaviour.

Twenty-one thousand children were invited to take part in the original data collection with this including a boost of 1,000 for each major ethnic group (Table 7.3). Wave Four included an additional ethnic boost due to high drop out in comparison to the wider sample. Of the invited sample, the achieved sample for Wave One was 15,770, a

response rate of 74%. The achieved sample fell through the seven waves with 8,682 children participating in Wave Seven.

Data for Waves One, Two and Three was collected through in-person interviews, with self-completion of particular sections including mental health. From Wave Four onwards, respondents could choose between in-person interviews, phone interviews or online completion.

Dataset indicators

Table 7.4 contains the indicator names, question wording and wave inclusion information for the young carers, mental health and selected demographic variables. Appendix F includes further details including the response options for each of the questions.

The original young carer status question concerned caring for any family member (*CareStatus*), with this in line with the definition developed in the concept analysis. However, it was revised in Wave Four to specify the care receiver as over 15 (*CareStatus1*). This greatly increased the potential for measurement invariance to the variable, and the decision was made to only use the first three waves of the young carer indicator. Respondents who identified as young carers were asked supplementary questions relating to time spent caring (*CareHours*), the person they care for (*CareWho*) and absence from school (*MissSchool*, *MissSchool1*).

Waves Two, Four and Seven included twelve indicators that together could represent a latent mental health variable. Item wording and response options for each indicator were consistent throughout the waves, therefore there was minimal risk of measurement invariance. Relevant demographic variables included *Sex*, ethnicity (*Ethnic*) and *Age*.

Table 7.1 Young carer status question and inclusion in data waves

		Wave						
Young carer question		1	2	3	4	5	6	7
LSYPE1*	Some people your age may have to look after other people. This could be a brother or sister, a relative or someone else who is disabled or sick. Is there anyone like this who lives here with you that you have to look after on a regular basis?	2004	2005	2006	-	-	-	-
	Do you regularly look after any ill, disabled or elderly relatives or friends aged 15 or more and in need of care, without being paid? This includes both people who live here with you and those who live elsewhere	-	-	-	2007	2008	2009	2010
LSYPE2	Some people your age have to provide regular help or support to people they live with who are physically or mentally ill, disabled or misusing drugs or alcohol. This could be a parent, brother, sister, a relative or someone else. Is there anyone like this who lives here with you that you have to look after on a regular basis?	2013	2014	2015	No further waves released to data			
SHRN	Some young people have to help look after other people in their family because they are disabled, physically or mentally unwell or have a problem with alcohol or drugs. Is there anyone in your family that you regularly look after or give special help to for these reasons?	-	-	2017 / 18	-	No further waves released to date		
MCS	Some people have extra responsibilities because they look after someone who has long-term physical or mental health difficulties or disability, or problems related to old age. Do you regularly look after anyone who is ill, disabled or elderly and in need of care, without being paid? This includes both people who live with you and those who live elsewhere. Please do not include caring you do for others that you do in a professional capacity (i.e., as a job).	-	-	-	-	-	-	2018 / 19

**The LSYPE1 question wording was amended at the start of the fourth wave.*

Table 7.2 Inclusion of question relating to participants self-perception of their mental health

	Wave						
	1	2	3	4	5	6	7
LSYPE1	-	2005	-	2007	-	-	-
LSYPE2	-	2014	-	No further waves released to data			
SHRN	2013 / 14	2015 / 16	2017 / 18	No further waves released to date			
MCS	-	-	-	2008 / 09	2012 / 13	2015 / 16	2018 / 19

Table 7.3 Sample size and response rate to the LSYPE survey for each wave (University College London 2020)

	Wave 1	Wave 2	Wave 3	Wave 4	Boost	Wave 5	Wave 6	Wave 7
Issued sample	21,000	15,678	13,525	12,468	600	11,793	11,225	9,791
Achieved sample	15,770	13,539	12,439	11,449	352	10,430	9,799	8,682
Response rate	74%	86%	92%	92%	59%	88%	87%	90%

Table 7.4 LSYPE1 variables relating to young carers, mental health and demographics. Includes the data waves each indicator was included in.

Variable	Question	Wave						
		1	2	3	4	5	6	7
CareStatus	Some people your age may have to look after other people. This could be a brother or sister, a relative or someone else who is disabled or sick. Is there anyone like this who lives here with you that you have to look after on a regular basis?	Y	Y	Y	N	N	N	N
CareStatus1	Do you regularly look after any ill, disabled or elderly relatives or friends aged 15 or more and in need of care, without being paid? This includes both people who live here with you and those who live elsewhere	N	N	N	Y	Y	Y	Y
CareWho	Who do you look after?	Y	Y	Y	N	N	N	N
CareHours	About how many hours a week would you say that you usually spend looking after this person (these people) or doing things for them?	Y	Y	Y	N	N	N	N
MissSchool	Do you ever have to miss going to school because you have to look after them?	Y	Y	Y	N	N	N	N
MissSchool1	How often do you have to miss school to do this?	Y	Y	Y	N	N	N	N
SleepLoss	Have you recently lost much sleep over worry?							
UnderStrain	Have you recently felt constantly under strain?							
Difficulties	Have you recently felt you couldn't overcome your difficulties?							
EnjoyActivities	Have you recently been able to enjoy your normal day-to-day activities?							
FaceProblems	Have you recently been able to face up to your problems?							
Depressed	Have you recently been feeling unhappy and depressed?							
LowConfidence	Have you recently been losing confidence in yourself?	N	Y	N	Y	N	N	Y
Happy	Have you recently been feeling reasonably happy, all things considered?							
Concentration	Have you recently been able to concentrate on whatever you're doing?							
Useful	Have you recently felt you were playing a useful part in things?							
Decisive	Have you recently felt capable of making decisions about things?							
Worthless	Have you recently been thinking of yourself as a worthless person?							
Sex	Respondent is...:	Y	Y	Y	Y	Y	Y	Y
DoB	What is your date of birth?	Y	Y	Y	Y	Y	Y	N
Ethnic	To which of the groups on this card would you say you belong?	Y	Y	N	Y	N	N	N

7.2.2 SEM procedure

Specification

SEM specification was informed by the realist model. This appears to be a highly novel aspect of the study, with only one previous study using SEM to test CMO configurations (Ford et al. 2018). Figure 7.3 displays the hypothesised relationships and references relevant CMO configurations. Hypothesis One states that carer status (*CareStatus*) is a long-term phenomenon, with Hypothesis Two that older (*Age*), female (*Sex*) and ethnic minority (*Ethnic*) children are more likely young carers.

The third and fourth hypotheses were split. Hypothesis 3A states that young carer status (*CareStatus*) negatively impacts mental health (MH), while Hypothesis 3B concerns increasing mental health impact with duration of care. The time spent caring variable enabled the additional Hypothesis 4A that mental health impacts (MH) are greater for higher-level young carers (*CareHours*), with Hypothesis 4B stating that impacts of this higher-level caring also increase with duration. Therefore, the models compare young carers with children without caring responsibility, but also higher-level young carers with all other children.

Three variables were not utilised as they were not considered in the realist model, specifically which family members were receiving care (*CareWho*), whether caring affected school attendance (*MissSchool*) and how often this occurred (*MissSchool1*). The *Age* variable was also not required as the annual waves of data, beginning when the child was 13, already incorporated this.

It is recognised, when specifying the model, that it does not truly represent the complexity of reality, especially as the use of pre-collected data limited the variables that could be included in the model. Elements of the realist model that are omitted include the quality of the relationship between the young carer and the care receiver, the reason for them becoming a young carer, and any data relating to the receiving of support. These are considered in detail in the phenomenology.

Figure 7.4 displays the structural components of the two specified models. The standard model compares children with and without caring responsibilities and the higher-level carer model compares those who spent more time caring with all other respondents. In line with standard SEM path diagrams developed by Wright (Ho et al.

2012), all observed variables are represented by a rectangle with latent variables in ellipses. The measurement component (i.e., the specific mental health indicators loading on the latent variables) is confirmed after the reporting of the data screening process.

Data screening

Variables from each wave were merged into a single dataset with the identification variable (*NSID*) ensuring alignment by case. All missing values and refusals were coded as NA. The young carer status (*CareStatus*) and time spent caring (*CareHours*) variables were compared for inconsistencies with one Wave One respondent spending time caring despite having not identified as a carer. The two values were changed to NA.

The Wave One and Wave Two time spent caring variable were continuous, but the Wave Three indicator (*W3CareHours*) had been categorised (1-5; 6-10; 11-15; 16-20; 21 plus hours). As a result, Wave One and Two data were categorised using the same scale. A new variable for each wave (*CareHoursHigh*) was then created denoting children who cared for over 11 hours a week as higher-level young carers.

Respondents' sex had been collected in each of the four waves but there was considerable missing data. Merging these into a single new variable (*SexMerge*) reduced this from 691 non-responses in Wave One to 18 non-responses. Similarly, ethnicity data for Wave One, Two and Four was merged (*EthnicMerge*), reducing non-responses from 391 to ten. For the minority of cases where the respondents changed responses in later waves their earliest response was included in the merged variable.

The data was screened for univariate normality (skew, kurtosis and outliers) to identify potential irregularities, and multivariate normality (scatter plot matrices) to assess linear relationships between variables. Collinearity tests assessed whether the mental health indicators represented different facets of the same factor. The screening resulted in the exclusion of four indicators for *Worthless*, *Concentration*, *Useful* and *Decisive*. Data screening results are reported with the quantitative results in Chapter Eight.

Figure 7.3 Hypotheses to be tested through SEM. CMOs reflect configurations in the realist model

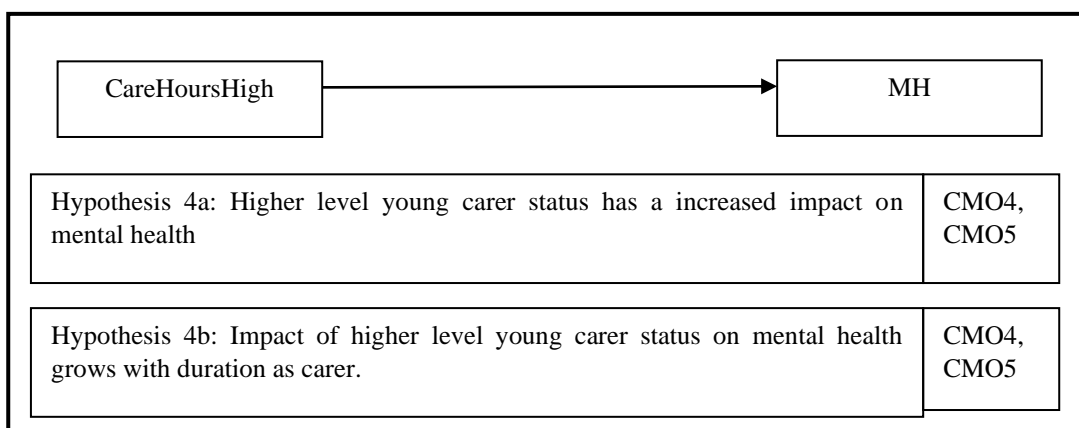
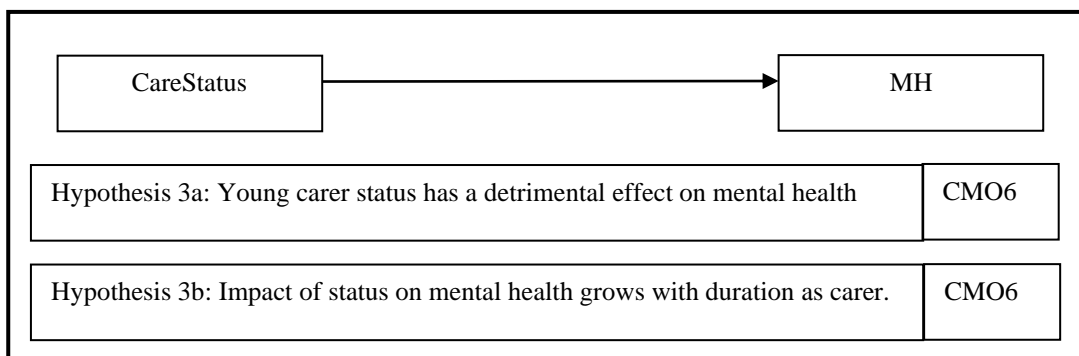
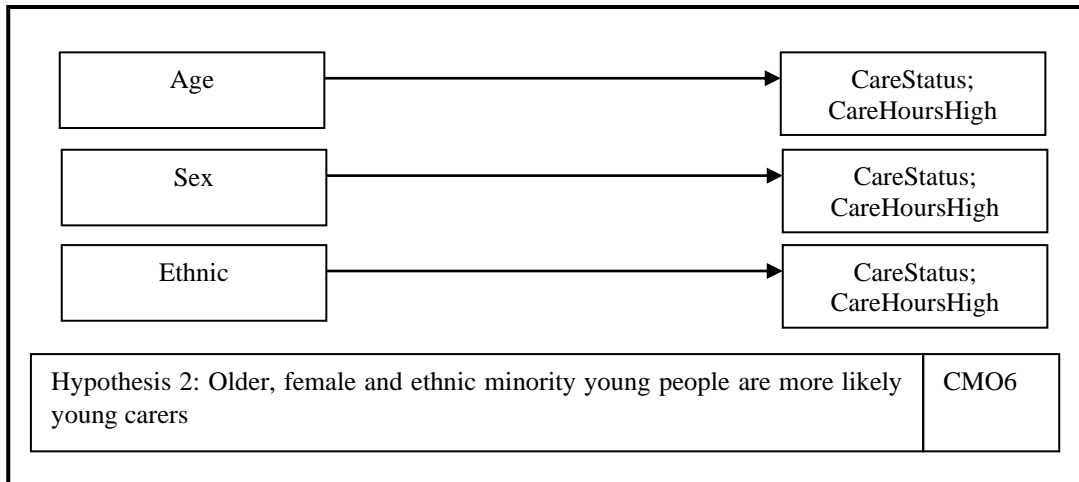
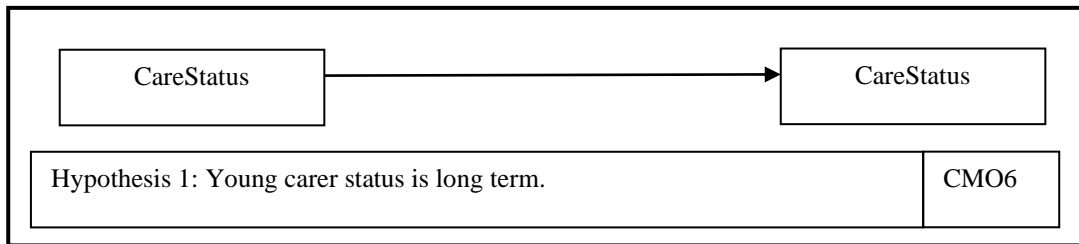
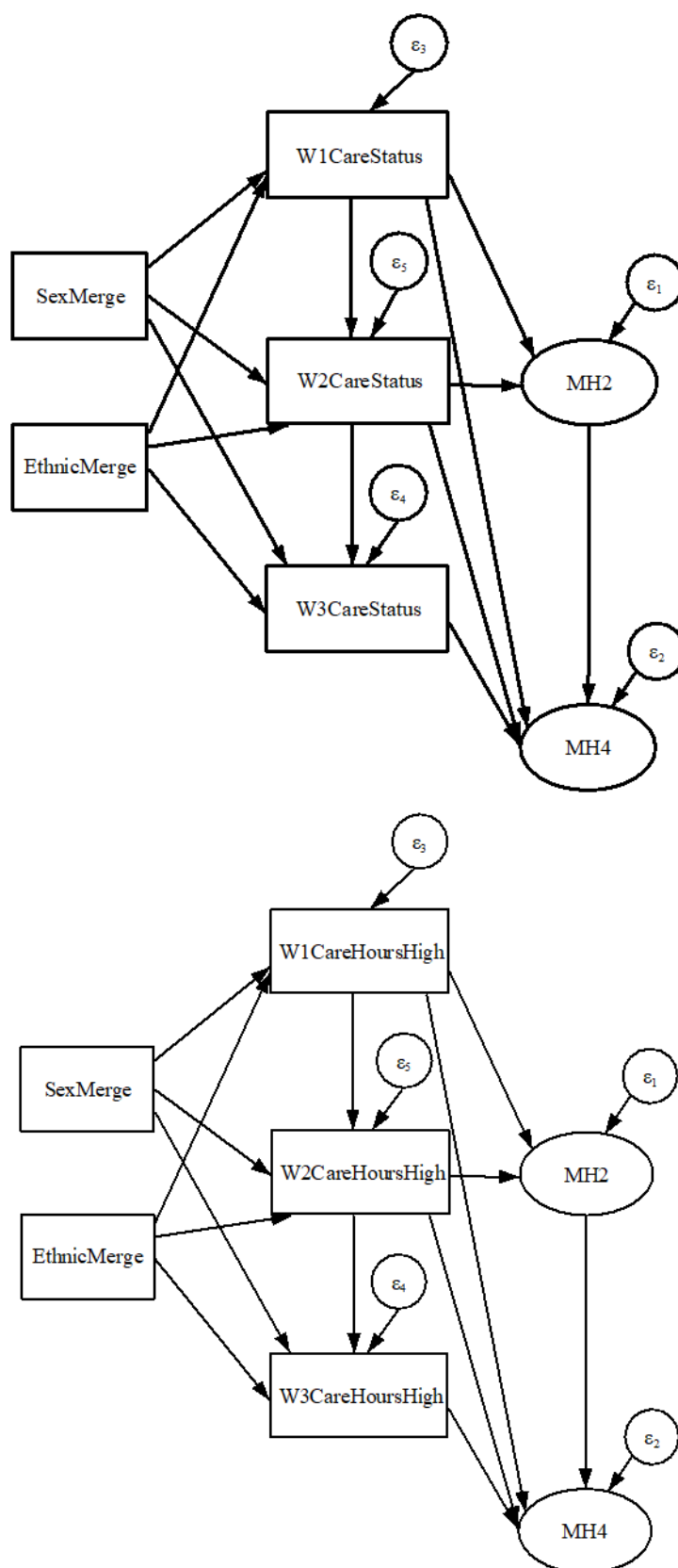


Figure 7.4 Standard young carer (top) and higher-level (bottom) young carer models. Excludes indicators on the latent variables (MH)



A Principal Component Analysis (PCA) was utilised to assess the optimal number of factors that explain the correlations between the observed mental health indicators. Reducing multiple indicators to a smaller number of factors aligns with the goal of parsimony (Revelle 2020), where a smaller number of components can sometimes explain a factor as well as a larger set. There are multiple tools to assist in this data reduction and specifically the number of factors to reduce a set of indicators to, including the VSS (Very Simple Structure) goodness of fit test, MAP (Minimal Average Partial) criterion and scree plots. Considering the tests together, there was a consensus for the eight indicators to load onto a single mental health factor.

Having identified the optimal number of factors, a confirmatory factor analysis was then conducted to check the relationship strengths between the components of the single factor. This included testing the relationships between each mental health indicator and the factor, and assessing the communality between each pair of mental health indicators.

These results of the PCA and confirmatory factor analysis are also detailed in Chapter Eight. With this confirmed specification was concluded with the addition of the measurement component to the standard (Figure 7.5) and higher-level carer model (Figure 7.6).

Identification

Mathematical representation was achieved by applying parameter constraints to the models to aid identification of the model. It should be noted that, with the exception of the high-level carer status indicators (*CareHoursHigh*) replacing the young carer status indicators (*CareStatus*), the identification of the models is identical. The measurement component concerning the mental health latent factors and indicators is considered first, followed by the structural component.

Scaling is needed to ensure that the loading of the eight mental health indicators on to the factors is calculated relative to each other. Newson (2015) considers three possible methods for the scaling of the measurement component: the referent indicator approach where a particular indicator has their loading parameter fixed to one and the others estimated relative to this; factor variance identification where the factor is fixed to one

and the indicators are freely estimated; and the effects coding identifications where the factor means are constrained. Newson advocates the use of the referent indicator approach for longitudinal modeling when there is expected low measurement invariance between data waves, and this was assessed as low during the data screening.

Figure 7.5 Identified standard young carers model

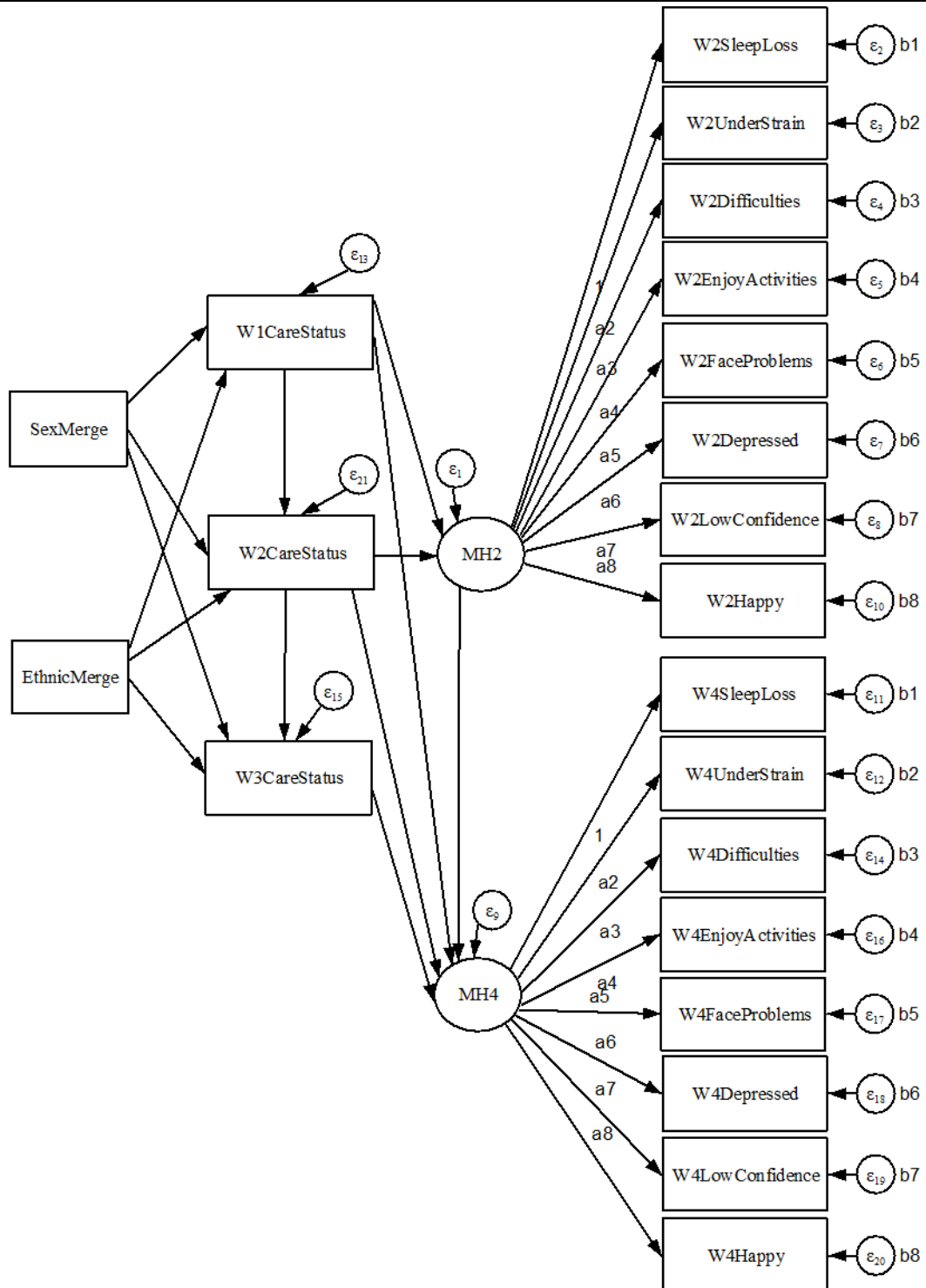
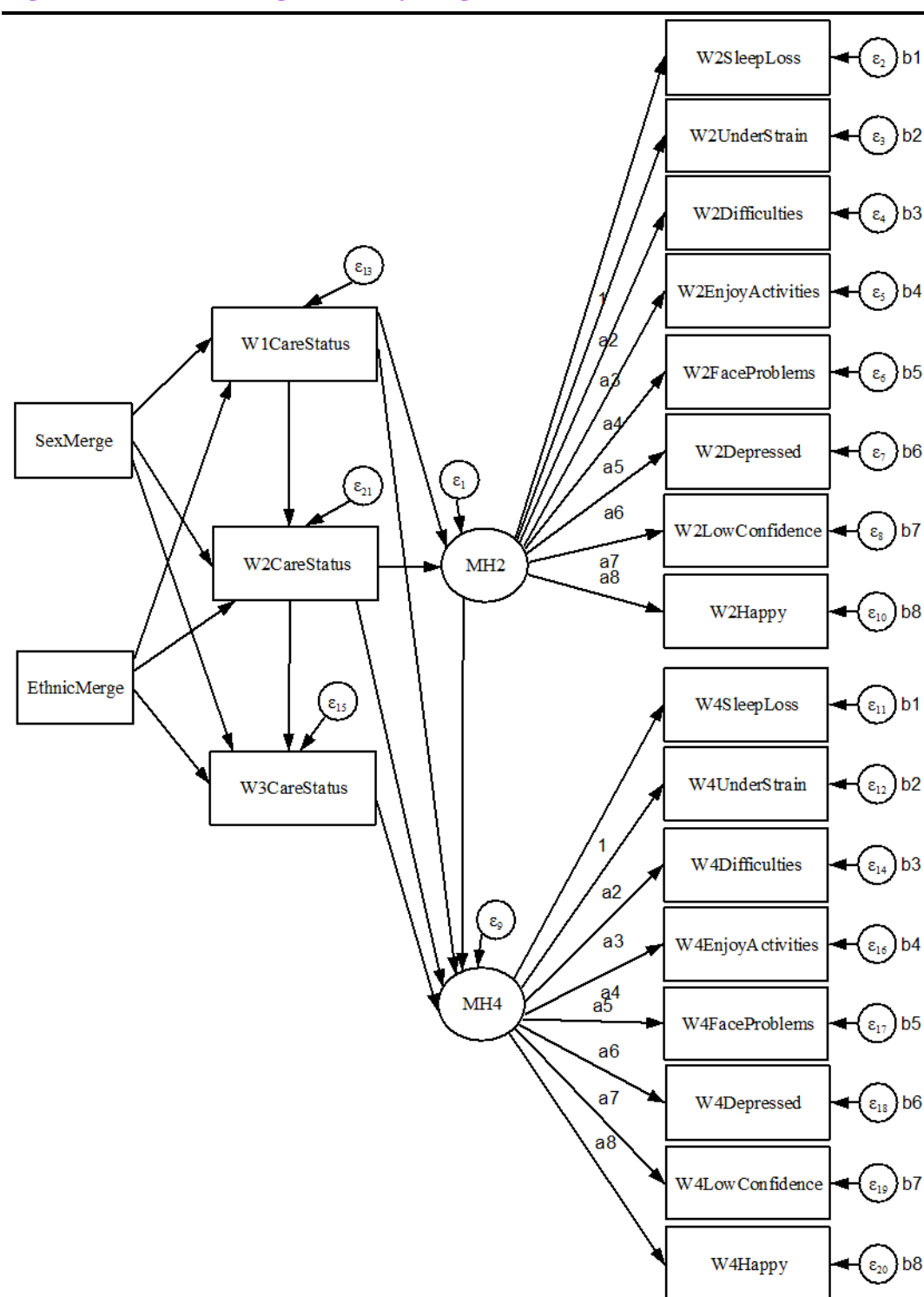


Figure 7.6 Identified higher-level young carers model



The first indicator on each factor, loss of sleep, was selected as the referent indicator and the parameters constrained to one ($[MH2 \rightarrow W2SleepLoss] = [MH4 \rightarrow W4SleepLoss] = 1$). Equality constraints were placed on the corresponding factor parameters (e.g. $[MH2 \rightarrow W2UnderStrain] = [MH4 \rightarrow W4UnderStrain] = a2$), again due to the expected low measurement invariance.

The mental health factors and indicators had residual variances which were designated free parameters to be estimated by the software. Thresholds were also required for the categorical data to aid estimation. The thresholds for indicators loading onto *MH2* were designated free parameters, with the equivalent *MH4* thresholds constrained to be equal (e.g., $e.W2SleepLoss = e.W4SleepLoss = b1$).

All parameters in the structural component of each model are free. This includes the intercepts on each of the carer status variables that are needed for longitudinal modeling, the residual variances, and all direct paths between the variables.

Table 7.5 summaries the model statistics including the number of free parameters that were introduced when considering the basic steps of SEM earlier in this chapter. A total of 50 free parameters in each model required estimation by the software. Identification is only possible when the software can derive a unique value for each parameter, and this is less likely in more complex models with greater numbers of free parameters and fewer observed variables (21 in each model). Based on a formula for calculating degrees of freedom (>0 is required for the model to be identified), the models have 202 degrees of freedom and can be estimated.

Estimation

The model was estimated using Mplus (version 8.3), specialist SEM software for the analysis of categorical data (Muthén and Muthén 2017). The software was therefore ideal for the analysis of the binary young carer status indicators and the categorical mental health indicators, and the use of the MLR (Maximum Likelihood with Robust standard errors and a chi-square test statistic) estimator was specified due to its strength in incorporating categorical outcome variables into models.

Table 7.5 Model statistics including free parameters and calculation of degrees of freedom.

Free parameters to be estimated by computer	
Latent factor indicators	7
Path analysis	14
Intercepts	8
Thresholds	3
Residual variances	18
Total free parameters (q)	50
Identification statistics	
Observed variables (v)	21
Observations ($p = \frac{v(v+3)}{2}$)	252
Degrees of freedom (df = p-q)	202

A key part of estimation is the calculation of the numerical value of integrals. Estimation begins with approximate values for the free parameters and, if successful, multiple iterations result in these values becoming definite to a given degree of accuracy. Mplus supports multiple numerical integrations algorithms, and the Monte Carlo algorithm was specified for use in this project. The Monte Carlo algorithm was developed for the purpose of modelling datasets with missing data and was therefore ideal for this study.

Chapter Eight reports the results of the quantitative analysis, including the data screening, descriptive analysis, prevalence estimates and SEM estimation.

7.3 Phenomenology procedure

The final element of this chapter details the phenomenological study procedure, beginning with the development of a school-based project to recruit young carers unknown to services. This was eventually expanded to include recruiting young carers who were accessing projects due to difficulties in recruitment. The development of

semi-structured topic guides for each of the three interview sets are also detailed, with the use of rapport building and creative methods enabling a natural conversation and authentic sharing of experiences. Steps for analysing the collected data are also detailed.

7.3.1 Recruitment of young carers not known to services

The study set out to recruit young carers who had not been identified by services. This was recognised as a challenge in Chapter One because many are reluctant to be identified, resulting in potentially large numbers of hidden young carers. Social media was initially considered as a way to disseminate information and recruit participants.

Fenner et al. (2012) considered multiple social media approaches to working with specific populations. The first approach, dissemination through a young carers organisation, would not be suitable for recruiting young carers that are unknown to services as the audience would largely be young carers who are accessing the group. Similarly, a snowballing approach through social media would struggle due to the lack of community and low awareness of other young carers.

A more promising approach suggested by Fenner was individualised advertisements based on social media profiles, though this was also not suitable for this study as young carer status information is not gathered by social media channels. However, there is evidence of studies targeting advertisements at users based on their digital footprint including ‘likes’ and interests (Matz et al. 2017), with examples including self-harm (Jacob et al. 2017). While it is difficult to assess the accuracy of this approach it does have potential. However, there are ethical concerns over whether users have given consent for their data to be used for this purpose (Henderson et al. 2013), and controversies relating to targeted advertisements being abused by companies and political organisations to influence behaviour (Sample 2017; Matz et al. 2017). Denecke (2014) has advocated for a new field of health web science to consider the ethics of social media profiling and, without this in place, the risks of social media profiling outweigh the considerable benefits.

As a result, a school-based approach was developed instead. The positives of this approach included project information being disseminated to a large and broadly representative population of children, though the sensitive nature of the research and the need to ensure confidentiality within the school environment presented an additional ethical challenge.

Ethical approval for the recruitment process

The recruitment target was 15 young carers of secondary school age in Southeast and South-Central Wales, with the expectation that each would be involved in three interviews. With recruitment expected to be difficult, the sampling was purposive and opportunistic, with the intention to recruit all interested children who identified as young carers.

A three-stage recruitment process was developed that included recruiting schools to participate in the project and host interviews, disseminating information to pupils, and seeking consent of the children and their families. The risk of participants dropping out at each of the three recruitment stages resulted in a time-consuming and hand-on approach being developed to increase retention.

Ethical approval was sought from Cardiff University's School of Social Sciences Research Ethic Committee, with a request for further information on how the study would be confidential. This led to the development of a flexible approach in each school to suit their individual policies and processes, particularly in relation to the dissemination of information, gaining of family consent and confidential hosting of interviews.

School recruitment

Recruitment for the project began in August 2018. Targeting was carried out through the School Health Research Network (SHRN) cohort study that is based in Cardiff University's public health research centre (DECIPHer). The 2017 survey had included a young carer status indicator, and 20 schools with a high proportion of young carers

were sent an information sheet (Appendix G). Schools who did not respond received a follow-up telephone call.

Meetings were held with interested schools to discuss how the confidential project could be facilitated in line with their policies and procedures. Four specific considerations were paramount. First, a named point of contact for the school was identified who would liaise with the researcher and the study participants while maintaining the participants confidentiality from the wider school. Second, schools identified the most appropriate way to disseminate information to pupils. Third, the most suitable approach to contacting and seeking the consent of families was discussed. Lastly, potential rooms for the hosting of confidential interviews were discussed. Schools which progressed were sent an individualised procedure of how the research would be run in their setting (Appendix H).

Pupil recruitment

Depending on school size the researcher ran a single whole-school assembly or separate assemblies for individual years. All assemblies were typically 10-15 minutes in length and combined young carer awareness raising with a brief explanation of the research and what involvement entailed. Questions during the assembly were avoided to prevent young carers disclosing their status in front of other pupils and school staff, though the researcher stayed behind to speak to interested pupils. Assemblies were reinforced with a pupil-appropriate information sheet that was individualised for each school (Appendix I).

Parental consent

Pupils who expressed an interest to the school point of contact were given additional information to take home. This included a parent information sheet with further details on confidentiality and data protection, and a consent form (Appendix J). Consent was opt-in with explicit permission from a family member required for their child to be involved. Non-responses were treated as a refusal with the child not participating in the research.

7.3.2 *Recruitment challenges and expansion*

The intensive approach to recruitment was expected to overcome some of the challenges of identifying young carers but, despite these steps, the process proved problematic.

Recruitment began in August 2018 with twenty school invited to participate, and an additional thirty schools were contacted in early 2019. Despite substantial interest and meeting with twelve schools to discuss how the project could be run in their setting, four schools did not go ahead with the opportunity. Six of the eight remaining schools opted for recruitment through assemblies with the researcher attending 17 assemblies. The remaining two recruited through Personal and Social Education (PSE) lessons on young carers, and dissemination of the project information through their social media channels respectively.

With no interest in four schools, seven families from the remaining four schools were contacted for consent. Five pupils became participants with consent not received from one family. The final pupil was due to begin participation in early 2020 but this was not possible due to the coronavirus pandemic.

Recruitment of young carers from young carer projects

By April 2019 it was evident that further recruitment beyond the 50 schools was needed. However, the school-based recruitment was protracted and couldn't be rolled out further due to the project length and the need to begin longitudinal data collection. Recruitment was therefore expanded to include identified young carers through projects. While this was not ideal, it did enable a greater comparison between those that were accessing support and those that were unknown to services.

Information was disseminated to young carer projects through Children in Wales, the national children's rights organisation for Wales who facilitated the Young Carers Network for practitioners at the time, and Carers Trust Wales who support, raise awareness and campaign for the rights of unpaid carers. The flexible approach developed for schools was maintained with initial meetings with interested service staff followed by attending young carer activity sessions to introduce the research. All young carers at the sessions received an information sheet, with parent information

sheets and consent forms sent to the families of interested children. Interviews were held in the young carer settings.

A further amendment to the method was the introduction of £10 vouchers at the first and last interviews. This was approved by Cardiff University's School of Social Sciences Research Ethic Committee and retrospectively applied to those participating through schools.

Chapter Nine is the first results chapter for the phenomenological results, and begins with a summary of the participants including their caring responsibilities and family circumstances. Details of the recruitment for the participants are also considered.

7.3.3 Interview development

The intention of the phenomenological study was to enable a 'fusion of horizons' with participants, as theorised by Gadamer (2004). The procedure was based on the five-step method detailed by Fleming et al. (2003). This including developing preunderstandings of the phenomenon based on the realist model detailed in Chapter Five, the use of open dialogue to maximise the potential for genuine understanding, and a combination of whole text and section level analysis.

The development and facilitation of the interviews were also informed by the work of Langdridge (2007), Moustakas (1994) and van Manen (2016). The researcher aimed to put participants at ease by holding the interviews in their respective school or young carer project, and by using informal icebreaker questions and creative methods to enable rapport-building. Interviews were limited to a maximum 60 minutes in length, and all three interviews were semi-structured with questions developed in advance but used as a guide. This enabled natural conversations with participants able to direct the conversation into new areas. Overall, the process was designed to be a positive experience for the participants, as well as a valuable opportunity for the researcher.

The first interview set were held between March 2019 and December 2019, with the second interviews between July 2019 and March 2020, and the final set between December 2019 and August 2020. The intention was to space each participant's three interviews equally over a year-long period but this varied slightly with school terms,

coronavirus restrictions and the time limitations of the research. As a result, the gaps between interviews for each participant varied from two to seven months. The content and methods for each interview are considered in more detail below.

Interview One

The first interview began with an ethical assent process, having gained parental consent before the meeting. The researcher reminded each participant of the project and how the interviews would work, with particular reference to them being informed and able to ask questions, permitting the audio being recorded, receiving a support sheet of potential people to talk to for advice, and recognising the voluntary nature of the interview. Participants agreed to each of the four statements and signed the assent form. The assent form is included in Appendix K, while Appendix L contains an example of a support sources sheet.

Participants were familiar with the researcher through the school assemblies and project visits, but building rapport was crucial during the first interview. Icebreaker questions on their likes and dislikes enabled the researcher and participants to get to know each other, and their responses provided informal topics to return to in later meetings.

The first interview includes data collection of contextual information relating to the young carer and their family. The first interview topic guide (Appendix M) includes questions relating to caregiving responsibilities (the care-receiver and their illness, the young carer's responsibilities, and the presence of other family members), support (assistance within the family, awareness by individuals and services of carer status, and support being accessed) and identity (perception of caring, choice and life balance). The final part of the first interview started to consider the impacts of caring.

The topic guide informed the conversations rather than dictating them, and participants were able to direct the conversation to new topics with the researcher clarifying details if needed and improvising additional questions. Approximately 15 minutes of the hour-long interviews were estimated and reserved for these deviations, and if time was running out the researcher delayed the planned content until the second interview, rather than interrupt the natural flow of the conversation.

Three activities were used during the first interview. For the first, participants were given a modified 'body in a box' template (Appendix N) of two bodies representing them and the person that they cared for. At certain points they were instructed to answer particular questions on the sheet, but they were also encouraged to write, draw or scribble on the paper at any point during the interviews and however they wanted. The second activity concerned rating scales for support from friends and community, health services, schools and social services (Appendix O), and their paper responses were the basis for a more detailed discussion of awareness, identification and support. The final mental health section of the interview was also activity-based with participants writing three impacts of being a young carer on slips of paper. They were then given a further set of paper slips (Appendix P), each of which had an impact identified from previous research and its opposite (for example independent and dependent; confident and unconfident). Participants selected those that were relevant to them in addition to their original three. They briefly explain the chosen impacts in preparation for the second meeting.

Interview Two

Conversations were transcribed prior to each participant's second interview. This enabled preparation including the identification and development of additional questions where clarification was needed. The second interviews were therefore more individualised, in order to help interpret and understand the experiences discussed in the initial meeting. Cross-fertilisation also enabled topics introduced by one participant to be raised with other participants if deemed relevant by the researcher. Appendix Q contains the individualised topic guide for Sophie's second interview.

The second interviews began with a recap of the first meeting, with the 'body in a box' materials from the first meeting utilised as a memory aid. The recap enabled the researcher to seek clarity on particular topics, and participants were also asked about contextual changes for them and their family since their first meeting.

The remainder of the second interview focused on their mental health and psychosocial wellbeing. Participants were given an impact triangle (Appendix R) with caregiving responsibilities, support and identity on the respective corners to reflect the domains of

the realist model of young carer mental health and psychosocial wellbeing. The mental health impacts selected by each participant during the first interview acted as a starting point, and they marked on the triangle whether they perceived each impact as due to their caregiving responsibilities, support, identity, or a combination of the three. This enabled discussion of the different impacts.

Interview Three

Transcription of the second interviews again enabled the identification of topics requiring clarification in the final meetings. The third interviews again began with a reminder of key discussion points from previous meetings and follow up questions. The focus on change was more prominent and participants considered their health and wellbeing in the context of changes in their wider circumstances.

The final interview then tested elements of the initial realist model with participants. Particular parts of the realist model were chosen on the basis of each participant's experiences, and they were able to agree, modify or challenge them and explain why. The use of this technique varied with the age and development of the different participants. Appendix S again contains the individualised topic guide for Sophie's third interview as an example of the content discussed.

7.3.4 Analysis

The procedures for the second and third interviews have already detailed the initial analysis of the first interviews to aid preparation. This enabled the researcher to remind each participant of what had been discussed before and to check any change in circumstances. In addition, the summary enabled the researcher to share his understanding of their experiences and to see if it reflected their understanding. This became the groundwork for further discussion in the main body of the interviews.

Following the end of data collection, all the first interviews transcripts were analysed in the order that the meetings were held. This initial analysis was at a whole-text level with key content identified and recorded on paper (see Appendix T for an example). This was followed by in-depth analysis of each individual section using Nvivo 11, with

findings considered alongside the key content identified in the first stage. This analysis also identified particularly revealing passages that demonstrated an understanding between the researcher and participants.

The second set of interviews were also analysed chronologically, and at a whole-text and section level. Analysis of each transcript was also informed by that participant's first transcript, enabling an additional focus on genetic phenomenology and how change in the participants health and wellbeing could relate to contextual change in their lives. Other adverse events unrelated to being a young carer were identified and this content analysed separately. The process was replicated again with third set.

7.4 Chapter summary

The previous chapter detailed the potential for a mixed methods research design to refine the realist young carers model, and justified the use of different methods to answer specific questions. This chapter has focused on detailing the quantitative and qualitative components of the mixed methods research. SEM was introduced with a focus on the basic steps of the technique and how progress has been made in the analysis of categorical data, while consideration of phenomenology focused on the hermeneutic approach that enables the development of understanding between the interviewer and interviewee. Procedures for the SEM and phenomenological elements of the mixed methods approach were then detailed.

The next four chapters present the results of the mixed methods. Chapter Eight contains the quantitative results, including the results of the data screening, the descriptive analysis and the modeling results. Chapters Nine, Ten and Eleven present the phenomenological results divided in line with the *caregiving responsibilities*, *support* and *identity* domains of the realist model.

Chapter Eight

Quantitative Results

Chapter Eight is the first of four results chapters and presents the quantitative findings of the mixed methods research. This is followed by the phenomenological results in Chapters Nine, Ten and Eleven.

The previous chapter detailed the structural equation modeling (SEM) procedure and the development of two longitudinal models. The first compares the mental health of all young carers with non-young carers over time, while the second compared higher level young carers with all other respondents.

This chapter initially present the results of the data screening, PCA (Principal Component Analysis) and confirmatory factor analysis that enabled the confirmation of the mental health factors and the development of the final models. The descriptive statistics are also reported before focusing on the SEM results and whether the theoretically derived hypotheses were supported by the evidence.

8.1 Data screening results

Chapter Seven detailed the data screening process that informed the resulting models and the SEM procedure, but the results of the data screening are reported in this section. The study indicators were screened for irregularities and Table 8.1 contains the skew and kurtosis statistics for the mental health indicators. Kline (2016) references a lack of consensus on the boundaries of a normal distribution but suggested limits for skew (<3.0) and kurtosis (-10.0 to $+10.0$). All indicators in the dataset were well within this range with skew <2.0 and kurtosis between -1.0 and 3.0 . The presence of outliers was also tested with Q-Q plots (Figure 8.1) comparing each data point with their expected value, and the systematic curved pattern indicated the need to utilise techniques for the analysis of nonnormal data.

Table 8.1 Skew and kurtosis statistics for the mental health indicators (Waves Two and Four).

Variable	Skew	Kurtosis	Variable	Skew	Kurtosis
W2SleepLoss	0.95	0.05	W4SleepLoss	0.69	-0.44
W2UnderStrain	0.66	-0.53	W4UnderStrain	0.38	-0.82
W2Difficulties	0.87	-0.01	W4Difficulties	0.75	-0.22
W2EnjoyActivities	0.72	1.69	W4EnjoyActivities	0.62	0.75
W2FaceProblems	0.75	1.66	W4FaceProblems	0.65	1.38
W2Depressed	0.83	-0.36	W4Depressed	0.73	-0.62
W2LowConfidence	1.14	0.31	W4LowConfidence	1.12	0.21
W2Happy	0.78	1.35	W4Happy	0.62	0.91
W2Concentration	0.66	1.69	W4Concentration	0.53	1.26
W2Useful	0.84	2.67	W4Useful	0.72	1.67
W2Decisive	0.56	1.54	W4Decisive	0.67	0.87
W2Worthless	1.69	2.01	W4Worthless	1.79	2.33

Scatter plot matrices visualise the bivariate relationships of indicator pairs. This enables assessment of linearity which is an indication of multivariate normality. The individual graphs in Figure 8.2 and Figure 8.3 for the respective MH2 and MH4 indicators indicated strong linear relationships for most indicator pairs, though the worthlessness indicators (*W2Worthless* and *W4Worthless*) had a poor linear relationship with multiple other indicators including strain, enjoying everyday activities and facing problems, particularly in the Wave Four data. As a result, these indicators were excluded at the end of the screening process. The second half of the matrix (above the diagonal) reported indicator pair correlations that are considered next.

Table 8.2 displays the correlation matrix with Wave Two data below and Wave Four data above the diagonal. The matrix indicates levels of collinearity within the indicator pairs, and ideally all correlations are high (>0.30), indicating that each of the indicators represents a different facet of the same factor. However, a large number of low correlations indicate instead that the indicators represent different factors. As a result, the indicators for usefulness (*W2Useful* and *W4Useful*), decision making (*W2Decisive* and *W4Decisive*) and concentration (*W2Concentrate* and *W4Concentrate*) were removed due to repeated collinearity with other variables. The problem facing

indicators (*W2FaceProblems* and *W4FaceProblems*) were retained as low collinearity scores with some indicators was compensated by higher scores with others. Despite the removal of the six indicators, some indicator pairs still had low correlation.

8.1.1 *Principal Component Analysis*

The remaining eight mental health variables from each data wave were included in the model. A PCA (Principal Component Analysis) was conducted to determine the optimal number of factors to represent the eight mental health indicators in each wave of data. The procedure for the SEM study in Chapter Seven considered the goal of parsimony and a number of tools for reducing large numbers of indicators to an optimal number of factors. Table 8.3 and Table 8.4 detail the results of these tests including the Velicer MAP (Minimal Average Portal) and the VSS (Very Simple Structure) Complexity 1 and Complexity 2 tests for the respective Wave Two and Wave Four indicators. Additional scree plots (Figure 8.4) present the results visually.

The Velicer MAP ($W2=0.037$; $W4=0.032$), VSS Complexity 1 ($W2=0.82$; $W4=0.82$) statistics and scree plots all suggested that a single mental health factor for each wave containing all the indicators was optimal, while the VSS Complexity 2 test suggested the need for two factors ($W2=0.87$; $W4=0.86$). Based on the consensus of three of the four tests, the measurement component of the model was confirmed to have a single factor for each wave (*MH2* and *MH4*) with eight loading indicators.

Confirmatory factor analysis

A Maximum Likelihood confirmatory factor analysis (Table 8.5) was utilised to assess the contribution of each indicator to the factor. Compared to accepted values for weak relationships ($ML<0.30$), the indicator scores ranged from 0.42 (*W2FaceProblems*) to 0.81 (*W2Depressed*), indicating medium to strong relationships. Communality (h^2) was also measured to assess the level of variance that each indicator has in common with the other indicators, with <0.20 indicating low communality. While the communality of the problem facing indicators was low (*W2FaceProblems*=0.18; *W4Faceproblems*=0.19), the remaining indicators ranged from 0.23 (*W2EnjoyActivities*) to 0.66 (*W2Depressed*).

Figure 8.1 Q-Q plots for Wave Two (left) and Wave Four data.

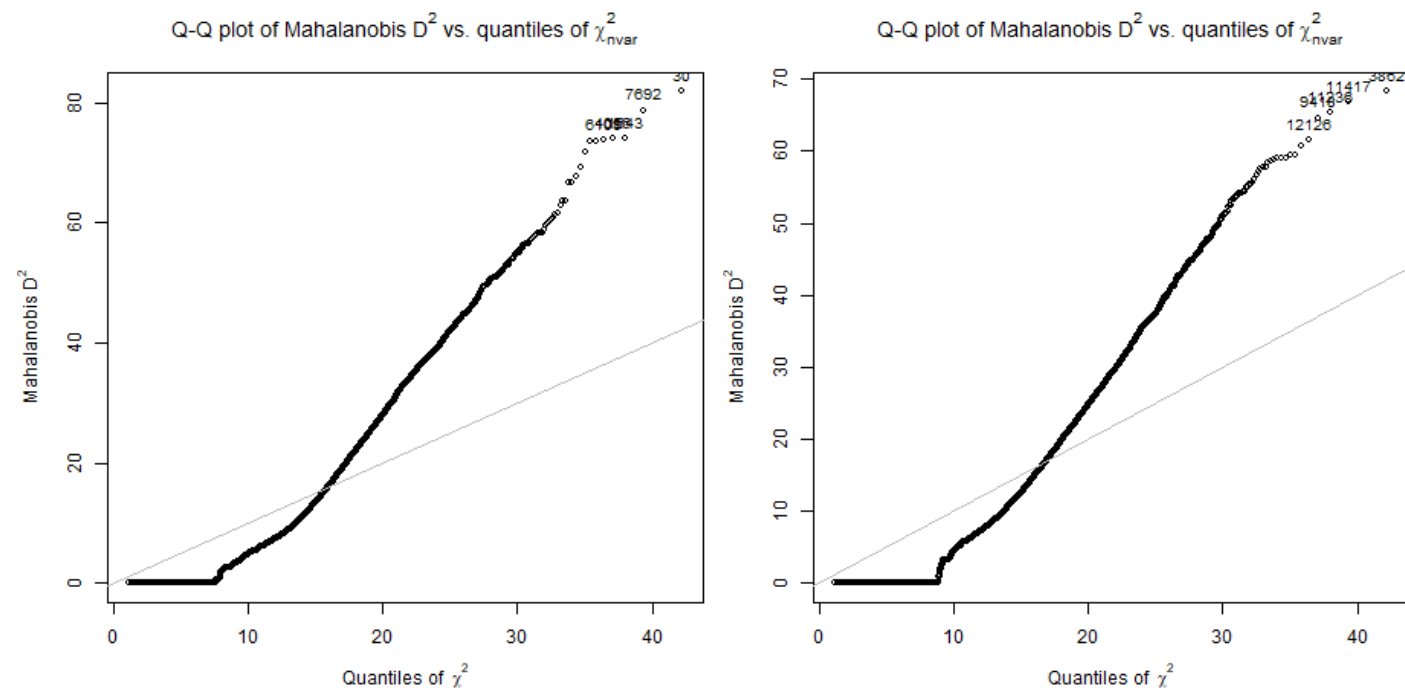


Figure 8.2 Scatter plot matrices for linear relationships between MH2 mental health indicators.

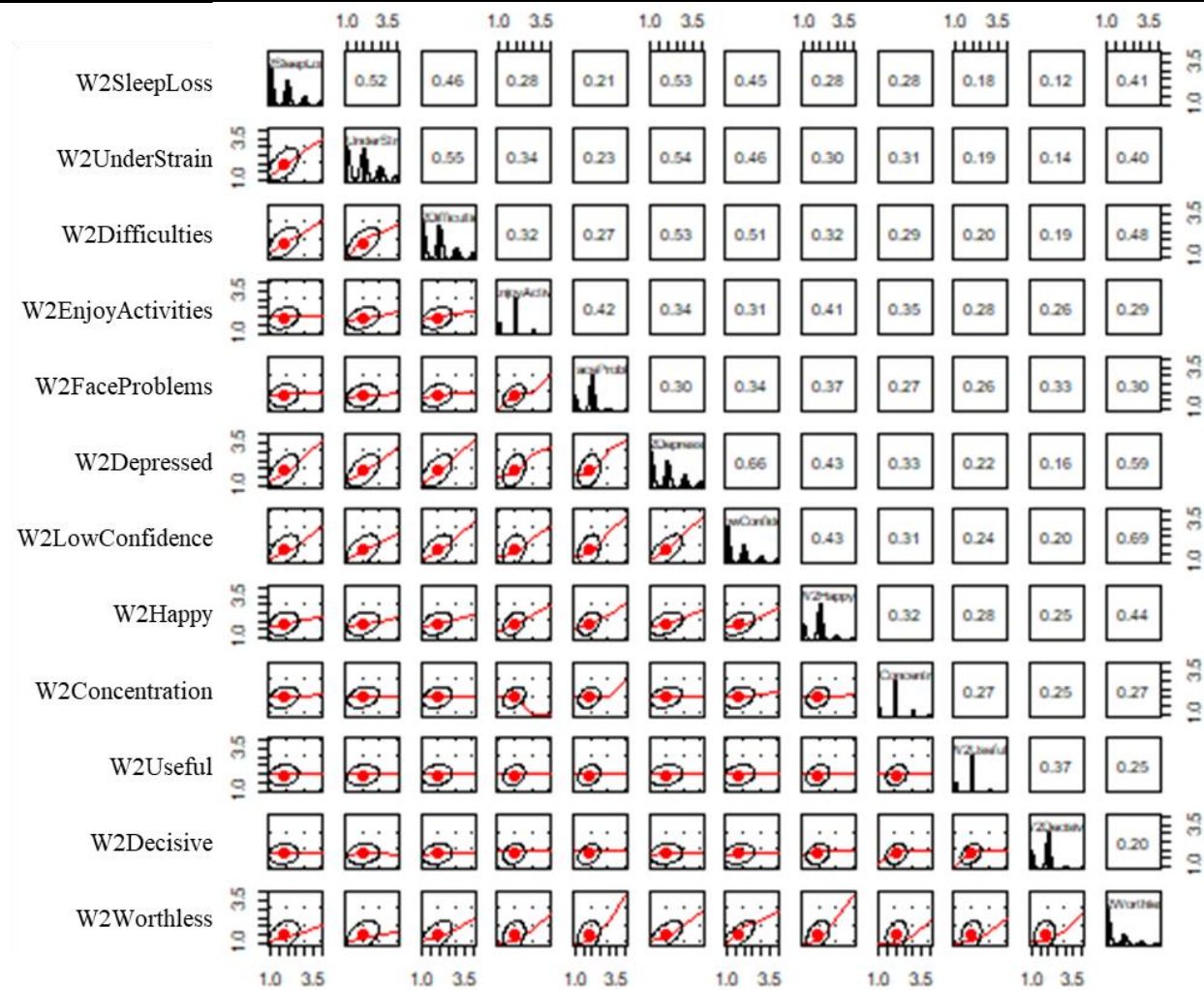


Figure 8.3 Scatter plot matrices for linear relationships between MH4 mental health indicators.

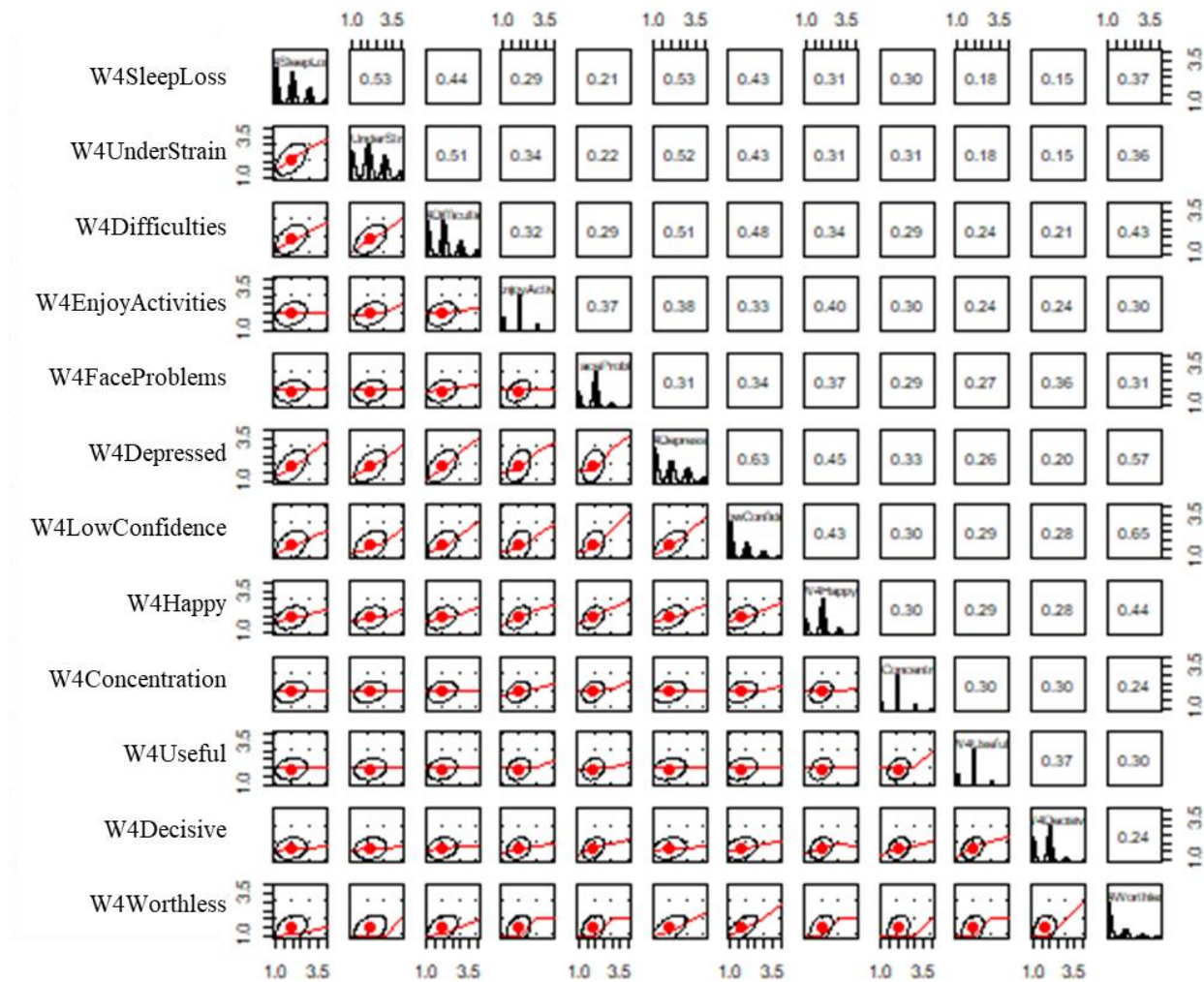


Table 8.2 Correlation matrices for mental health indicators (indicators marked in red were removed). Wave Two indicators below the diagonal with Wave Four indicators above.

	W4 SleepLoss	W4 UnderStrain	W4 Difficulties	W4 EnjoyActivities	W4 FaceProblems	W4 Depressed	W4 LowConfidence	W4 Happy	W4 Concentrate	W4 Useful	W4 Decisive	W4 Worthless
W2SleepLoss		0.53	0.44	0.29	0.21	0.53	0.43	0.31	0.30	0.18	0.15	0.37
W2UnderStrain	0.52		0.51	0.34	0.22	0.52	0.43	0.31	0.31	0.18	0.15	0.36
W2Difficulties	0.46	0.55		0.32	0.29	0.51	0.48	0.34	0.29	0.24	0.21	0.43
W2EnjoyActivities	0.28	0.34	0.32		0.37	0.38	0.33	0.40	0.30	0.24	0.24	0.30
W2FaceProblems	0.21	0.23	0.27	0.42		0.31	0.34	0.37	0.29	0.27	0.36	0.31
W2Depressed	0.53	0.54	0.53	0.34	0.30		0.63	0.45	0.33	0.26	0.20	0.57
W2LowConfidence	0.45	0.46	0.51	0.31	0.34	0.66		0.43	0.30	0.29	0.28	0.65
W2Happy	0.28	0.30	0.32	0.41	0.37	0.43	0.43		0.30	0.29	0.28	0.44
W2Concentrate	0.28	0.31	0.29	0.35	0.27	0.33	0.31	0.32		0.30	0.30	0.24
W2Useful	0.18	0.19	0.20	0.28	0.26	0.22	0.24	0.28	0.27		0.37	0.30
W2Decisive	0.12	0.14	0.19	0.26	0.33	0.16	0.20	0.25	0.25	0.37		0.24
W2Worthless	0.41	0.40	0.48	0.29	0.30	0.59	0.69	0.44	0.27	0.25	0.20	

Table 8.3 PCA results (VSS1, VSS2, Velicer) for Wave 2 data.

	vss1	vss2	map	dof	chisq	prob	sqresid	fit	RMSEA	BIC	SABIC	complex	eChisq	SRMR	eCRMS	eBIC
1	0.82	0	0.037	20	4.50E+03	0.00E+00	3.2	0.82	0.118	4332	4395.9	1	4.20E+03	6.80E-02	0.081	4040.9
2	0.66	0.87	0.056	13	1.70E+03	0.00E+00	2.2	0.87	0.089	1551	1592.5	1.3	8.20E+02	3.00E-02	0.0444	698.7
3	0.46	0.81	0.095	7	1.50E+02	2.40E-28	1.9	0.89	0.035	78	100.7	1.7	5.80E+01	8.00E-03	0.0161	-9.6
4	0.47	0.81	0.205	2	6.30E+00	4.30E-02	1.8	0.9	0.012	-13	-6.7	1.8	3.00E+00	1.80E-03	0.0068	-16.4
5	0.47	0.81	0.296	-2	7.20E-06	NA	1.7	0.9	NA	NA	NA	1.8	3.40E-06	1.90E-06	NA	NA
6	0.47	0.81	0.533	-5	8.10E-08	NA	1.7	0.9	NA	NA	NA	1.8	3.30E-08	1.90E-07	NA	NA
7	0.47	0.81	1	-7	2.30E-09	NA	1.7	0.9	NA	NA	NA	1.8	8.70E-10	3.10E-08	NA	NA
8	0.47	0.81	NA	-8	2.30E-09	NA	1.7	0.9	NA	NA	NA	1.8	8.70E-10	3.10E-08	NA	NA

Note: vss=very simple structure; map=minimal average partial; dof=degrees of freedom; chisq=chi-square test; prob=probability of residual matrix; sqresid=squared residual correlations; fit=factor fit of complete model; RMSEA=Root Mean Square Error of Approximation; BIC=Bayesian Information Criterion; SABIC=Sample-size Adjusted BIC; eChisq=empirically found Chi square; SRMR=Standardised Root Mean Square Residual; eCRMS=empirically found Mean Residual Corrected for degrees of freedom; eBIC=empirically found Bayesian Information Criterion.

Table 8.4 PCA results (VSS1, VSS2, Velicer) for Wave 4 data.

	vss1	vss2	map	dof	chisq	prob	sqresid	fit	RMSEA	BIC	SABIC	complex	eChisq	SRMR	eCRMS	eBIC
1	0.82	0	0.032	20	3.40E+03	0.00E+00	3.2	0.82	0.102	3205.7	3269.3	1	3.00E+03	5.80E-02	0.0687	2853
2	0.61	0.86	0.055	13	1.20E+03	3.20E-256	2.4	0.86	0.076	1110	1151.3	1.4	6.40E+02	2.70E-02	0.039	512
3	0.44	0.76	0.099	7	1.80E+02	5.90E-36	2.1	0.88	0.039	114.6	136.89	1.8	8.50E+01	9.70E-03	0.0194	17
4	0.44	0.76	0.181	2	1.30E+01	1.90E-03	1.9	0.89	0.018	-6.8	-0.47	1.9	5.70E+00	2.50E-03	0.0094	-14
5	0.41	0.71	0.279	-2	1.10E-05	NA	1.7	0.9	NA	NA	NA	2.1	5.00E-06	2.30E-06	NA	NA
6	0.45	0.78	0.456	-5	2.70E-09	NA	1.8	0.89	NA	NA	NA	1.9	1.50E-09	4.10E-08	NA	NA
7	0.45	0.78	1	-7	0.00E+00	NA	1.8	0.89	NA	NA	NA	1.9	8.80E-16	3.10E-11	NA	NA
8	0.45	0.78	NA	-8	0.00E+00	NA	1.8	0.89	NA	NA	NA	1.9	8.80E-16	3.10E-11	NA	NA

Figure 8.4 Scree plots for Wave Two (left) and Wave Four data.

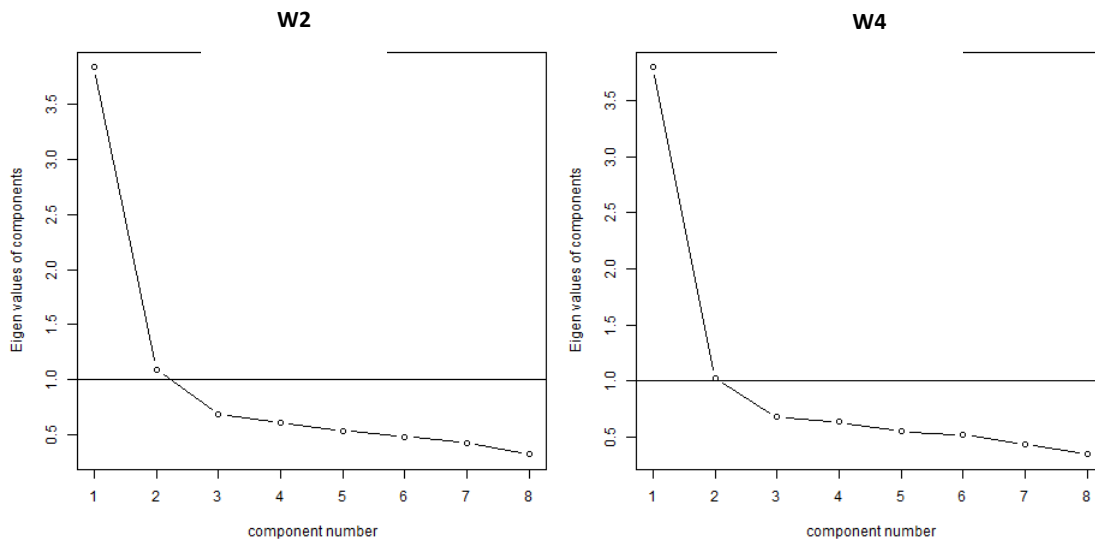


Table 8.5 Maximum likelihood confirmatory factor analysis results for Wave Two (left) and Four data.

	ML1	h2	u2	com		ML1	h2	u2	com
W2SleepLoss	0.64	0.42	0.58	1	W4SleepLoss	0.64	0.41	0.59	1
W2UnderStrain	0.68	0.46	0.54	1	W4UnderStrain	0.66	0.44	0.56	1
W2Difficulties	0.69	0.47	0.53	1	W4Difficulties	0.67	0.44	0.56	1
W2EnjoyActivities	0.48	0.23	0.77	1	W4EnjoyActivities	0.51	0.26	0.74	1
W2FaceProblems	0.42	0.18	0.82	1	W4FaceProblems	0.43	0.19	0.81	1
W2Depressed	0.81	0.66	0.34	1	W4Depressed	0.8	0.64	0.36	1
W2LowConfidence	0.75	0.57	0.43	1	W4LowConfidence	0.72	0.53	0.47	1
W2Happy	0.54	0.29	0.71	1	W4Happy	0.57	0.32	0.68	1
	ML1					ML1			
SS loadings	3.28				SS loadings	3.23			
Proportion Var	0.41				Proportion Var	0.4			

8.2 Descriptive statistics

Having considered the data screening process, this section presents the results of the descriptive analysis. This includes the prevalence of young carers among children with demographic breakdown by ethnicity, sex and age, and the reporting of individual mental health variables for young carers in comparison with non-caring peers.

8.2.1 *Young carer prevalence*

Chapter Seven considered the properties of the dataset including the overall sample size which decreased throughout the four waves (W1=15,770; W2=13,539; W3=12,439; W4=11,449). Despite this, the sample size remained large enough to have a high level of confidence in the results, and the random probability sampling with stratification by deprivation ensured a representative sample.

Table 8.6 displays the dataset prevalence estimates, with further consideration of specific demographics. Respondents were aged 13 during Wave One with subsequent annual waves collected. Prevalence increased with age (W1=5.13%; W2=5.76%; W3=6.21%) and over 750 respondents in each wave identified as young carers. Prevalence in all waves was higher amongst females (W1=5.40%; W2=6.21%; W3=6.62%; W4=6.51%) than males (W1=4.87%; W2=5.32%; W3=5.81%; W4=5.74%), with the difference more pronounced amongst minority ethnic children (W1=7.0%; W2=7.85%; W4=8.02%) compared to white children (W1=4.22%; W2=4.82%; W4=5.37%).

The trends were similar for higher level carers, with prevalence increasing with age in subsequent waves (W1=0.79%; W2=0.86%, W3=1.03%), though the limited subsample (<130 in each data wave) means that the results should be interpreted with caution. Again, higher-level carers were more likely female (W1=0.93%; W2=1.01%; W3=1.29%; W4=1.25%) than males (W1=0.65%; W2=0.72%; W3=0.78%; W4=0.77%), and from ethnic minorities (W1=1.29%; W2=1.41%; W4=1.65%) compared to white children (W1=0.54%; W2=0.62%; W4=0.75%).

8.2.2 *Mental health of young carers combined to children without caring responsibilities*

Table 8.7 displays the means and standard deviations of the mental health variables for young carers compared to children without caring responsibilities. Young carers scored marginally higher on every Wave Two variable indicating comparatively poor mental health. This was most notable for depression with young carers scoring substantially higher (1.97 compared to 1.87, degrees of freedom=801.41; $t=-2.55$; $p=.011$), as well as sleep loss (1.89 compared to 1.77; $df=793.85$; $t=-3.47$; $p=.000$).

The results were similar for the Wave Four data with young carers scoring slightly higher on seven of the eight mental health indicators. The one exception was facing problems with young carers scoring lower (1.83 compared to 1.87; $df=747.17$; $t=1.40$; $p=.163$), though there was a lack of evidence that this finding was statistically significant.

Considering longitudinal change in the mental health of the young carer population, paired t-tests were not possible due to carer status for some respondents changing over time. Therefore, statistical significance of the longitudinal change could not be considered. However, scores were higher for six of the eight variables at Wave Four compared to Wave Two, indicating deterioration in mental health. The detrimental impact was greatest for strain (+0.17) and enjoying day to day activities (+0.11). Change in the two remaining variables was marginal but there was an indication that they felt better able to face their problems (-0.01) and had increased confidence (-0.02). While the mental health scores of young carers increased over time it should be noted that the scores for children without caring responsibilities also increased for seven of the eight variables.

The mental health of higher-level young carers

Table 8.8 displays the equivalent results for higher-level young carers compared to all other respondents combined. Higher level young carers scored lower on seven of the eight mental health variables at Wave Two. This indicated better mental health for those with greater responsibilities, contrasting notably with the results for all young carers. The scores were particularly low for the facing problems variable (1.71

compared to 1.83; $df=102.61$; $t=1.85$; $p=.067$) and the enjoying activities variable (1.79 compared to 1.9; $df=105.53$; $t=1.60$; $p=.113$). Sleep loss was the only variable where young carers scored higher (1.83 compared to 1.77; $df=109.71$; $t=-0.61$; $p=.544$). However, there was a lack of evidence that these findings were statistically significant, with this partly due to the limited sample size of higher-level young carers.

While the short-term impacts of greater amounts of care appeared to be beneficial, many of the results were reversed at Wave Four, with higher-level young carers having higher scores on six of the eight variables than other respondents. The difference was greatest for the enjoying activities variable (2.12 compared to 1.95; $df=109.47$; $t=-2.07$; $p=.040$), and the finding was statistically significant despite the small sample size. Higher-level young carers also scored notably higher on the indicator for sleep loss (2.05 compared to 1.92; $df=110.63$; $t=-1.23$; $p=.221$) though the evidence was not strong enough for the finding to be statistically significant.

There was a notable longitudinal change within the higher-level young carer population between Wave Two and Wave Four, with an increase in every mental health variable indicating deteriorating mental health. Deterioration was most substantial for activity enjoyment (+0.33), feeling under strain (+0.25) and sleep loss (+0.22). Again, this should be considered alongside the whole dataset where mental health also deteriorated, though to a lesser extent.

In summary the descriptive analysis identified trends in the prevalence of young carers, with older, female and ethnic minority children more likely to identify as young carers. Analysis of the eight individual mental health variables enabled a comparison of young carers and children without caring responsibilities, with an indication that the impacts of caring on mental health can become increasingly negative over time. The mental health of those with higher level caring responsibilities compared positively to other respondents at Wave Two but significantly worse at Wave Four, indicating short term benefits but long-term deterioration of a greater magnitude.

Table 8.6 Standard and higher-level young carer prevalence for age, sex and ethnicity demographics.

Data wave	Carer prevalence					Higher level carer prevalence				
	Demographic	N	Carer	Non carer	Prevalence	Demographic	N	High carer	Standard / non carer	Prevalence
W1	Age					Age				
	13	15411	791	14620	5.13%	13	15345	121	15224	0.79%
W2	14	13273	764	12509	5.76%	14	13213	114	13099	0.86%
W3	15	12276	762	11514	6.21%	15	12236	126	12110	1.03%
W1	Gender					Gender				
	Male	7837	382	7455	4.87%	Male	7810	51	7759	0.65%
	Female	7574	409	7165	5.40%	Female	7535	70	7465	0.93%
W2	Male	6715	357	6358	5.32%	Male	6680	48	6632	0.72%
	Female	6558	407	6151	6.21%	Female	6533	66	6467	1.01%
W3	Male	6200	360	5840	5.81%	Male	6185	48	6137	0.78%
	Female	6076	402	5674	6.62%	Female	6051	78	5973	1.29%
W4	Male	5605	322	5283	5.74%	Male	5591	43	5548	0.77%
	Female	5544	361	5183	6.51%	Female	5521	69	5452	1.25%
W1	Ethnicity					Ethnicity				
	White	10326	436	9890	4.22%	White	10297	56	10241	0.54%
	ME	5071	355	4716	7.00%	ME	5034	65	4969	1.29%
W2	White	9113	439	8674	4.82%	White	9074	56	9018	0.62%
	ME	4141	325	3816	7.85%	ME	4120	58	4062	1.41%
W4	White	7873	423	7450	5.37%	White	7854	59	7795	0.75%
	ME	3417	274	3143	8.02%	ME	3399	56	3343	1.65%

Table 8.7 Descriptive statistics for the mental health indicators, by carer status.

Wave	Indicator	Carer			Non carer			T-tests		
		N	Mean	SD	N	Mean	SD	Dof	T-value	P-value
2	W2SleepLoss	717	1.89	0.94	11970	1.77	0.88	793.85	-3.47	0.000
4	W4SleepLoss	670	1.97	0.95	10271	1.92	0.91	752.11	-1.44	0.151
2	W2UnderStrain	683	1.98	0.94	11557	1.96	0.94	764.96	-0.42	0.678
4	W4UnderStrain	666	2.15	0.96	10235	2.14	0.94	750.72	-0.18	0.854
2	W2Difficulties	682	1.89	0.93	11520	1.85	0.89	756.8	-1.07	0.285
4	W4Difficulties	659	1.92	0.92	10229	1.88	0.88	736.42	-1.04	0.300
2	W2EnjoyActivities	716	1.9	0.72	12001	1.9	0.64	783.92	-0.16	0.871
4	W4EnjoyActivities	675	2.01	0.75	10321	1.95	0.7	752.4	-2.04	0.042
2	W2FaceProblems	707	1.84	0.74	11955	1.83	0.64	769.71	-0.47	0.636
4	W4 FaceProblems	673	1.83	0.7	10289	1.87	0.64	747.17	1.40	0.163
2	W2Depressed	718	1.97	0.99	11868	1.87	0.96	801.41	-2.55	0.011
4	W4Depressed	663	2.03	1.05	10230	1.9	0.97	738.44	-3.29	0.001
2	W2LowConfidence	722	1.78	0.99	11945	1.7	0.9	796.17	-2.22	0.268
4	W4LowConfidence	666	1.76	0.98	10273	1.69	0.9	739.34	-1.77	0.077
2	W2Happy	691	1.91	0.76	11627	1.87	0.68	757.5	-1.61	0.108
4	W4Happy	663	1.94	0.72	10229	1.9	0.67	739.99	-1.34	0.182

Table 8.8 Descriptive statistics for the mental health indicators, by higher-level care status.

Wave	Indicator	Higher level carer			Standard / non carer			T-Tests		
		N	Mean	SD	N	Mean	SD	Dof	T-value	P-value
2	W2SleepLoss	109	1.83	0.93	12527	1.77	0.89	109.71	-0.61	0.544
4	W4SleepLoss	110	2.05	1.07	10794	1.92	0.91	110.63	-1.23	0.221
2	W2UnderStrain	93	1.88	0.92	12098	1.97	0.94	93.498	0.88	0.38
4	W4UnderStrain	106	2.13	1.01	10760	2.14	0.95	106.8	0.07	0.943
2	W2Difficulties	97	1.82	0.97	12057	1.85	0.89	97.313	0.26	0.798
4	W4Difficulties	106	1.88	0.92	10748	1.88	0.88	106.88	0.07	0.944
2	W2EnjoyActivities	105	1.79	0.69	12560	1.9	0.64	105.53	1.60	0.113
4	W4EnjoyActivities	109	2.12	0.85	10851	1.95	0.7	109.47	-2.07	0.040
2	W2FaceProblems	102	1.71	0.65	12509	1.83	0.65	102.61	1.85	0.067
4	W4 FaceProblems	110	1.91	0.84	10815	1.86	0.64	110.29	-0.57	0.571
2	W2Depressed	105	1.88	0.94	12431	1.88	0.96	105.86	0.00	0.997
4	W4Depressed	108	2.01	1.1	10749	1.9	0.98	108.71	-1.01	0.316
2	W2LowConfidence	108	1.67	0.92	12507	1.7	0.91	108.82	0.42	0.678
4	W4LowConfidence	110	1.74	1.04	10793	1.69	0.91	110.7	-0.45	0.651
2	W2Happy	98	1.83	0.76	12171	1.87	0.68	98.266	0.53	0.594
4	W4Happy	108	2.02	0.74	10748	1.9	0.67	108.82	-1.67	0.097

8.3 Structural Equation Modeling results

The descriptive analysis identified findings concerning the impacts of short and long-term caring on individual mental health variables, and the potential for different outcomes depending on the level of responsibilities undertaken. However, interpretation of the descriptive statistics is limited due to each mental health variable being analysed individually and independently of the remaining variables. In addition, the claim that the mental health of young carers deteriorate over time is weakened by the fact that this trend is also present for children without caring responsibilities.

The strengths of SEM were considered in detail in Chapter Seven, but the approach enables the simultaneous analysis of mental health as a single latent factor consisting of eight indicators, rather than as a collection of individual variables. This enables the results of the descriptive analysis to be challenged and potentially strengthened.

The SEM results briefly consider the estimation process in Mplus and the properties of the final dataset. The results of the measurement component concerning the mental health factors (*MH2* and *MH4*) are then reported, ahead of consideration of the structural component and the model hypotheses detailed in Chapter Seven.

Statistical significance is reported for all parameters, with consideration of whether the evidence is strong enough to be confident of the findings. The discussion at the end of the chapter then differentiates between statistically significant findings that will be considered when refining the model in Chapter Twelve, and weaker findings that will not be incorporated unless they can be triangulated with qualitative findings during the integration stage.

8.3.1 *Estimation*

The models were estimated in Mplus. The software identified and excluded 199 observations from the standard model due to insufficient data, compared to the 15,923 observations that were included. Response rates for all variables was high (>71%), especially the young carer status variables (*W1CareStatus*=96.8%; *W2CareStatus*=83.4%; *W3CareStatus*=77.1%). Covariance response was also high for every pair of variables (>63%).

Observation exclusion was slightly higher in the higher-level young carer model with the removal of 216 observations (15906 included). This was due to slightly greater missing data on the *CareHoursHigh* variables. Despite this, response rates remained high for all variables (>71%), in particular the higher-level carer variables (*W1CareHoursHigh*=96.5%; *W2CareHoursHigh*=83.1%; *W3CareHoursHigh*=76.9%). Covariance response also remained high for the second model (>63%).

The estimation of the two models completed successfully without respecification. They are therefore *a priori* and fully informed by theoretical knowledge. The Mplus standard young carer model script, including the input commands and results, are included in Appendix U, with the higher-level young carer model script in Appendix V.

8.3.2 *Measurement component*

The measurement components of the models concerns the mental health factors (*MH2* and *MH4*) and the eight indicators that load onto each of them. Table 8.9 displays the tabulated results of the SEM models including parameter estimates and statistical significance, while separate path diagrams display the parameter estimates visually for the standard young carer model (Figure 8.5) and the higher-level young carer model (Figure 8.6). As the identification of the measurement component is the same for the two models, with any minor differences in the results due to the exclusion of additional observations from the higher carer model, the results are considered together.

Factor loading

Change in each of the mental health factors (*MH2* and *MH4*) correlated positively with impact on their eight respective observed indicators. With the sleep loss indicators designated referent indicators and fixed to one, the depression ($\beta=1.331$; $p<.001$) and low confidence ($\beta=1.144$; $p<.001$) indicators had the highest loading on the mental health factors. While the indicators for facing problems ($\beta=0.472$; $p<.001$) and enjoying everyday activities ($\beta=0.567$; $p<.001$) had the lowest loading, this was still moderate. With the exception of the reference indicator (sleep loss) due to it being constrained, the loading of all indicators on to the factors were significant ($p<.001$).

Residual variances

The residual variances estimated the proportion of each indicator caused by omitted variables rather than the mental health factor. This was lowest in the Wave Two data for the enjoying activities (var=.319; $p < .001$) and depressed (var=.324; $p < .001$) indicators, and in the Wave Four data for the happiness (var=.316; $p < .001$) and the facing problems (var=.342; $p < .001$) with approximately a third unexplained. Residual variance was highest in the Wave Two data for the strain (var=.481; $p < .001$) and sleep loss (var=.458; $p < .001$), and also in the Wave Four data for the strain (var=.505; $p < .001$) and sleep loss indicators (var=.495; $p < .001$) with almost a half unexplained. However, all residuals were low to moderate and in acceptable range. All residual variances were statistically significant ($p < .001$) and therefore meaningful.

Factor correlation

There was a moderate positive factor correlation between *MH2* and *MH4* ($\beta = 0.521$; $p < .001$), indicating that mental health at age 14 was a significant predictor for mental health at age 16. The residual variances were low with approximately a third of the mental health factor *MH2* due to omitted variables ($\beta = 0.344$; $p < .001$). This unexplained variance decreased to a quarter of *MH4* ($\beta = 0.251$; $p < .001$), with the residual variances for the two factors statistically significant and meaningful.

8.3.3 *Structural components*

The model results have so far concerned the measurement components that were identical in identification for the two model. The identification of the structural components for the two models varies substantially due to the use of *CareStatus* variables in the standard young carer model and *CareHoursHigh* variables in the higher-level model. The results are considered in the order of the hypotheses detailed in Chapter Seven. Selected mediated effects are also reported in addition to the SEM findings.

Table 8.9 Parameter estimates for young carer model (left) and higher-level young carer models.

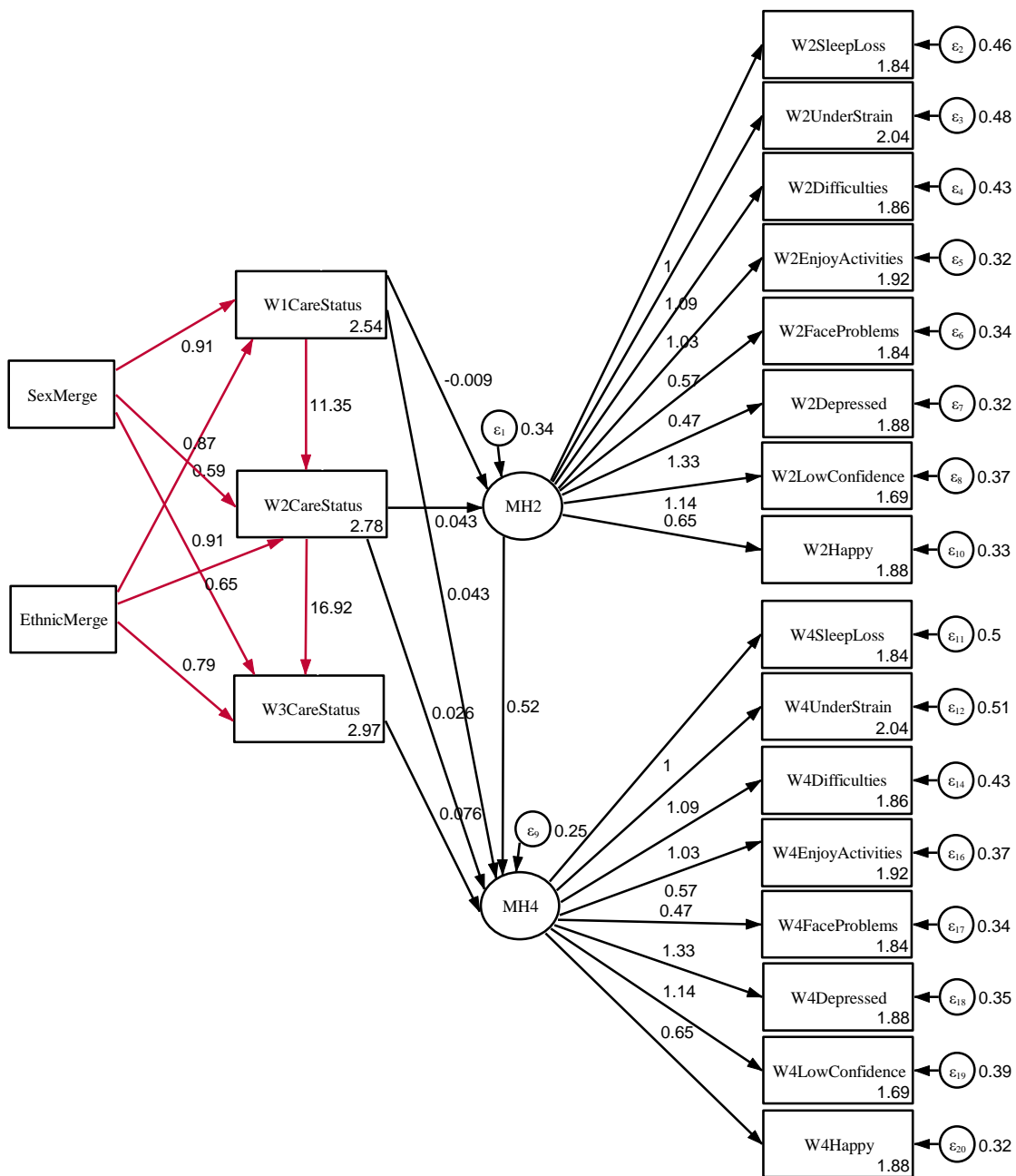
Young carer model		Higher level young carer model	
Paths	Estimate	Paths	Estimate
Factor loading		Factor loading	
MH2 BY		MH2 BY	
W2SLEEPLOSS	1	W2SLEEPLOSS	1
W2UNDERSTRAIN	1.092***	W2UNDERSTRAIN	1.092***
W2DIFFICULTIES	1.026***	W2DIFFICULTIES	1.026***
W2ENJOYACTIVITIES	0.567***	W2ENJOYACTIVITIES	0.567***
W2FACEPROBLEMS	0.472***	W2FACEPROBLEMS	0.472***
W2DEPRESSED	1.331***	W2DEPRESSED	1.331***
W2LOWCONFIDENCE	1.144***	W2LOWCONFIDENCE	1.145***
W2HAPPY	0.645***	W2HAPPY	0.645***
MH4 BY		MH4 BY	
W4SLEEPLOSS	1	W4SLEEPLOSS	1
W4UNDERSTRAIN	1.092***	W4UNDERSTRAIN	1.092***
W4DIFFICULTIES	1.026***	W4DIFFICULTIES	1.026***
W4ENJOYACTIVITIES	0.567***	W4ENJOYACTIVITIES	0.567***
W4FACEPROBLEMS	0.472***	W4FACEPROBLEMS	0.472***
W4DEPRESSED	1.331***	W4DEPRESSED	1.331***
W4LOWCONFIDENCE	1.144***	W4LOWCONFIDENCE	1.145***
W4HAPPY	0.645***	W4HAPPY	0.645***
Residual variances		Residual variances	
W2SLEEPLOSS	0.458***	W2SLEEPLOSS	0.458***
W2UNDERSTRAIN	0.481***	W2UNDERSTRAIN	0.481***
W2DIFFICULTIES	0.425***	W2DIFFICULTIES	0.425***
W2ENJOYACTIVITIES	0.319***	W2ENJOYACTIVITIES	0.319***
W2FACEPROBLEMS	0.343***	W2FACEPROBLEMS	0.343***
W2DEPRESSED	0.324***	W2DEPRESSED	0.324***
W2LOWCONFIDENCE	0.366***	W2LOWCONFIDENCE	0.366***
W2HAPPY	0.333***	W2HAPPY	0.333***
W4SLEEPLOSS	0.495***	W4SLEEPLOSS	0.496***
W4UNDERSTRAIN	0.505***	W4UNDERSTRAIN	0.505***
W4DIFFICULTIES	0.429***	W4DIFFICULTIES	0.429***
W4ENJOYACTIVITIES	0.37***	W4ENJOYACTIVITIES	0.37***
W4FACEPROBLEMS	0.342***	W4FACEPROBLEMS	0.342***
W4DEPRESSED	0.347***	W4DEPRESSED	0.348***

	W4LOWCONFIDENCE	0.388***		W4LOWCONFIDENCE	0.388***
	W4HAPPY	0.316***		W4HAPPY	0.316***
	MH2	0.344***		MH2	0.344***
	MH4	0.251***		MH4	0.251***
Factor correlation			Factor correlation		
	MH4 ON			MH4 ON	
	MH2	0.521***		MH2	0.521***
Direct effects			Direct effects		
	MH2 ON			MH2 ON	
	W1CARESTATUS	-0.009		W1CAREHOURSHIGH	-0.017
	W2CARESTATUS	0.043		W2CAREHOURSHIGH	-0.054
	MH4 ON			MH4 ON	
	W1CARESTATUS	0.043		W1CAREHOURSHIGH	0.061
	W2CARESTATUS	0.026		W2CAREHOURSHIGH	0.175*
	W3CARESTATUS	0.076**		W3CAREHOURSHIGH	0.08
	W1CARESTATUS ON			W1CAREHOURSHIGH ON	
	SEXMERGE	-0.097		SEXMERGE	-0.326
	ETHNICMERG	-0.533***		ETHNICMERG	-0.863***
	W2CARESTATUS ON			W2CAREHOURSHIGH ON	
	W1CARESTATUS	2.429***		W1CAREHOURSHIGH	3.313***
	SEXMERGE	-0.136		SEXMERGE	-0.262
	ETHNICMERG	-0.431***		ETHNICMERG	-0.77***
	W3CARESTATUS ON			W3CAREHOURSHIGH ON	
	W2CARESTATUS	2.829***		W2CAREHOURSHIGH	3.429***
	SEXMERGE	-0.098		SEXMERGE	-0.462*
	ETHNICMERG	-0.231**		ETHNICMERG	-0.707***
Logistic regression odds ratio results			Logistic regression odds ratio results		
	W2CARESTATUS ON			W2CAREHOURSHIGH ON	
	W1CARESTATUS	11.348***		W1CAREHOURSHIGH	27.458**
	SEXMERGE	0.873		SEXMERGE	0.769
	ETHNICMERG	0.65***		ETHNICMERG	0.463***
	W3CARESTATUS ON			W3CAREHOURSHIGH ON	
	W2CARESTATUS	16.924***		W2CAREHOURSHIGH	30.845**
	SEXMERGE	0.907		SEXMERGE	0.63**

ETHNICMERG	0.794**	ETHNICMERG	0.493***
W1CARESTATUS ON		W1CAREHOURSHIGH ON	
SEXMERGE	0.907	SEXMERGE	0.722*
ETHNICMERG	0.587***	ETHNICMERG	0.422***
Intercepts		Intercepts	
W2SLEEPLOSS	1.836***	W2SLEEPLOSS	1.841***
W2UNDERSTRAIN	2.038***	W2UNDERSTRAIN	2.043***
W2DIFFICULTIES	1.859***	W2DIFFICULTIES	1.864***
W2ENJOYACTIVITIES	1.921***	W2ENJOYACTIVITIES	1.923***
W2FACEPROBLEMS	1.84***	W2FACEPROBLEMS	1.842***
W2DEPRESSED	1.882***	W2DEPRESSED	1.888***
W2LOWCONFIDENCE	1.692***	W2LOWCONFIDENCE	1.698***
W2HAPPY	1.883***	W2HAPPY	1.886***
W4SLEEPLOSS	1.836***	W4SLEEPLOSS	1.841***
W4UNDERSTRAIN	2.038***	W4UNDERSTRAIN	2.043***
W4DIFFICULTIES	1.859***	W4DIFFICULTIES	1.864***
W4ENJOYACTIVITIES	1.921***	W4ENJOYACTIVITIES	1.923***
W4FACEPROBLEMS	1.84***	W4FACEPROBLEMS	1.842***
W4DEPRESSED	1.882***	W4DEPRESSED	1.888***
W4LOWCONFIDENCE	1.692***	W4LOWCONFIDENCE	1.698***
W4HAPPY	1.883***	W4HAPPY	1.886***
Thresholds		Thresholds	
W1CARESTATUS\$1	2.541***	W1CAREHOURSHIGH\$1	4.19***
W2CARESTATUS\$1	2.778***	W2CAREHOURSHIGH\$1	4.345***
W3CARESTATUS\$1	2.965***	W3CAREHOURSHIGH\$1	4.113***

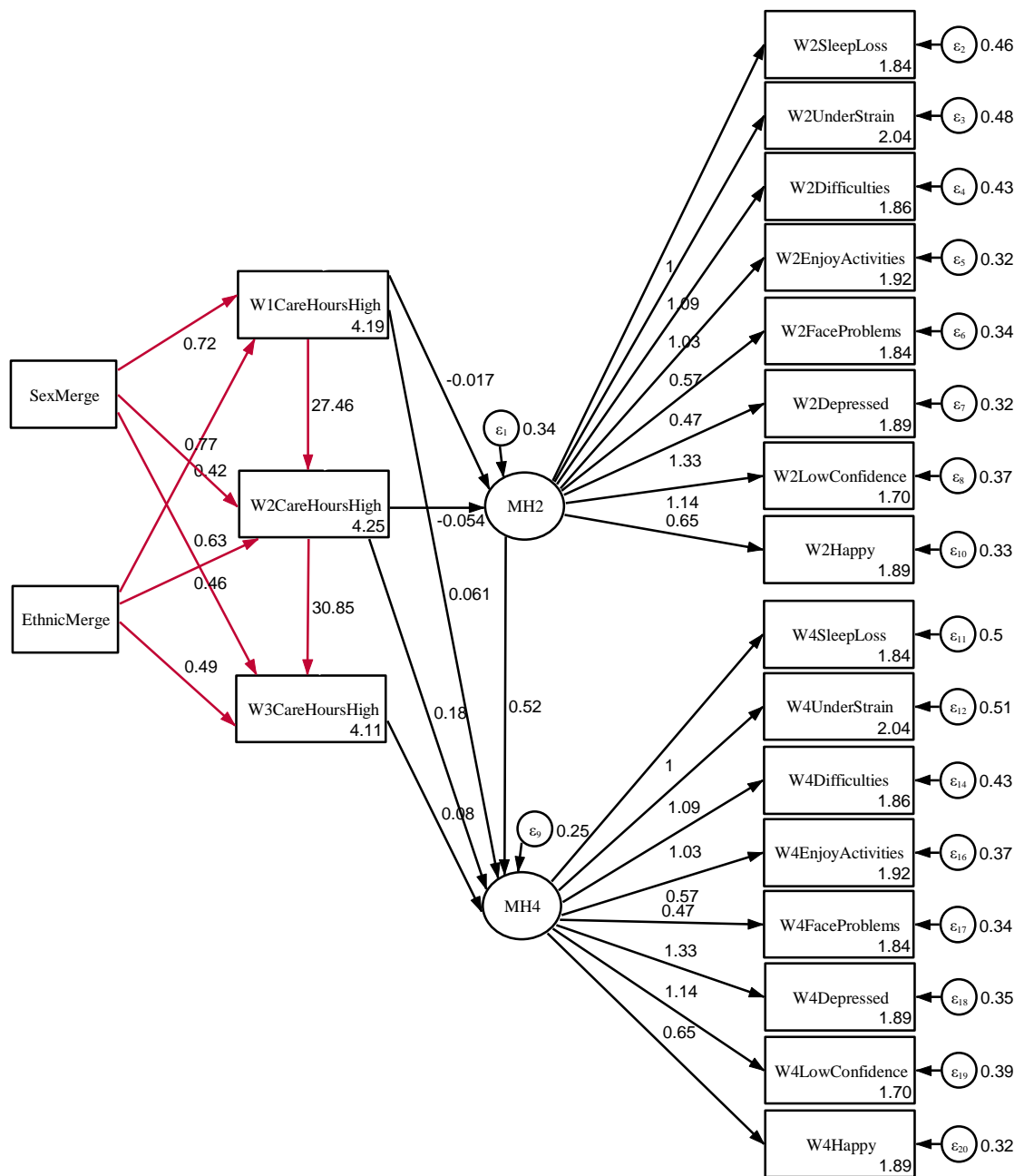
*** p<0.001; ** p<0.01; * p<0.05

Figure 8.5 Path diagram for young carer status model.



NB. Black paths = coefficients (β); Red paths = Odds ratios (OR)

Figure 8.6 Path diagram for high carer status model.



NB. Black paths = coefficients (β); Red paths = Odds ratios (OR)

Hypothesis One: Young carer status is long term.

The first hypothesis was fully supported with a sizeable odds ratio for the direct relationship between the first two caring status indicators in the standard model (*CareStatus1* → *CareStatus2*, OR=11.348). This association was increased further for the parameter between Wave Two and Three (*CareStatus2* → *CareStatus3*, OR=16.924), evidencing that prolonged caring is common. Parameter estimates were statistically significant ($p < .001$).

The equivalent odds ratios in the higher-level young carer model were of a greater magnitude than in the standard model (*CareHoursHigh1* → *CareHoursHigh2*, OR=27.458; *CareHoursHigh2* → *CareHoursHigh3*, OR=30.845). The parameter between the Wave Two and Wave Three variables was again higher than the previous parameter, and both estimates were statistically significant ($p < .01$).

Hypothesis Two: Older, female and ethnic minority young people are more likely young carers.

The young carer models included sex and ethnicity as variables, but age was incorporated through the annual *CareStatus* and *CareHoursHigh* variables. Therefore, the SEM results did not consider age, but the descriptive analysis results presented earlier in this chapters highlighted increasing prevalence in young carers from 5.13% at the age of 13, to 6.51% when 15. The trends were similar among higher-level young carers with prevalence increasing from 0.79% to 1.03% over the same three-year period.

Sex and ethnicity

Hypothesis Two was supported with respect to ethnicity though the evidence was weaker concerning sex. All parameters between the demographic variables (*SexMerge* and *EthnicMerge*) and the three carer status variables were direct relationships, with the second and third estimates adjusted to control for antecedent variables. The negative associations for the sex of young carers indicated higher young carer prevalence among females in comparison to males (*SexMerge* → *W1CareStatus*, OR=.907, $p=.164$; *SexMerge* → *W2CareStatus*, OR=.873, $p=.064$; *SexMerge* → *W3CareStatus*, OR=.907,

p=.205), with the lower parameter estimate at Wave Two evidencing a stronger effect. However, there was a lack of evidence that the finding was statistically significant.

The greater prevalence of young carers amongst ethnic minority children compared to white children at Wave One was more substantial (*EthnicMerge* → *W1CareStatus*; OR=.587; p<.001). After controlling for antecedent variables, the adjusted direct effects at Wave Two and Three reinforced this finding, though the relationships were weaker (*EthnicMerge* → *W2CareStatus*, OR=.650; p<.001; *EthnicMerge* → *W3CareStatus*, OR=.794; p<.01). All three parameters were statistically significant.

The results of the higher-level carer model indicated that the difference in prevalence by sex was of a greater magnitude amongst those with greater responsibilities compared to all young carers. This was demonstrated with the first parameter (*SexMerge* → *W1CareHoursHigh*, OR=.722; p<.05), and the adjusted subsequent parameters when controlling for antecedent variables (*SexMerge* → *W2CareHoursHigh*, OR=.769; p=.122; *W3CareStatus*, OR=.630; p<.01).

The difference in prevalence by ethnicity is also of a greater magnitude for higher-level young carers, as evidenced in the first direct effect (*EthnicMerge* → *W1CareStatus*, OR=.422, p<.001). When controlling for antecedent variables, the negative associations for the subsequent parameters were slightly weaker (*EthnicMerge* → *W2CareStatus*, OR=.463, p<.001; *EthnicMerge* → *W3CareStatus*, OR=.493, p<.001) but all evidenced greater young carer prevalence amongst ethnic minority than white children. All six parameter estimates in the higher-level model, with the exception of sex as a predictor of high-level carer status at Wave Two, were statistically significant.

Hypothesis Three-A: Young carer status has a detrimental effect on mental health.

The short-term impacts of caring were inconclusive. Wave One care status had a direct effect on Wave Two mental health (*W1CareStatus* → *MH2*, β =-.009), with an additional indirect effect through *W2CareStatus* as a mediating variable. While the direct effect indicated a slight negative correlation and suggested initial benefits of caring on mental health, the evidence was very weak (p=.738).

The equivalent parameter for the carer status at Wave Two was a direct effect, adjusted to control for Wave One care status. The positive association between Wave Two care status and Wave Two mental health ($W2CareStatus \rightarrow MH2$, $\beta=0.043$; $p=.103$) indicated negative impacts, though again the evidence was not strong enough for the finding to be statistically significant.

Hypothesis Three-B: Impact of status on mental health increases with duration as carer.

Hypothesis 3B was supported. In considering the Wave Four mental health factor, care status at Wave One has a direct effect on Wave Four mental health, with the positive association ($W1CarerStatus \rightarrow MH4$, $\beta=0.043$, $p=0.121$) indicating long-term negative mental health impacts. Effects were also partialled through $W2CareStatus$ and $MH2$ as mediating variables, and the significance of $MH2$ was tested using bootstrapping (Table 8.10). In contrast to the direct effect, the mediated effect evidences a smaller mental health benefit ($\beta=-0.005$, $CI=-0.032, 0.023$). The inclusion of zero in the 95% confidence interval indicates the evidence is not strong enough for the finding to be statistically significant.

Wave Two carer status had a slightly negative direct effect on Wave Four mental health ($W2CarerStatus \rightarrow MH4$, $\beta=0.026$, $p=0.339$) when adjusted to control for Wave One. Indirect paths were partialled to $MH2$ and $W3CareStatus$, and $W3CareStatus$ was tested as a mediating variable. The result indicated a more substantial mediated negative impact on mental health ($\beta=0.22$, $CI=0.066, 0.367$) that was statistically significant.

The final direct relationship ($W3CarerStatus \rightarrow MH4$) was adjusted to control for antecedent variables ($W1CareStatus$, $W2CareStatus$ and $MH2$). The result indicated a negative mental health effect ($\beta=0.076$, $p<0.01$). Of the three direct parameters between a carer status indicator and Wave Four mental health, this was the only effect to be statistically significant.

Table 8.10 Mediated effect results for mental health parameters

Direct effect 1			Direct effect 2			Mediated effect		
Parameter	M	SD	Parameter	M	SD	Estimate	LCI	UCI
Standard young carer model								
W1CareStatus → MH2	-0.009	0.027	MH2→MH4	0.521	0.011	-0.005	-0.032	0.023
W2CareStatus → W3CareStatus	2.829	0.092	W3CareStatus→MH4	0.076	0.027	0.22	0.066	0.367
Higher-level young carer model								
W1CareHoursHigh→MH2	-0.017	0.065	MH2→MH4	0.521	0.011	-0.009	-0.076	0.057
W2CareHoursHigh→W3CareHoursHigh	3.429	0.288	W3CareHoursHigh→MH4	0.080	0.074	0.003	-498.877	499.506

Hypothesis Four-A: Higher level young carer status has an increased impact on mental health.

The short-term effects of higher-level responsibilities on mental health were beneficial and of a greater magnitude compared to all young carers in the first model, though the evidence of significance was weak. Initial higher-level care status had a direct effect on Wave Two mental health ($W1CareHoursHighs \rightarrow MH2$, $\beta=-0.017$; $p=.797$), with the partialling of an indirect effect through the mediating variable $W2CareHoursHigh$.

Wave Two carer status also had a direct effect on Wave Two mental health, with this adjusted to control for initial care status ($W2CareHoursHigh \rightarrow MH2$, $\beta=-0.054$, $p=.389$). The negative correlations for the two parameters indicated a slight mental health benefit, though the evidence that this was significant was very weak.

Hypothesis Four-B: Impact of higher-level young carer status on mental health grows with duration as carer.

Hypothesis 4B was supported. Concerning Wave Four mental health, the first parameter ($W1CareHoursHigh \rightarrow MH4$, $\beta=0.061$, $p=.372$) was a positively correlated direct effect indicating detrimental impacts, though evidence of significance was weak. Of the two indirect paths, $W2CareHoursHigh$ and $MH2$, Wave Two mental health was tested as a mediating variable. The slight negative correlation ($\beta=-0.009$, $CI=-.076$, $.057$) evidenced minor mental health benefits though the confidence interval again indicated that the evidence was too weak for the finding to be statistically significant.

The second parameter controlled for $W1CareHoursHigh$ and indicated a more sizeable negative impact ($W2CareHoursHigh \rightarrow MH4$, $\beta=0.175$, $p<.05$) which was also statistically significant. Of the two mediating variables, $MH2$ and $W3CareHoursHigh$, the second was tested through bootstrapping. The result indicated a slight negative effect ($\beta=0.003$, $CI=-498.877$, 499.506) though the confidence interval was extremely broad as a result of the small subsample of higher-level young carers.

The final parameter ($W3CareHoursHigh \rightarrow MH4$) was adjusted to control for $W1CareHoursHigh$, $W2CareHoursHigh$ and $MH2$ as antecedent variables. The result also indicated a negative effect on mental health ($\beta=0.08$, $p=.282$) though the evidence was not strong enough to be significant.

8.3.4 *SEM summary*

The standard young carer model and the additional higher-level model were *a priori*, fully informed by the results of the realist synthesis and estimated without the need for respecification. The results strengthened the descriptive analysis of the LSYPE1 data.

Estimation of the measurement component, identical for the standard and higher-level models, was satisfactory with all mental health variables having at least a moderate fit to the respective *MH2* and *MH4* factors, and all variables and factors having low to moderate residual variance.

Results for the structural component of the standard young carer model included statistically significant findings that many young carers had long-term responsibilities, especially those with higher-level responsibilities. In addition, both young carer prevalence and higher-level young prevalence was greater for ethnic minority children than white children. The higher-level carer prevalence of females was also statistically significant, though similar findings amongst all young carers were undermined by the evidence being weaker. Due to greater confidence as a result of the statistical significance, these findings will inform refinements to the initial model of young carer mental health and psychosocial wellbeing in Chapter Twelve.

In contrast, there was also evidence of how caring affected mental health over time. Amongst standard young carers this included evidence of slightly negative short-term impacts on mental health, with the impacts increasingly negative in the long term, but the majority of the findings were not statistically significant. This was also an issue with the second model which indicated larger magnitude short-term benefits for higher-level young carers compared to other respondents. In contrast, their mental health was comparatively worse at Wave Four, indicating the detrimental long-term effects of substantial responsibilities. While these results are interesting, the lack of statistical significance undermines confidence in the results, and the potential for these findings to refine the model without triangulation of quantitative evidence is limited.

8.4 Chapter Summary

This chapter has presented the quantitative results of the mixed methods research, beginning with the results of the data screening procedure that informed the model development, and the descriptive analysis.

The structural equation modeling results reinforced the descriptive analysis findings that young carer prevalence is higher for female and ethnic minority young people, with these differences more pronounced amongst higher-level young carers. The modeling enabled the mental health of young carers to be compared with children without caring responsibilities, with an indication that marginal benefits and negative impacts become increasingly negative over time. For higher-level young carers there was evidence of greater short-term benefits, but the long-term impacts were negative and of a greater magnitude compared to the standard model.

The next three chapters present the results of the phenomenological study. The first of these, Chapter Nine, continues the focus on how the impacts of caregiving responsibilities change over time depending on family circumstances. Chapters Ten and Eleven concerns support and the caregiving identity respectively, with these being parts of the realist model not possible to investigate using SEM. Chapter Twelve integrates the quantitative results from this chapter with the qualitative phenomenological findings.

Chapter Nine

Impacts of caring responsibilities

Having presented the quantitative results in Chapter Eight, the next three chapters report the results of the phenomenological analysis. Each relates to a domain of the realist model explained in Chapter Five, with this chapter concerning the impacts of *caregiving responsibilities*. Chapter Ten relates to the potential for *support* to moderate the caring impacts, and Chapter Eleven focuses on the development of the caring *identity*.

This chapter includes a summary of the ten participants, followed by consideration of the shared impacts of multiple participants as young carers, rather than their specific individual circumstances. The central focus concerns perception of control over the caring role and the development of routine. Initial focus is on participants who had greater levels of control, with this followed by exploration of the contextual factors that can threaten this control including instability of the care receiver's condition, excessive responsibilities, night-time caring and medical responsibilities.

The genetic phenomenology approach, introduced in Chapter Seven, enabled the longitudinal gathering of contextual information, with mental health and psychosocial wellbeing impacts attributed to the changing circumstances of participants and their families. The method also enabled these impacts to be attributed to the additional adversities often faced by young carers and their families. Two sets of inserts in the results chapters highlight longitudinal change witnessed within the research, and the impacts of additional adversities respectively.

9.1 Sample summary

Table 9.1 presents a summary of the ten participants including their demographics, recruitment setting and caring responsibilities, as well as details of the care receivers. All names, including those of participants, family members and service professionals are pseudonyms. Appendix W includes a short biography for each participant and the dates of their respective interviews.

Table 9.1 Participant sample characteristics

No	Setting	Interviews completed	Demographics			Care receiver details			Caring details (at Interview 1)	
			Name	Sex	Age	Care receiver	Reason for need	Duration as young carer	Level of care	Key responsibilities
1	School1	3	Sophie	F	13	Mother	Diabetes, hearing impairment	9 years	Main	Medical care (monitoring, injection); companionship; translation
2	School2	3	Angela	F	13	Mother	MS	2 years	Main	Physical support; companionship; domestic responsibilities
3	School2	3	Kirsty*	F	14	Mother	Spina bifida, hydrocephalus, epilepsy	5 years	Joint	Domestic responsibilities; companionship
4	School3	3	Martin	M	13	Mother	Aplastic anaemia	9 months	Main	Physical support; domestic responsibilities
5	Project1	1	Lyra**	F	13	Mother	Bipolar disorder	4 years	Joint	Domestic responsibilities
6	Project1	1	Lucy**	F	11	Mother	Bipolar disorder	2 years	Joint	Domestic responsibilities; nursing
7	Project1	3	Harry***	M	16	Brother (Sean)	Autism	11 years	Joint	Getting up; physical support; going to school
8	School4	3	Patrick***	M	14	Sister (Charlie)	Cerebral palsy; learning difficulties	9 years	Joint	Physical support; monitoring
						Grandfather*	Old age, dizziness, confusion			Domestic responsibilities
9	Project2	2	Richard	M	16	Mother	Former substance misuse; mental health	11 years	Main	Emotional support; domestic responsibilities
10	Project1	2	Thea**	F	16	Mother	Bipolar disorder	4 years	Main	Companionship; nursing; physical support; domestic responsibilities

Notes

* Care receiver deceased at time of first interview.

** Participants were siblings.

***Third interview was online due to coronavirus restrictions

Five participants were recruited from and interviewed in their school (Sophie [YP1], Angela [YP2], Kirsty [YP3], Martin [YP4] and Patrick [YP8]), and an additional five through young carer projects (Lyra [YP5], Lucy [YP6], Harry [YP7], Richard [YP9] and Thea [YP10]). Six participants were female with four males, and their ages ranged from 11 (Lucy) to 16 (Harry, Richard and Thea).

Eight were carers for their mother, with Harry and Patrick supporting a brother and sister respectively. All the care receivers had an illness or disability, including Richard's mother who had mental health issues as a result of past substance misuse. Kirsty was a former young carer as her mother had died, and her accounts of caring were retrospective. Patrick had also cared for a second person, his grandfather, until his death shortly before his first interview.

The sample varied in terms of duration of care with Sophie, Kirsty, Harry, Patrick and Richard becoming carers before the age of five. Angela had grown up with a disabled mother and became a young carer approximately two years before her first interview, while Lyra, Lucy and Thea became carers following the onset of their mother's bipolar disorder four years before. Martin was the newest young carer and was accustoming to the role after nine months. Five of the ten self-identified as the main carer in their household (Sophie, Angela, Kirsty, Richard and Thea).

A final feature of the sample was that three of the participants (Lyra, Lucy and Thea) were siblings who together cared for their mother, and this created a number of challenges. First, with the sample of ten participants being relatively small, there was the potential that the participants being from eight different families would limit the potential for data further. Second, there was a concern that the experiences of the different siblings would conflict. I considered if (and how) conflicting evidence from different siblings would need to be resolved, and came to the conclusion that differing perceptions of the same experiences should be respected and, if possible, explained.

Despite these potential challenges, the involvement of multiple siblings became a positive aspect of the study. As expected, the three siblings had conflicting perceptions of the same experiences, but, despite them being from the same family, there were still significant differences in their circumstances including their age that affected understanding of their mother's illness and caring responsibilities. The three qualitative

results chapters include examples of shared understandings between the researcher and each of the siblings, which helped to explain how their perspectives varied as a result of these differing circumstances.

9.1.1 Participant retention

Data collection was protracted due to the challenges of recruiting young carers that were unknown to services, and interviews were held between March 2019 and August 2020. While six participants completed the three interviews, there were data collection challenges relating to the topic sensitivity. While participants reported finding it useful to talk to an external person about their lives, Lyra decided not to participate beyond the first interview, and contact was also lost with Lucy.

The coronavirus also presented difficulties to contacting participants due to the closure of schools and projects. At the time of the services closing in March 2020, Harry, Patrick, Richard and Thea had not had their third interviews. Delayed online interviews were subsequently held with Harry and Patrick but contact with Richard and Thea was lost.

9.2 Shared impacts for children with caring responsibilities

This study considers how the impacts of caring responsibilities varied with individual circumstances but there were a number of shared impacts as a result of them being young carers rather than more individual factors. These predominantly positive impacts, including satisfaction from making a difference, psychosocial and practical skills, are presented first before considering impacts that varied with context.

9.2.1 The satisfaction of making a difference

Several participants reported that making a difference to the life of the person that they cared for gave them satisfaction. For Kirsty this satisfaction was retrospective as she

reflected on her former responsibilities due to the death of her mother, while for Martin it was an impact of his relatively new role:

There are some things she would not have been able to do if I hadn't been there by her side to help out. I, my mum and I were quite similar, in fact that we were never keen on relying on others... If she was in a shop and she couldn't reach something she'd ask me, or I would automatically clamber up on her chair and grab it... she wasn't as limited as she would be on her own and that's why I feel it's so important.

Kirsty (I1)

Sometimes it makes me happier because I'm helping my mum and stuff... and she appreciates me, and she's like 'Thank you for helping me upstairs'.

Martin (I2)

This satisfaction manifested itself differently for participants, with Harry reporting feelings of usefulness as a result of fulfilling his substantial responsibilities. The wider impacts of these responsibilities are explored later in this chapter.

It makes me feel like useful... Because it makes me feel like I'm helping someone, in this case it would be my brother, so I can make a huge impact on his life.

Harry (I1)

9.2.2 *The development of psychosocial skills*

Participants reported that caring responsibilities helped them to develop, and in some cases boosted pre-existing, psychosocial skills. Harry and Angela reported that they had become more understanding of the needs of others, resulting in them becoming friendlier and better able to support the people around them:

I think I listen to people more now, because it's like I understand that a lot of people have other issues and things like that so, and I can see that in people when I talk to them and things like that.

Angela (I1)

Maturity was another common impact, and while too much maturity at a young age can be viewed as detrimental, Angela, Harry and Thea viewed this maturity in comparison to their peers positively:

I believe that me being a young carer personally, has made me take a lot of responsibility on myself, on looking after my sisters, looking after my mum, obviously, but it's made me more mature, it's made me realise that I'm not a person who messed about, I've got a strong head, I know how to cope with some situations.

Thea (I2)

Because I have to look after her I have more responsibility because of that but it also means I'm more mature which is probably, a better, one of the better sides of it... I like that.

Angela (I1)

Thea emphasised that her caring had helped her develop coping strategies and the resilience to tackle other adverse events in her life including bereavement following the death of her father, and feelings of abandonment after her mother was sectioned. The impacts of these other adverse events are considered later in this chapter, but positive coping strategies from her caring included problem-solving, acceptance of her mother's illness, and self-education about bipolar disorder:

[Caring] has taught me how to cope with my mum's Bipolar, it has taught me how to look after my sisters, it has taught me how to how to look after myself as well. So I do cope with my mum, I have to like accept that my mum's got this illness, it's never going to go away... when I first found out, I always used to cry about it, but then, as time went on, I did more research about it, to find out what it actually does, what, how it's affecting her, how it came, how she developed it and everything.

Thea (I2)

If I do this, it could have this outcome, but if I do it this way, it will have a different outcome. So, for example, if I'd took my mum, I don't know, to the park, it would be a lot of work for her, than maybe taking her to the cinema, so she can actually enjoy it. So, it's just me thinking, how can I cope with her Bipolar, but also keep her entertained and active.

Thea (I2)

At the same time Thea also recognised that these coping strategies for managing her own mental health could be destructive as well as constructive:

[Self-harm] is my personal coping strategy, like I have done drugs, I have drank until I couldn't walk, I smoke, I've punched things, I've broken things, I drew, I, I made my own music, just to try and cope with it, but how I felt like I could

release the pain in my head, because I don't actually know how to talk about it, or I don't know necessarily how to prepare the words that I feel, so I cut, that's how I feel like releasing them.

Thea (I2)

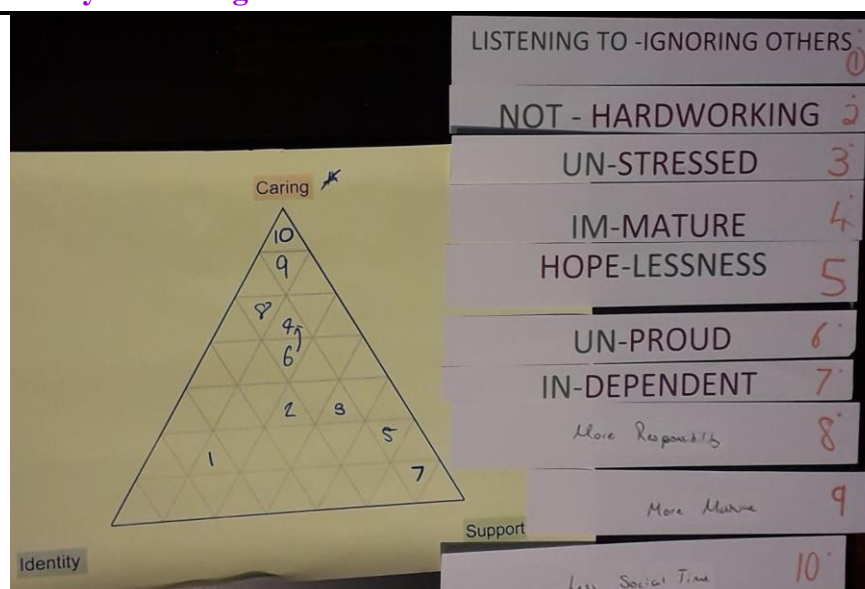
Natural attributes and predispositions to caring

Angela and Thea highlighted that some of the psychosocial skills were pre-existing attributes which were boosted by their caring. For Angela this included listening and kindness (Figure 9.1), while both agreed that their hardworking nature aided their transition to being young carers partway through their childhood.

- P: Generally I think I'm a hardworking person, I've learnt to be more hardworking because of that [caring].
 R: The caring element almost boosts it?
 P: Increased it a bit yeah. That's a good thing.

Angela (I2)

Figure 9.1 Angela's natural kindness, listening skills and hardworking attributes were boosted by her caring role



- P: I think I'm a general nice person anyway so I think I like to listen to people but I listen to people more as well, more because I care for people, like I have to like listen to them
 R: When you say identity do you mean not your kind of young carer identity, just your wider.
 P: Yeah, I thought of me.

Angela (I2)

They also talked about negative pre-existing attributes included worries and stress about the world, their education and future aspiration. There were times when caring increased this stress further, but the familiarity of caring could also help them relax:

I'm stressed at school and things like that obviously because my GCSEs are next year, but then it's like I'm even more stressed about it because I'm looking after my mum and things like that, so it's like that's on top of it. But also, I'm also less stressed because it's like, when I look after her sometimes it's just nicer... so if we're having a nice chilled night in and I'm just making sure she's got company then.

Angela (I1)

When my, my mum first went in, I was always stressed about her, but then getting to the end of year eleven, so I'm really stressed about am I going, good enough in GCSE's? Stressing about what am I going to do for college? Am I going to get in? Am I going to get accepted? Stressing about, oh is this homework going to get in on time? Stressing, I have to eat something and stressing that I actually need to sleep, because my sleep pattern is terrible. Yeah, it's just, sometimes I'm overly stressed, and sometimes I'm not stressed at all.

Thea (I2)

9.2.3 *Domestic and caring skills*

Thea, Angela and Richard highlighted the practical side of caring and the development of skills that other children may not develop until adulthood. Thea in particular highlighted how this was making a difference to how she cared for other people but also how she looked after herself:

Shopping, I've just taken that as a full positive because one, I'm learning life skills for when I'm older, two, it's making me stronger... and I feel a lot more confident in my abilities to do stuff.

Richard (I1)

It took me a few weeks for, for my Aunty to teach me new skills, or how to properly iron, how to properly set clothes out, how to not take too much time with it to dry and to actually look after my sisters properly and, and to even look after myself properly, because when I get depressed, I just don't care about myself.

Thea (I2)

9.3 Maintaining control in a dynamic system

The first part of these caring results considered impacts of caring that were common among participants as young carers but not related to more specific aspects of their roles. These were predominantly benefits, including satisfaction from making a difference, psychosocial and domestic skills, though coping strategies could be constructive or destructive.

The remainder of this chapter concerns management of caring responsibilities and whether young carers felt in control of their caring role. High levels of control enabled some participants to develop a positive routine for balancing their responsibilities alongside other aspects of their life, but it was more problematic for others. Consideration of the effects of high levels of control are considered first, followed by exploring how the different threats to positive management of responsibilities affect young carers.

Stability was key to control, and several participants had stable responsibilities as a result of a lack of change in the care receiver's condition. This included Angela whose mother had MS (Multiple Sclerosis). While MS is a progressive illness, her mother had increasingly learnt how to manage her condition in order to reduce tiredness and maximise independence:

She goes into the office like once a week or something like that, because she works from home.

Angela (I3)

She does have a wheelchair as well but that's only used when the scooter can't be there... It's just that she doesn't like get tired out when she goes out, and she's got enough energy to do stuff when she goes back home... she's getting, not getting better but learning to handle it better so it makes everything easier.

Angela (I2)

While her mother occasionally needed increased support after busy days, Angela's responsibilities had been relatively consistent since transitioning from living with a disabled person to becoming a carer. She also recognised that her responsibilities were relatively low-level and usually included brief and regular tasks:

Throughout the week I do little stuff, it's not like that's an entire day. Like helping her out, so my mum will be like 'Shopping's coming tomorrow, Dad's not here, make sure you're home'.

Angela (I2)

Angela viewed her education as her main priority ahead of her caring, and she was able to develop a caring routine that enabled her to manage the two:

It's that simple, if I've got to write an essay, I write an essay and I do my other stuff around it, I have my priorities and school comes first and then the other two [caring and social] kind of balance off each other.

Angela (I3)

The routine also had a third aspect, her personal and social time. Angela was usually able to plan these activities in advance but on occasions when this was not possible, perhaps due to either additional responsibilities or unexpected social opportunities, she was forced to prioritise:

Yeah it makes it easier, because it's like, I know if I'm going to have to do anything that evening, and if I'm not going to, it makes it easier to plan stuff, so I know that if I want to binge watch a new episode of like, you know, Sherlock.

Angela (I3)

If there's like other people in the house or not... if it's something I've booked already, I just say I'm going out anyway, but yeah it depends. If someone texts me and says "Can you come out?", which never usually happens... and there's no one home [except for mother], I might stay home.

Angela (I3)

Harry had been a young carer for his brother Sean since before the age of five. His responsibilities were substantial and had changed markedly due to his increasing age and capability, but also his brother's changing needs:

He's grown up since then, so before like six or seven years ago I used to like settle him down in bed and stuff like that. Now he usually just goes to bed, if we get him in his bedroom he usually just goes to bed on his own and stuff like that.

Harry (I1)

In the mornings I get him up, get him in the shower. I sometimes help to change him, but like, you know, like put clothes on him and stuff, but it's usually my

parents do that. I help him get, he like gets a bus to school, so I help him get off the bus when he comes home from school. I also sometimes feed him if I have to, if say my parents are busy or something like that. I get him drinks and stuff like that.

Harry (I1)

However, he also viewed his responsibilities as having stabilised in recent years and reported little change in his role between the first and second interview:

Everything is pretty much the same... like apart from him getting hard, you know older and bigger it's harder, everything else is pretty much the same.

Harry (I2)

Sean needed constant care and Harry was one of three carers in his family. Family support is considered further in Chapter Ten but there was a regular pattern of care provided by Harry and his parents. For example, Harry cared for Sean before school most days when his parents were looking after his other brother, and after school while they were still at work, but his parents then cared more at the weekend, giving Harry time for homework and to see his friends:

For example getting him up in the mornings, I do that the most out of everyone, because it's sometimes hard for my parents when they're also trying to help my other brother, you know, in the morning.

Harry (I1)

I am allowed to go out on like weekends and stuff, because like my parents stay in so like, both of them are there to help out with my brother and stuff so... Homework I usually just do that all on the weekend anyway. I only get given like a bit of homework, not really much.

Harry (I2)

Harry shared a range of impacts of his substantial responsibilities, and this included regularly feeling tired:

Quite a lot, I can say that. I don't know how much exactly, but I know most of the time I am helping out my family with him and stuff like that... pretty much when I'm at home most of the time I've got to look after him and stuff like that, which is quite a long time because, you know, school's only like six hours so.

Harry (I1)

It can sometimes make me feel tired, so you know, helping out a lot can cause me to go to bed late, wake up feeling really tired and stuff like that.

Harry (I1)

However, Harry otherwise presented an array of benefits including happiness, confidence, maturity and independence. While his caring responsibilities were often inflexible due to his role fitting in with the commitments of other family members, the routine largely worked for him. A key part of this was the support that Harry received from sources including his family and young carers project as key and this is explored further in Chapter Ten:

It makes me feel happy, because helping my brother makes me feel happy. And [not] lonely, I feel like I've got lots of people, lots of support, you know, helping me and stuff like that. Confident, I feel confident in my ability to care for my brother, and to not let him down I guess... And then helping me to feel mature, because it makes me feel independent.

Harry (I1)

Harry's first two interview preceded the coronavirus pandemic, but the third was held shortly after the first coronavirus lockdown ended. The longitudinal approach enabled the chance to study how the pandemic affected Harry and his family's circumstances and lives, and his positive routine appeared largely resilient to the changes (Insert 9.1).

Richard's caring responsibilities had stabilised for different reasons. He cared for his mother who had previously been a substances misuser and, following the separation of his parents, Richard was the sole carer for his mother when she stopped taking drugs:

She's given up heroin when I was about five-ish and she went on substitutes... she's given up the drink for two years and given up the weed for about a year and three months now.

Richard (I1)

Richard estimated that he had been spending about five hours each day caring in the past, supporting his mother through withdrawal symptoms and with her poor mental health. This had decreased more recently, and Richard was providing approximately two hours of predominantly domestic responsibilities each day at the time of his first interview:

Insert 9.1 Longitudinal change 1: The impact of the coronavirus on Harry's routine

Harry's family circumstances changed during the first national lockdown. Before the pandemic Harry and his brothers had been in school, with his mother not working and his father employed in the automobile industry. During the national lockdown all three siblings were at home and his father had initially been furloughed. Sean had adjusted to this change over time:

I'm not in school and neither is any of my brothers, so I'm at home more often, so I'm caring for my brother more, because he's not at school either, my dad still goes to work, from, eight o'clock and he comes back around seven... He was on furlough for a bit but then he's had to go back now, because, obviously more, like you know, they're like slowly over time, they're opening stuff more and more.

Harry (I3)

At first he [Sean] was a bit upset, because it was different from the fact that he hasn't been going to school for a while, but he's just kind of adapted to it now, so in the morning, he like expects not to get up early and stuff, so [chuckling]. He's dealing with it pretty well.

Harry (I3)

Harry had expected to be taking his GCSEs exams that summer, but instead he was spending less time on schoolwork. He was less stressed due to the exams being cancelled, though was worried about predicted grades:

All my exams for Year Eleven have been cancelled and they're going off teacher predicted grades, so some people are happy, some people aren't happy, stuff like that, me, I'm kind of mixed because, one, it takes the stress out of me doing obviously my exams and stuff, but then it is also the fact that you know, I could be placed like, I could have underperformed, because some teachers I know have given me a lower grade than what I could have got.

Harry (I3)

With less schoolwork and fewer social opportunities Harry was dividing his time between caring and personal interests. His caring had increased marginally and included tasks he didn't usually provide but his routine was resilient, and he viewed his caring as largely unchanged:

Mostly my schedule's just been staying at home, doing really what I want to, or caring for Sean.

Harry (I3)

I still had to do like some of the stuff, like get him out of bed in the morning and stuff, and like help him down to the car, if I need to go out shopping or stuff. There's been, there's been a bit more, because he's at home more, so like help feeding and stuff, like feeding him, because usually he's at school so but yeah apart from that, those things have been the same.

Harry (I3)

I've had like a lot of conversations, like 'Are you ok?', 'Yeah I'm fine', 'Ma, I know the look on that face, I know the look on your face, do you wanna, do you wanna talk about it?' And she's like 'Yeah', and she'll vent to me for hours and hours and hours on end. We'll start a conversation at like 6pm and we'll end up at like five in the morning, and that's because she needs it sometimes.

Richard (I1)

Now I think the average per day is like two hours, that actually sounds mathematically correct in my head so about two hours, every day.

Richard (I1)

His mother substance misuse was indicative of a difficult upbringing that also included domestic abuse and unhealthy relationships. In addition, Richard had been diagnosed with autism. Insert 9.2 considers the impact of these additional challenges separate from his caring responsibilities.

Insert 9.2 Richard's additional challenges: Familial substance misuse and disability

Richard's parents had misused substances and he discussed the effects on his upbringing. While Richard did not feel he grew up in a violent home he shared events that his mum felt guilt over:

The first year, this is all her words not mine, he [father] was great, he was fine, there was one incident where, because he had like really, dogs, really rough dogs, like they were rough housing each other, and they were used, my dad was used to them climbing on top of him, he mistook me as one of the dogs and I went flying across the room at about two months old, there was another thing to do with the car and I went and hit, I went and hit the back of one of the front seats.

Richard (I1)

Following their eventual separation his mother had wanted to ensure that Richard had a positive male role model, but this resulted in additional relationships that were also characterised by substance misuse and domestic abuse:

One ended up cheating on my mother with another man, another was a very, was very alcohol-abusive so let's just say he got my mam on the drink and the weed, and smoking even more than usual... Then she went out with this other guy, which was actually quite recent, a year or two back, it was like four years long, and that ended, well as I said that ended quite recently in comparison. He had lost his brother, like his younger brother, then he started going to the drink, then he was, you know verbally abusive and then the next day he'd wake up and he wouldn't even know he said any of those things. My mam said no, you know, after, well after, enough is enough.

Richard (I1)

Richard had been diagnosed with low tier autism. He described his symptoms as including poor eye contact and social skills, and an occasional loss of control where he would punch things or scratch himself. He managed these symptoms by having a plan for every day, and this helped reduce stress:

I don't like it when I've made like my plans for the day, and it gets thrown out of the window due to a wrench thrown into the works if you understand what I'm saying there. Like say for example I've got my timetable, I think I'm on Week One of two weeks for my timetable. I walk into the school, I think 'right I've got to go to this lesson' and I don't have to think about any others because if I do then I'll be thinking too far ahead, and then I was actually, it was actually a Week [Two].

Richard (I1)

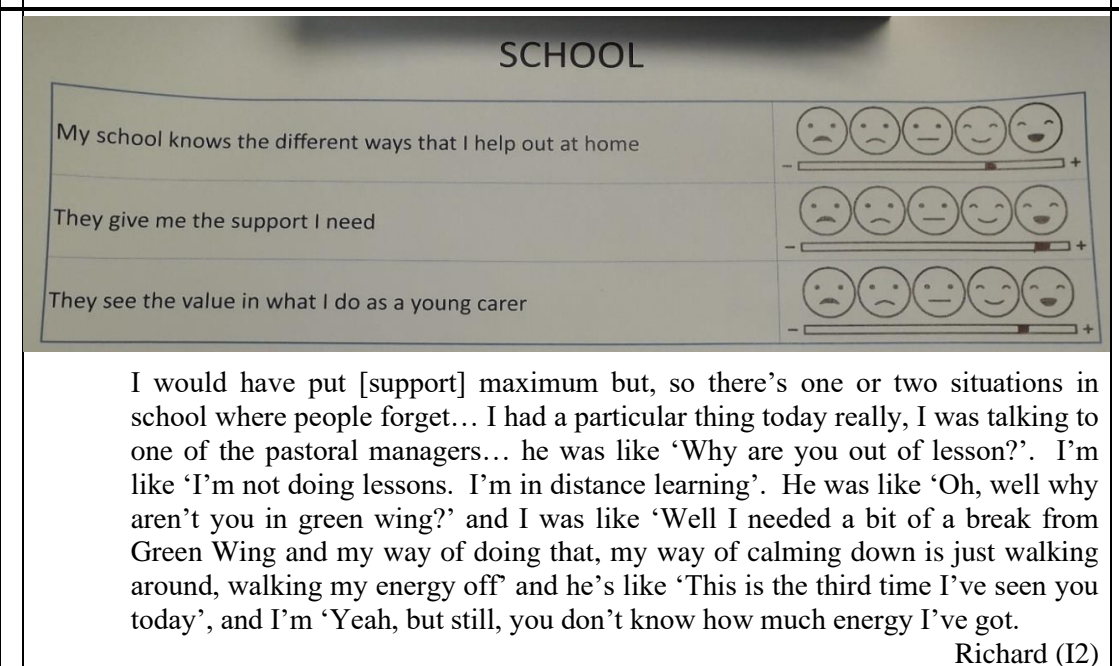
Chapter Ten discusses Richard's reluctance to assess young carer support, but his school were supporting him with his autism. They had agreed for him to have reduced attendance, and had provided him with the resources to learn as a distance learner:

I go into school, get, get a few pieces of work, maybe do work a bit there. I can go the school has given me a school issue of laptop to do stuff online. I've got home access and stuff like that. They've got me on, they've got me on Office 365, doing work there, go on Teams, go on and attend meetings.

Richard (I2)

While he occasionally had issues with individual school staff (Figure 9.2), he appreciated how his school were supporting his learning, and he was expected to do well in his exams:

Figure 9.2 Richard's satisfaction with his school's support of his disability



I feel confident in my ability to go into school, and my exams, because I haven't attended pretty much a single lesson of school... So I was like 'Right ok, get these exams, I'll get these papers done now', and I had a pleasant surprise when the head of science, also my chemistry teacher, gave me a little of a recap and gave me a little bit of a lesson just before the exam, and he was really confident, he's like, his words literally was 'You don't even need to be in school'.

Richard (I2)

9.4 Threats to control of the caring role

The previous section focused on Angela, Harry and Richard who were able to develop positive caring routines despite different levels of responsibilities. This enabled them to stay in control of their caring and resulted in a range of benefits, especially for Harry despite his large caring role.

This was not possible for all the participants, and a number of threats hampered this control. This included instability in the caring role that was often due to fluctuation in the care receiver's health, excessive responsibilities, caring during the night, and the inclusion of medical responsibilities.

9.4.1 *Fluctuating conditions and instability in the caring role*

Central to positive management of the caring role was stability but this was not possible when the care receiver's health fluctuated over time. Thea, Lyra and Lucy were three sisters who participated in the study. Their mother had been diagnosed with bipolar disorder after their father's death, and she had initially been sectioned for four months in 2015. She was in hospital again at the time of Lyra and Lucy's first interview in August 2019 and released two months before Thea's first interview in December.

Thea detailed how their mother's support needs were greatest when she was released from hospital in 2015 and how her overall health had improved over time. Having recently been sectioned again, her needs were again greater upon release:

When [being released] first happened she was able after two and a half, three years to go out on her own, and she felt that was a big achievement. She was shopping all the time for herself. But then now it's happened again we're taking baby steps.

Thea (I1)

The sisters recognised that her health affected their caring responsibilities. As the oldest sibling, Thea saw herself as her mother's main carer and estimated that she was caring for six to seven hours a day at the time of her first interview. This was less than at the

time of her mother's release two months before, and had dropped further by her second interview three months later:

I help my mum when she gets ready in the mornings... so I'd say that's about hour and a half getting her ready and getting myself ready. As soon as I come home, we usually do a daily shop because it's not too much for my mum. So I'm there helping her with her shopping, and then I'm helping her then with the dishes. So about two hours then after school. Then we eat, so I help her with the food. It's a good six/seven hours a day I would say... I think this is, this is a lot lower than from when she first come down, because I was proper, I was doing everything. Make sure nothing went wrong. But now she's been out nearly two months, my hours of being a young carer has gone down.

Thea (I1)

Much better than any time before, she's productive, she likes to be independent, she likes to clean the house, she likes to make sure we're getting ready for school, she likes to go out with some friends... it's still a bit overwhelming for her, but she's just getting back into the routine of getting everything sorted again.

Thea (I2)

However, while these improvements in their mother's overall health led to decreasing responsibilities in the long-term, it still fluctuated on a daily or weekly basis:

When my mum is depressed I find it kind of hard to make her do something, so like she doesn't want to get up, and things like that so that's kind of hard to function, then when she's a maniac she's kind of hard to calm down, so it like depends, but sometimes she will be in the middle where like she's easy.

Lyra (I1)

When she'll ill I'll say about, basically all day caring for her, like doing her sick bowl and all. But then other times I just do the dishes.

Lucy (I1)

During periods when their mother was sectioned, the siblings had supported each other emotionally, and Thea had taken on a practical role supporting her sisters in school:

Lucy, she was getting bullied... so I went to the little brother and went 'Stop bullying my sister, otherwise we will have a problem', and just spoke to the [older] brother about it as well. 'You don't sort it out, I'll sort it out'... Because at the end of the day I didn't have anyone when I was in school. Now my two sisters are in school and they got me. I'm not letting my little sisters go through what I had to go through. So I take the responsibility of being the mother of them in school, like they got a problem they know where I am.

Thea (I1)

In seeking to understand the complexities of Thea's caring, the research suggested that she had two roles; caring for mother when she was at home and supporting her sisters when she was away. This was something she agreed with:

My mum was very depressed, so I stood up, I made sure everything was clean. When my mum got sectioned the first time we all lived together, because we were a lot younger and then the second time I moved away and they stuck together, but even in school, I was always there, making sure they were okay.

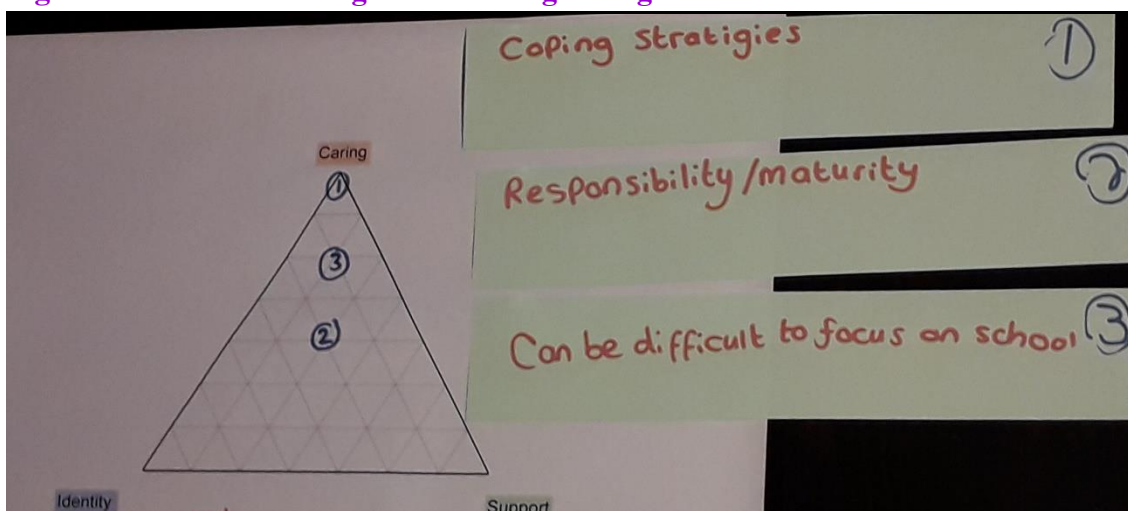
Thea (I2)

There were periods when their mother's health was particularly poor and Lyra and Thea focused on caring. This had the effect of de-prioritising other parts of their lives. For Lyra this meant attempting to fit homework around her mother sleeping, while Thea took sizeable periods off school to provide care (Figure 9.3). At the time of Thea's second interview, she was returning to school after a break, and Chapter Ten focuses on how Lyra and Lucy increased their caring to enabled Thea to focus on her exams:

It depends with how my mum is feeling because sometimes she's like, when she's ill she's ill for weeks so, it it's then, then like if I have homework or something I balance that when my mums asleep.

Lyra (I1)

Figure 9.3 Thea's challenge of balancing caring and her education



When I come back into school, I got my head down like, focused as much as I could, because I didn't want to let myself down, didn't want to let myself fade away, it's my last year, I've literally got about nine months left, there's no point me messing it up now... It was hard at first, but I got back into the routine of, I'm doing well in school.

Thea (I2)

Caring also affected their social lives at times with them preferring to stay home and keep their mother company when she was struggling:

She's been out more, I go out a bit more. I've been out most days this week with my best friend. Yeah, so it's just, and I had that much homework, I've nearly finished it all actually... So it's just if she gets ill then I focus more on home, but if she's actually having a good day like she had today, I'm allowed out. I say I'm allowed out, I choose to go out then.

Thea (I1)

When my mum is better I can balance it because she goes out with her friends and if I want to go out with my friends or something like that.

Lyra (I1)

Their family had also faced additional challenges that were linked but separate to their caring. These were not raised by Lyra and Lucy, potentially due to them being younger at the time, but Thea had struggled with the death of her father as well as feelings of abandonment following their mother being sectioned. These are considered in Insert 9.3.

Thea had multiple mental health issues including anger, suicidal tendencies and self-harm, and she attributed them to her caring but also these additional adversities:

Anger, definitely comes in, but not just my young carer role... I have tried to calm down a lot more, yeah so my anger isn't as bad as it used to be, I don't break things as much no more.

Thea (I2)

I am proud of myself for being where I am now, because I was at a very low point when I finished school last year, I was extremely suicidal, tried to commit suicide three times last year, because of everything that happened.

Thea (I2)

Chapter Ten considers the caring unit that the three sisters formed, but also the support received from their young carers project as well as school and health professionals.

Insert 9.3 Thea's additional challenges: Bereavement and abandonment

Thea's father died from cancer when she was nine. Her family had decided that she was not old enough to know about his illness and she only found out when she saw him shortly before he died. Thea felt that this gave her maturity, but she grieved for her father and resented not being informed. Chapter Ten considers her protectiveness and reluctance to disclose her carer status, and Thea attributed these character traits as partly due to this event:

I've been through a lot of situations... which has allowed me to gain, maturity for like losing my dad, and having to look after my sisters, and not see my brother as much, then going through school. It's just allowed me to become a better person.

Thea (I2)

Being protective, is, when I lost my dad, I didn't know until the very last time... I was eight when I found out, no nine actually, but I felt like I got betrayed that no one told me sooner, and then that's why I don't really trust that many people, because I lost my dad, and no one told me, until the very last minute.

Thea (I2)

Her father's death affected her mother's mental health, and she was sectioned with bipolar disorder. Thea had been close with her mother but felt abandoned at the point that she was transitioning to secondary school:

She was my best friend when it happened the first time, then it took me four years to gain that trust back, because she left me for four months and I had to fend for myself, I'd just started, new people, you want your mum there, but my mum weren't there.

Thea (I2)

Her mother was sectioned again during her GCSEs. The need to revise led to her living with her aunt after her mother's release but she also admitted not wanting to see her:

The second time, I hated it, I didn't speak to anyone for six weeks, didn't want nothing to do with it, I didn't even think about moving back, I just knew I was going to stay with my Auntie until I finished my GCSE's... They went, "Is that the decision you want?", I went "Yeah, that's what I want".

Thea (I2)

I hated her, I hated her guts... Yeah, I wanted to run away... I just wanted to go. I wanted no one to find me.

Thea (I1)

At the time of Thea's first interview the situation had improved, with Thea at home and increasingly accepting that it wasn't her mother's fault:

Six weeks to actually finally talk to my mum, because I just didn't want nothing to do with her. Didn't want to talk to her, but then I thought well she's my mum at the end of the day. She's going to come home sooner or later.

Thea (I1)

9.4.2 *Transition into the caring role*

While the other participants had caring roles with different levels of stability, Martin had recently entered the role nine months before his first interview. He discussed his mother's sudden onset of aplastic anaemia which caused chronic fatigue:

She was cold and it was one of the hottest days in summer and she was freezing cold sitting there with a blanket, and my grampie's girlfriend said that something's wrong because it was boiling and me and my cousin were out there playing and she was just sat there with a blanket.

Martin (I1)

Her levels of fatigue varied but were also affected by a fortnightly medical treatment that typically took a week to recover from, and this resulted in cycles of varying responsibilities for Martin. He shared his experiences of the increased responsibilities that followed her treatment:

She has that every other week. Normally the week that she's had it, she's like tired and... week that she hasn't had it, we play games until like eight o'clock.

Martin (I2)

Normally we relax for like half an hour, and then I help her for an hour normally, half an hour, getting stuff before we start to cook tea, and then around half past four we start cooking tea and that's about an hour, so about an hour and a half there, and then we eat tea, and then I normally help get her stuff ready, so that's about another half an hour grabbing all her stuff and helping take it upstairs, and then normally I'm in her room for about half an hour, talking to her and just helping her around her room, closing her curtains,... I'd say about two and a half, three hours... It's not much.

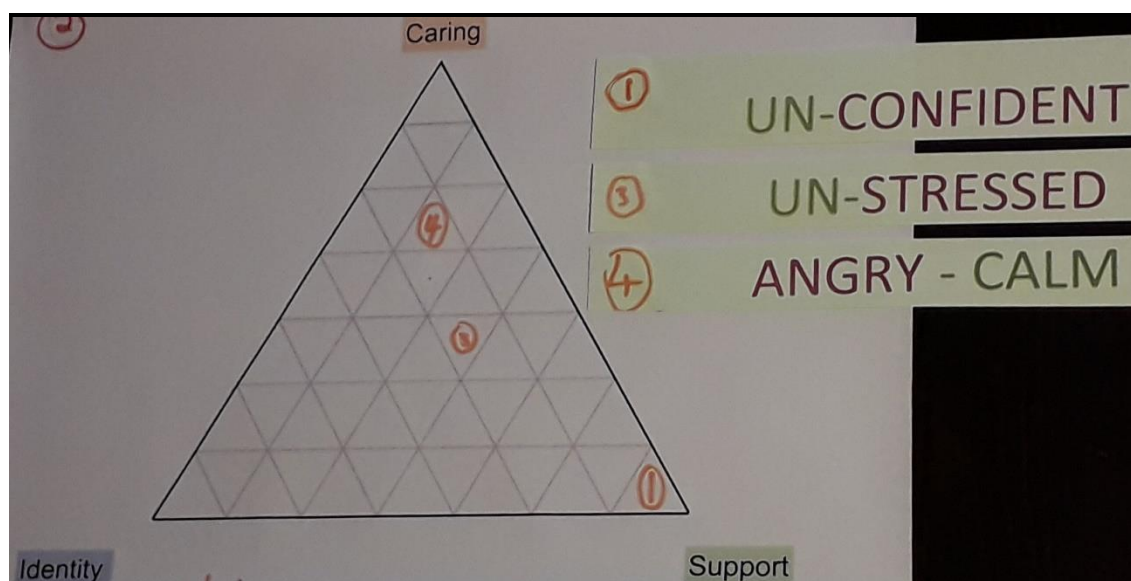
Martin (I1)

While Martin downplayed the amount of time that he spent caring, he was still becoming accustomed to his new role. He admitted that he had always had a tendency to become annoyed, but the new responsibilities had increased his frustrations (Figure 9.4):

It was kind of a, like a punch in the face for me, and I was like 'Whoa she needs more help'... as soon as she got out of hospital she tried to do stuff... because obviously no one had lived there for three months, for two months, and she was trying to do the house and she couldn't.

Martin (I2)

Figure 9.4 Impacts of caring responsibilities for Martin as a new young carer



It's not good but I always like, I'm always annoyed. Like I value what I do but like I'm always annoyed and stuff, I have a really short temper. It's like I used to but now, when my mum asks me to do stuff I'm always like 'Argh', and I know it's not nice for my mum but I'm just, and when I wake up I'm a bit mean. But I, I don't really know what I can do to stop that.

Martin (I1)

The research followed Martin's transition, and by his third interview he reported the development of a routine that eased his frustrations and increased his confidence. This routine was also partly aided by his mother being able to manage during the day, resulting in his caring not interfering with school:

It's become routine, it's just like not as stressful and like I've just gotten used to it.

Martin (I3)

She normally can manage when I'm in school... it's just she gets really worn out when she does too much.

Martin (I1)

9.4.3 *Excessive and night-time caring*

Having considered fluctuation in the care receiver's condition and young carers role as the first threat to control, and transition into the caring role as the second, the next threat is excessive care. While Harry had a positive routine that enabled him to manage

substantial responsibilities, this was not possible for most participants with higher-level roles. Routines for these young carers were often either not possible or, particularly for those with night-time responsibilities, detrimental.

Kirsty had cared for her mother, who had spina bifida, until she died a few years before the research began. She had spent large amounts of time caring and keeping her mother company, but had been able to balance this with her education:

Never had any problems... I cared for her briefly in the morning, go to school, come home, so it was kind of, it fitted together.

Kirsty (I1)

For Kirsty the main challenge was balancing caring with socialising, and she increasingly prioritised caring for her mother over maintaining friendships:

When I was younger I would go to clubs and stuff. I used to do Brownies and swimming club and all that carry on... but as I got older, like I, I would opt to stay at home with her than like go out with friends for example.

Kirsty (I1)

I would spend time with friends but not as much as some of the other people did, you know I, for absolutely no reason I fell out with a lot of people, I've lost a lot of people over the past few years in particular, for absolutely no reason, no valid, no valid reason... I was very, very attentive. You know I, if, if something happened like, amongst my group of friends in school I couldn't really care, couldn't really care less but whereas something happened at home I kind of like lockdown panic mode.

Kirsty (I2)

Kirsty attributed part of her maturity to the large amounts of time she spent caring but, while Thea and Angela viewed their maturity positively, it continued to affect Kirsty's relationships with peers, three years after the death of her mother.

Mature... this old Year One teacher where I, a few weeks back, she's like 'I still remember you saying to me in Year One 'Miss, I don't like kids'...'I was spending more of my time with adults, because of where we were and the fact I was caring for my mum, yeah it kind of influenced how I function.

Kirsty (I2)

In addition to the effects of her caring, other adversities included the death of her mother, and an increasingly distant relationship with her father. Insert 9.4 considers these challenges and how she increasingly sought the support of teachers rather than friends or family. Chapter Eleven also considers Kirsty's strong caring identity but also how this was threatened by the loss of her caring role following her mother's death.

Insert 9.4 Kirsty's additional challenges: Bereavement

Kirsty cared for her mother for several years, until her death. Kirsty was in the final year of primary school at the time, and she described the experience of not being able to reach her family and knowing something was wrong:

I remember the day she passed like it was yesterday... I was called down to reception during the day and told just to go out with this, go straight out with this friend. After I left, I rang my dad to ask why because I knew he was off work because my mum wasn't well, and I probably spent the next three hours trying to get hold of my family in some way, shape or form... the urgency I had was because I knew she was unwell I think my, my biggest fear was kind of coming true. I'd always had a fear that I would lose her.

Kirsty (I3)

Kirsty and her mother were very close, with their relationship detailed in Chapter Ten, and Kirsty was continuing to grieve for her mother. She attributed the maturity that resulted from being a young carer as also due to the death of her mother and growing up alone with her father:

It still hits me pretty hard sometimes. You know, it's like, I suppose it could have been kind of described as the doldrums in the Southern Ocean, you know, it's all, it's all fine, calm and smooth and plain sailing for a while, and then the waves just crash up you know, it's pretty sucky.

Kirsty (I2)

Following her mother's death Kirsty had had an increasingly distant relationship with her father. This contributed to her loneliness having previously lost touch with friends due to her caring:

We [Kirsty and her father] used to be quite close but I think over time that's kind of, I think we kind of grew apart a little bit, but you know we're still close just not as close, and it can be frustrating and we, we do talk just not a lot, you know not often and not for long.

Kirsty (I3)

There's been times in the past where I've, I've been in such a, such a touch place like emotionally and mentally that I've, I've virtually, practically begged him not to go, but like he's, he's still gone, and it, it gets really lonely... he tends to get in from work and he'll go through to the bedroom and just lie down and watch TV. I don't really see him but it's its knowing that he's there, it kind of stops me from being so lonely, but you know, it's very lonely.

Kirsty (I2)

Chapter Ten considers the close relationship that Kirsty developed with individual teachers as a result of her caring. This increased following her mother's death due to the limited support from family and friends. Kirsty highlighted the importance of this and noticed the difference when she was unable to see these teachers:

It's been brilliant, it really has, I can't fault it, but I think sometimes it, like the level of it, it kind of wanes a bit. I mean, it, it's quite variable, so like sometimes I'll have like a week where everyone I meet, well everyone I need I've got them all there and I'll speak to them all in that week, and then I go four, five, maybe six weeks without speaking to any of them or very few of them... the hope just drains, you know I start to think 'well, you've seen this happen before, it's not going to happen'.

Kirsty (I2)

At the time of the second and third interviews Kirsty was facing a new challenge with two of these teachers leaving the school. As a result, she was increasingly anxious about developing new relationships:

A little bit shaky, there are a couple of members of staff here who I've been pretty close to, able to confide in from day one three years ago, and, so my two originals, they're both leaving... the ones I'm comfortable talking to and they always kind of, just like find a way of picking up the pieces of me and putting them back together.

Kirsty (I2)

I'm struggling to so far... there's a couple more now that I'm getting on with quite nicely, I'm kind of happy to sort of stop and kind of open up to but not as in as greater detail as the others. I mean yesterday, I had a test first thing yesterday morning and didn't feel like I did particularly well and come second lesson I was so stressed out about it, about what I'd done that I just completely fell apart. It got to the point where it was just like well one of the two that had left it's just this is the point where I'd normally [see them] and I can't.

Kirsty (I3)

Patrick had been a young carer for his sister Sara since before the age of five. Similarly, to Harry and his brother Sean, Sara needed constant support and Patrick had an agreed routine within the wider family support provision. There were other similarities with

Harry, with Patrick helping Sara get ready for college in the morning, caring for four to five hours after school and having fewer responsibilities at the weekend:

They both work quite late so it's usually me helping her out... So my stepdad won't get back until like half seven, eight. So that's like from three till then, there's nobody there and then like my mum works from home and does stuff so she'll be off doing something else so somebody still needs to be watching Sara.

Patrick (I2)

I'm up before everyone else so I can do all the stuff so she's ready, they [his parents] do care for her like on the weekends so I have my own time to like do homework.

Patrick (I1)

In addition to caring for Sara, Patrick had also previously cared for his grandfather before he died. This was also a large amount with Patrick typically spending two hours after school with his grandfather, and up to several hours a day during school holidays. Patrick had noticed the difference since caring for one person:

It does make a massive difference, because obviously I'm not rushing from place to place, trying to look after two different people... I'd always go in straight from school, I'd get dropped off there, and I would look after him for like two hours. And then when I got like a week off, I'd spend like hours and hours down there... I did then like six hours down [each day], like in a week off maybe.

Patrick (I3)

These excessive responsibilities also included monitoring during the night, and Patrick would monitor Sara in case she woke up and needed anything. This combination of late nights and early mornings were causing long-term tiredness:

I'd wait until she is asleep and then I would just wait a couple of hours in case she does get up and then maybe, maybe I'll go to sleep... she usually goes to bed at like ten... So I'll be up until like two maybe just in case she does get up which has happened before.

Patrick (I1)

Patrick was fully focused on putting Sara's needs first and seemed to have little consideration of his own health and well-being. His focus on caring led to the deprioritisation of other aspects of his life, with socialising happening during the school day and homework completed late at night or during lessons:

Social time's done in school. Sister's like after school and homework is trying to fit in anywhere possible like I'll try and do homework before helping her but you never know when she needs help so it's sort of keeping an eye on her whilst trying to do my work... sometimes it's like I'll forget about doing the homework because something else will crop up like she needs something and so it'll be like the night before that I'm trying to rush trying to do it, so it is quite difficult... Priority comes down to her, I try and do homework like at school or on the way there or in class sometimes... so it's out the way.

Patrick (I1)

Patrick's final interview was held online during the coronavirus pandemic. He had continued to provide care during lockdown but the closure of his school and the presence of other adults in the home had resulted in changes in his routine (Insert 9.5). While these changes were positive, Patrick was still pessimistic about his situation, partly due to the difficult relationship that he and Sara had. Chapter Ten considers how the relationship deteriorated further during the lockdown.

Sophie was a long-term young carer for her mother who had diabetes and a hearing impairment. While her condition remained largely unchanged, Sophie's responsibilities had increased from helping her mother communicate as a small child, to increasingly supporting her with her diabetes. This included monitoring her mother on a nightly basis as she was prone to sudden changes in blood sugar levels:

When I was little, I would just answer a phone maybe but now I'm older my mum relies on me in public, at home, everything like that.

Sophie (I1)

I think it's called like Dawn phenomenon which links in with the hormones in Type One diabetes, where she'll go to sleep and her blood sugars might be fine, and then three o'clock in the morning they'll just shoot straight up and she'll wake up with really high blood sugars. But sometimes in the night she goes down really low. Sometimes in the day she does as well but it's like, in the night she goes really really low, she doesn't realise sometimes.

Sophie (I1)

Sophie would be up until after midnight every night monitoring her mother, but this could be as late as four o'clock if her levels were abnormal and Sophie was concerned. This resulted in tiredness which affected her mood:

Insert 9.5 Longitudinal Change 2: Impact on the coronavirus on Patrick's routine

Patrick's sister Sara had shielded from an early stage of the pandemic due to her cerebral palsy affecting her immune system:

- P: She was sort of the first one to lockdown, because obviously before they sent out a warning for like asthmatics and people with disabilities, including cerebral palsy, so she's been there for a while... it makes her very vulnerable, she's ill quite a lot because she's not as strong.
- R: So is she in the shielding group?
- P: Yes she is.

Patrick (I3)

Other changes included Patrick's school being closed and his mother being furloughed and at home more than normal. While Patrick was undertaking the same type of responsibilities, the amount of caring had decreased:

[Before Covid] my mum works part time, at work, and then when she came back in the evening, she worked from home... she's been home constantly. And my stepdad's still working, because he's classified as a key worker, because obviously in food, so he has to keep working.

Patrick (I3)

It's still the same stuff that I did, just other people are doing it, and I still do the same stuff.

Patrick (I3)

While Patrick was still staying up late to monitor Sara, the overall reduced time caring meant that he was less tired than before. The school closures had also made a difference as Patrick had more spare time for socialising with friends than usual:

Yeah, I suppose I'm less tired now, because I've been doing half the work because there's someone else doing it. Which is quite beneficial.

Patrick (I3)

I've literally just been playing with my friends online, that's been the best bit... I've been able to catch up with them more than I have ever before. Because I've just been constantly playing with them, and then obviously still helping Sara.

Patrick (I3)

I feel like I can't go to sleep unless like, everything's ok in that way, so like I don't go to bed til past midnight... I'll like wake her up and be like 'Check your blood sugars' and then see what they are and then decide if I want to go to bed.

Sophie (I1)

If I'm out in public and I'm tired and I don't want to start talking to people because I'm tired, then I'll get really angry about the fact that my mum can't do it, but most of the time I'm fine with doing it.

Sophie (I1)

Sophie had a negative caring routine due to the amount of caring, and particularly the night-time responsibilities. As a result, Sophie found balancing her caring and schoolwork stressful:

[If] you do a lot of caring for them, then you can often get like really tired, and then, if you have like schoolwork on top of that then that can just make you really really stressed, and then like, if you don't really balance your caring well then you can also get really stressed.

Sophie (I2)

She viewed caring and education as equally important but often found herself being pulled in two directions. She shared her experiences of first prioritising caring which affected her education, and then prioritising homework which impacted her mother's health:

P: I think it does because like sometimes I'll be doing homework or I'll have lots of homework to do and then my mum will need my help. And it's like deciding which one's more important.

R: Let's say you do like the caring side rather than the homework side. How do you feel after that?

P: I feel like I've helped my mum but then I've got to catch up on my own work.

Sophie (I3)

It makes me feel like I've done all my homework so I'm gonna be up to date, but then like, my mum might still be struggling, and like sometimes she's like shaking as well so she can't do it, and that's why she asks me to do it... I feel like quite bad in the sense that I didn't help her at the start.

Sophie (I3)

9.4.4 *The provision of medical care*

The final threat to young carers' control was the provision of medical care. This also concerns Sophie as the only participant with substantial medical responsibilities which included monitoring her blood sugar and occasionally administering injections or more often force feeding her mother when her levels had spiked or collapsed. Sophie had

been carrying out these responsibilities for several years without professional training, and the development of medical skills through experience had helped her to remain calm most of the time:

If mum's having a hypo I know what to do... you have to be quite skilled to like remember things like that, especially if you're panicking about it. Then you might forget, but you have to be quite skilled to remember what to do.

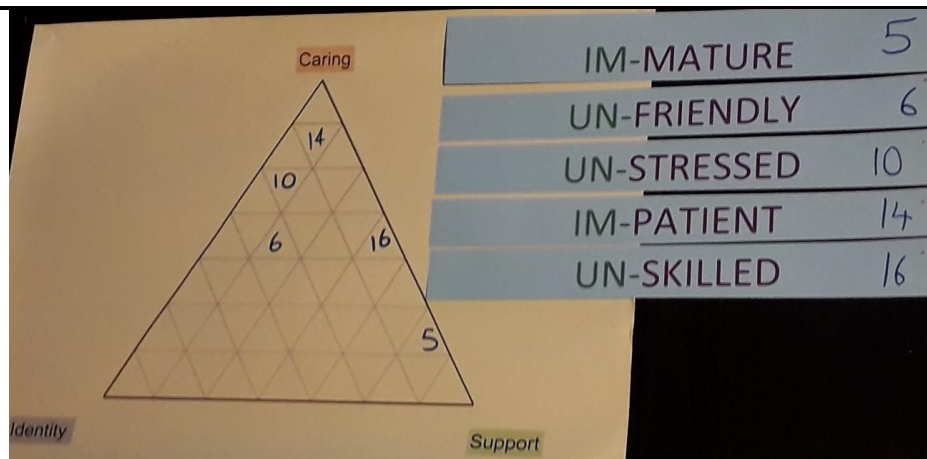
Sophie (I2)

While Sophie did not find caring itself to be stressful, she sometimes became distressed, impatient and frustrated when her attempts to control her mother's blood sugar levels were unsuccessful (Figure 9.5). At these times she was also prone to overthinking, particularly concerning the potential for her mother's newly stabilised blood sugar levels to spike again:

I don't get that stressed about the caring itself, it's just that if my mum's having a hypo and it's not going up I do, like, start to cry.

Sophie (I2)

Figure 9.5 The effects of unsuccessful medical care on impatience and anger



It's gotta take its time for the sugars to go through properly and then go through her blood so when you test it it will start to show an improvement and she'll start to feel better. If it doesn't then you can get really, really impatient and angry about it... she had a hypo, I think it was last month or something, and it went down to like two or something and my mum didn't wanna like, she didn't wanna eat, so I was like force feeding her to eat, and then she was like, she just didn't want to do anything, and then she was getting really hot and sweaty, and she had two or three cups of orange juice and two Twirls and it still took her a good 20 minutes for it to get back to a reasonable level that she could then go back to sleep.

Sophie (I2)

While Sophie was largely unknown to services as a young carer, she had been identified by a diabetic nurse shortly before the first interview. Chapter Ten follows her experiences before, during and after she received training and information following her mother being fitted with a new diabetic pump.

9.5 Chapter summary

This first qualitative results chapter has focused on how the participants managed their caring responsibilities and the resulting impacts. Those with control of their responsibilities were more able to develop a positive routine that balanced caring with education and personal time. In contrast, challenges including fluctuating illnesses and unstable responsibilities, transitioning into the caring role, excessive or night-time caring, and medical responsibilities acted as threats that reduced control. These young carers often struggled to balance caring with other parts of their lives, resulting in the de-prioritisation of social time and education to focus on caring.

Chapter Ten considers how support can moderate the impacts of the caring responsibilities reported in this chapter. In particular it focuses on the relationship with the care receiver and support within the family, the self-disclosure of young carers and their families in order to access support, and the identification by services when self-disclosure does not occur.

Chapter Ten

Support as a moderator of caring impacts

Chapter Nine reported the impacts of caring responsibilities. This included impacts shared by participants due to them being young carers and irrespective of individual circumstances, but the majority of the findings relate to control over the caring role and contextual factors that aided or threatened this control.

This chapter reports on support as a moderator for the impacts of caring responsibilities. Positive support has the potential to mitigate negative impacts and enable benefits, but the detrimental effects can be exacerbated when support is poor. Support sources include family, friends and neighbours, schools, health authorities, social services and young carer projects, and young carers have different relationships with each.

This chapter initially considers family support in terms of the young carer's relationship with the care receiver and the presence of a wider family caring unit. Moving beyond the family, the chapter focuses on the reluctance of young carers and families to be identified, and differentiates between self-disclosure by some young carers and the attempts of services to identify others. Participant's experiences of support following self-disclosure or service identification are also explored.

As with the previous chapter, the use of inserts highlight changes in participants lives that were witnessed due to the longitudinal research focus. Specific inserts concern how the impacts of caring were moderated by the changing relationship with the care receiver, how family and community support aided transition into the caring role, and how the identification and accessing of health service support mitigated the effects of caring.

10.1 Participant access of support sources

Table 10.1 summarises participant involvement with the different support sources and whether the young carer and their family had disclosed their status, been identified, or remained unknown to the specific source. While all participants were known as young carers within the immediate household and usually the wider family, there was greater variation in awareness beyond this point.

This was partly due to the joint decisions of young carers and their families over whether to disclose their status and who to. Among the sample of ten participants, the five participants who were accessing young carers projects (Harry, Thea, Lyra, Lucy and Richard) were more likely to have also self-disclosed their status to other services and sought the informal support of friends and neighbours. In contrast, the five participating through their schools were often reliant on informal assistance alone, though there was also the potential that they would be identified by services.

Table 10.1 Summary details of young carer identification and support for participants

No	Setting	Name	Informal support				Formal intervention		
			Family	Friends	Neighbours	School	Health authorities	Social services	Young carer project
1	School1	Sophie	I	SD	U	U	I	U	U
2	School2	Angela	I	SD	U	U	U	U	U
3	School2	Kirsty*	I	I	U	U	U	U	U
4	School3	Martin	I	SD	SD	U	I	U	U
5	Project1	Lyra	I	SD	SD	SD	U	SD	
6	Project1	Lucy	I	SD	SD	SD	U	SD	
7	Project1	Harry	I	SD	U	SD	U	SD	
8	School4	Patrick	I	I	U	U	U	U	U
9	Project2	Richard	I	I	U	I	I	I	SD
10	Project1	Thea	I	SD	SD	SD	SD	SD	

Notes

U (Unidentified); SD (Self-disclosed); I (Identified)

* Care receiver deceased at the time of the research. Data retrospective from when child was a young carer

10.2 Family support and the caring unit

The findings of this chapter begin with the family, including the immediate household and relatives outside the home. The relationship with the care receiver is considered first, followed by the presence of a family caring unit where the child's responsibilities are one part of wider family provision.

10.2.1 *The young carer – care receiver relationship*

Of the ten participants two were caring for disabled siblings, and eight for their mother. The relationships of Harry and Patrick with their respective brother and sister are considered first. For those caring for a parent, the carer – care receiver dynamic is considered alongside the traditional parent – child dynamic.

Relationships with disabled siblings

As detailed in Chapter Nine, Harry reported a positive experience despite having substantial responsibilities caring for his brother. Central to him valuing the role was their relationship and, while Sean had a limited ability to communicate verbally, Harry highlighted how he showed affection and appreciated him. Harry also had a very open relationship with his parents and felt able to talk to them about his caring:

He can't really like show it, but now and again he will reach out for a hug. Sometimes you know, like kiss you and stuff like that. So I'd say it's pretty good with him yeah, he like trusts me if you know what I mean. I think he does yeah, because when we do stuff for him, and like you know, he like, so he's very happy about it.

Harry (I1)

I can talk to them [parents] really about anything, because like they understand the situation about my brother and what I'm like looking after them and stuff.

Harry (I3)

Like Harry, Patrick had substantial responsibilities but his experiences of managing his responsibilities were more negative. This was underpinned by a problematic relationship with his sister Sara and, while Chapter Nine evidenced how the coronavirus

pandemic had the indirect effect of improving the balance between caring, schoolwork and social time, Insert 10.1 details how their relationship deteriorated further during lockdown.

Relationships with disabled parents

The remaining eight participants were caring for their mothers. These young carers and care receivers had dual dynamics with the child providing care for an adult while the adult parented the child.

Chapter Nine considered the responsibilities of the participants and most of the young carers including Sophie, Angela, Martin and Kirsty reported positive relationships with their parent. A key part of this was feeling appreciated for the support that they gave, which was often given in terms of gratitude, affection, and activities together:

We always talk, we always do things together, stuff like that.

Sophie (I1)

Well, she tells me she like, she appreciates it as well.

Angela (I1)

In terms of the traditional parent – child dynamic, participants discussed whether they felt that their mothers were able to provide care for them. They acknowledged that parts of their parenting could be limited by illness or disability, but several participants including Kirsty and Angela highlighted the aspects of care that they did provide and the overall normality of their relationships:

Within her ability she did everything that any mother would do. You know, she was there if you needed a chat, you know she'd, she'd do dinner sometimes as well, you know, she'd do my lunch if I was having a packed lunch to school, brush my hair, make sure I was dressed, teeth cleaned, etc on time.

Kirsty (I2)

Insert 10.1 Longitudinal Change 3: Patrick and Sara's deteriorating relationship

During his first two interviews Patrick shared his complex feelings about his sister. He worried about Sara and was proud of her for facing challenges including her disabilities, bullying and a lack of friends:

I'm proud of my sister because of who she is and how she manages to cope through each day without giving up because of what she's got and she just carries on.

Patrick (I2)

At the same time Sara had mood swings which he attributed to her frustrations over her disabilities. Patrick found these mood swings difficult to handle and felt largely unappreciated despite the large amount of support he gave her:

A good day is her not being, well she'll be in like a real bad mood and then she'll be really wobbly so she really struggles to walk on those days and that's like a bad day and anything that's opposite of that is usually the best.

Patrick (I2)

I think somewhere she probably does but she doesn't ever show it, she sometimes can be quite nasty to me because I didn't do something quick enough or I haven't done it like there and then so she can get quite evil at me because of it ... she can be quite loud and aggressive.

Patrick (I1)

In his second interview Patrick talked about his anger, which was mainly directed at his situation rather than Sara. His perception of his situations informed his caring identity and is discussed in Chapter Eleven:

I suppose I don't feel angry towards her only, if it's like on a bad day then it can affect me just because she doesn't appreciate what I do for her and then that can aggravate me.

Patrick (I2)

Patrick's third interview was held near the end of the first national coronavirus lockdown. Sara had been shielding for some time due to her cerebral palsy and had become increasingly isolated. Patrick found her behaviour increasingly challenging and felt targeted by her. At the same time, Patrick had also become more impatient, with his anger increasingly directed at his sister. Therefore, despite the improvement in his life balance during the lockdown, their deteriorating relationship had exacerbated the already negative effects of his caring:

She's definitely more, you know, problematic, because she's obviously not getting the social time from her friends and stuff, because they're obviously doing course work, and so she's just sat by herself really.

Patrick (I3)

I think she thinks she can get away with more with me, because obviously I'm her brother. But that does not happen, because she cannot win.

Patrick (I3)

Concerning Patrick's family, they were extremely private and reluctant to seek support from outside the household, to the extent of not discussing it with close relatives. In addition, Patrick was personally very private and did not talk to his parents about his caring or his relationship with Sara. This limited the support that his parents could give and left him isolated especially as he was not accessing support from outside of the home either:

Ed: Do you talk to your parents?
Patrick: Not really about ... no, I don't actually, about her.
Ed: Is there a reason why not, because obviously your mum and your stepdad, they are people that obviously know you're a young carer...
Patrick: I just don't feel like there's any need to talk to them about it. Like they know what's going on, so that's like enough, how it is.
Patrick (I3)

It's most normal. It's like with my parents my dad's more my friend, my mum's more my parent, because she's a lot stricter than my dad is, my dad's like 'Yeah, stay up till 11 on a school night, it's fine', my mum's like 'It's ten o'clock get your arse to bed [laughs].

Angela (I2)

Chapter Nine introduced Martin as a relatively new young carer and, over the course of three interviews, demonstrated how his initial frustration with his caring became confidence as he became accustomed to his role and developed a positive routine. Insert 10.2 considers how his strong relationship with his mother, as well as the support of his grandmother and his mother's partner, were also key to moderating the impacts of caring and easing his transition.

Lyra, Thea and Lucy's mother had bipolar disorder, and this had a more substantial impact on their relationships with her than for many of the other participants. This was partly due to the nature of her illness, but her medication also affected her emotions and ability to provide care:

When she was taking the medication like I just knew something still wasn't right, like she wasn't like how she was. So like it, like she's not going to be the same that she was but like I feel like she still can't look after me how I need to be looked after if that makes sense... I think sometimes I feel like she doesn't realise what we actually, what we actually do for her, so, like, I, but she does say like the odd thank you and stuff. Other than that I don't know.

Lyra (I1)

Insert 10.2 Longitudinal Change 4: The benefits of improving relationships and support in Martin's family

Martin explained that he had always had a close relationship with his mother, and how their openness helped when she initially became unwell:

She's definitely there for emotional support like, the first time I went to visit her in hospital we both just sat there and cried, it was when we hadn't seen each other for like a week. And she was in hospital, and she said, ever since I was born she's told me that I can talk to her about everything anything... so any time I need to say anything to her, we just have quite an open like, we're best friends like, we talk about anything.

Martin (I1)

Chapter Nine considered his initial frustrations about his caring role, but also his irritation with his mother due to his feeling that she was doing too much. This had resulted in an increasingly tense relationship and Martin becoming upset:

The other day I had a like a mental breakdown because of all the stress... I got really annoyed and I accidentally shouted at her, and she was like 'What's wrong', and then we just had a long talk and then my nan came over and my nan gave me a hug as well.

Martin (I2)

The argument appeared to have the effect of bringing his family closer together. His mother and grandmother had had a strained relationship since she had become ill, resulting in him rarely seeing his grandmother, but he started to see her more:

I don't see my nan like every single time, like I've seen her quite a bit more since I've got into painting like these little figures and stuff and it's been fun, because my nan's really into painting and stuff... My nan pops down like quite a bit now because obviously like, she brings things down for me like a palette or something.

Martin (I3)

In addition, his mother's partner Sam did not live locally but would stay every weekend. Sam recognised Martin's caring, and he would provide support when there, reducing Martin's responsibilities:

Sam always comes down and I guess that's showing appreciation for what I do because he always helps my mum and gives me a break and stuff. I always, I still do have to help her but nowhere as much as I would if he wasn't there.

Martin (I1)

At the time of Martin's final interview his relationship with his mother was strong. This was partly due to their improved communication, and they were discussing the help that she needed and any issues that Martin had. This helped to make his caring as easy as possible:

It's not that bad... she does ask me to do a bunch of things now but we have had a couple of chats about it and stuff and she's just going to ask me like one at a time.

Martin (I3)

Despite these concerns, Chapter Nine considered how her mother's condition improved over time, and this enabled her to take on parts of her previous parenting role:

She does actually a quite good job of what state she's in at the moment... She makes sure our uniform's ironed, because she likes the ironing... she's getting back into cooking now. She's finally started making her own cup of teas, she's trying to, she's doing little washing, trying to do it on herself... She's helping me with my mental health, because I'm not the best person with my mental health.

Thea (I1)

10.2.2 *Young carers as part of family caring units*

This chapter has highlighted the positive nature of most relationships between the young carer and care receiver, with most young carers feeling appreciated for the support that they provided, as well as cared for when the care receiver was also their parent. At the same time the results highlighted the rare occasions when the relationship was more problematic, and the substantial negative impacts of a young carer not feeling valued.

Presence of a family caring unit was also key to perceptions of appreciation, though the potential for this unit was dependent on family size. Four of the participants' families (Angela, Harry and Patrick, plus Kirsty at the time that she was a young carer) had two parents in the household, while the remainder lived in single parent households and cared for that parent. This included Thea, Lyra and Lucy who formed a caring unit together, Sophie who had a younger sister, and Martin and Richard who lived alone with their mothers. Relatives and partners outside the household were particularly important in these smaller households.

Harry and Patrick's routines in the context of wider family provision have already been reported in Chapter Nine. This was due to the constant supervision needs of their care receivers, resulting in their routines being set within the wider family provision and characterised by substantial amounts of care during the week and fewer responsibilities at the weekend. Harry's routine appeared manageable while Patrick's was more negative, potentially due to the extensive night-time monitoring.

Considering the remaining participants, Thea, Lyra and Lucy formed a caring unit together. Their unit had changed over time with Thea and Lyra initially dividing most of the responsibilities due to Lucy's younger age. Age remained a key factor in who took on what tasks:

I wasn't able to kind of do a lot of the stuff. Mum didn't want me to do the dishes or cooking because like she might think I'll burn myself. So I didn't do a lot of things until I turned nine or ten.

Lucy (I1)

I'll say [Thea] like will do... like the most responsible I think... So Thea will do the ironing, so we don't burn ourselves. I'll do the cleaning, like washing and the clothes. Lyra will like tidy up a lot more, and like bring it out onto the line, make sure it's all dry and bring it back, fold it. Then Thea will like take it up to the rooms, put it on our beds, then we put it in the drawers.

Lucy (I1)

The sisters saw the benefits of them working together and Thea felt that her sisters would struggle to provide care alone, something that was reinforced by Lucy:

Because my sisters, I'm not saying they're not mature enough, but then yeah, I don't think they'd be mature enough to look after her, because they're still a little bit younger.

Thea (I2)

If I was the only child I don't know what, I don't know how I could handle cooking, cleaning and getting myself ready in the morning all on my own.

Lucy (I1)

The caring unit changed again during the research and, at the time of Thea's second interview, she was increasingly focused on her GCSE exams. While this was partly due to their mother's improving condition and decreasing needs, Lyra and Lucy had been taking on additional responsibilities, therefore allowing Thea to do less:

That's what my other sisters do, they take over the part of me doing, because I'm trying to get the best GCSEs, so I get a nice job when I can, I do the dishes, I help them with the washing, the drying, sorting out the cats, our bedrooms, just keeping everything on top of everything, so it's not too cluttered, it's all clean.

Thea (I2)

The importance of relatives in smaller households

Relatives were particularly important in small families and Insert 10.2 highlights the importance of Martin's grandmother and his mother's partner in easing his responsibilities. This was similar for Sophie who had a younger sister but was her mother's sole carer in the home. Her grandparents lived nearby and, having previously cared for her mother, they would help during emergencies and support hospital appointments on school days:

My nan will ring the hospital about appointments, or me and my nan will, sort out my sister, like if my nans in hospital or something, my bamps will pick up my sister. If I can't handle my mum's hypo my nan will come round to help. My nan goes with my mum to appointments as well.

Sophie (I1)

Chapter Nine highlighted the mixed impacts of Sophie's caring. She reported benefits including friendliness, maturity and domestic skills, and felt that the support and appreciation of her family increased her confidence in her caring ability. This confidence then boosted the initial benefits of caring further:

I've picked un-friendly... But I don't think I am un-friendly because I get a lot of support from like my family and friends.

Sophie (I2)

If you have to care for someone then you are gonna be quite skilled in how you care for them... And then I also feel like it's support as well, because if you're not supported by people you might get really down about it and think that you're really bad at it if something goes wrong, you might think it's your fault even though it isn't.

Sophie (I2)

At the time of his first interview Richard was a sole carer, but his mother had a new partner, Jeremy, by the second meeting. While Chapter Nine considered his mother's substance misuse and unhealthy relationships as separate adversities to his caring, Richard viewed Jeremy as a positive influence in terms of support. His presence contributed to his mother's improving health and he was also providing care, with this reducing Richard's responsibilities:

The nature of the relationship has helped out tremendously, plus he does take a few things on. I do the shopping still but I do that by my choice because I ask to go shopping, and also because it helps me with, you know, staying healthy.

Richard (I2)

Dysfunctional caring units

While most participants were part of functioning family caring units this was increasingly not the case for Angela. She reported that her responsibilities were generally manageable, enabling her to fit caring around school and social activities when planned in advance, but at times Angela felt that she was increasingly becoming her mother's main carer. This was partly due to her brother's increasing independence, but Angela questioned the willingness of her brother and father to provide care:

[Father] doesn't do a lot to be honest. He's a bit lazy and he gets frustrated. He doesn't like to do it so I usually end up doing it.

Angela (I1)

P: My dad and my brother, they take me for granted to be honest in a way, because if I wasn't there they'd have to do a way lot more.

R: Do you think they recognise that?

P: No.

Angela (I1)

This led to Angela feeling undervalued at times and other relatives were particularly important in supporting her mother and giving Angela respite:

I've got people that support me so it's like, I think 'Oh I don't want to stay home this weekend' and my nan's like 'It's fine I'll take your mum out somewhere'. I'm like 'Yes I can go out see 'Far From Home', you know, that sort of thing.

Angela (I2)

10.3 Self-disclosure of young carer status

The first part of this chapter has considered family support. There was evidence of support for most participants due to positive relationships with the care receiver and other family taking on caring responsibilities, and this served to mitigate negative

impacts and increase benefits of caring. However, for the minority of participants who felt unappreciated and in particular had difficult relationships with the care receiver, this moderated the effects of caregiving negatively.

While all participants were known as young carers within the immediate household and usually the wider family, there was variation in awareness beyond this point. This section explores the motivations to disclose their status to different sources of support, with the decision to inform services and neighbours often made by the wider family, while the child decided whether to confide in friends. Following that the remainder of the chapter splits into two sections, the first concerning their experiences of accessing support once disclosed. The second part concerns the ability of services to identify those who do not disclose.

10.3.1 Motivations behind the self-disclosure decision

Levels of disclosure varied amongst the participants, and most were selective in who they told in order to balance the need for support with their wish for privacy. For example, Thea explained her family's decision to inform their schools and social services, but she was also personally protective of herself and them. This was partly due to her experiences of preventing Lucy from being bullied but also her bereavement and perceived abandonment that was explored in Chapter Nine:

My family had to tell the school what was going on the first time. Because they needed to change all the details of our addresses, and purely because if any, if we was depressed they needed to know, and just so we could get the support we needed in schools as well.

Thea (I1)

I'm protecting myself, mainly my family, my sisters come first, like if they have a problem, like when Lucy first started school, she started getting bullied, so I sorted that straight out, and she hasn't been bullied since...

Thea (I2)

Martin was also selective about telling people, due to a previous experience of dealing with false rumours about his mother in school:

A girlfriend at the time when I was in [school name], told me that someone in this school had been going round telling people that my mum had cancer, and that my mum was dying and that was fun.

Martin (I2)

There was one exception with Harry's family disclosing his status to services, and Harry himself being open about his caring to his friends. He attributed this to a sense of community that he benefitted from, and that is considered as a part of his caring identity in Chapter Eleven:

My friends know, because they know I've got, my younger brother's autistic. Obviously you've got the young carers group who know I'm a young carer because I go. Family members know. School knows about it, but they don't really do anything about it as such.

Harry (I1)

Privacy and normality in young carer families

The main reason for young carers and their families not to disclose their status was privacy. As discussed in Insert 10.1, this was most extreme in Patrick's family who were keen to be self-reliant to the extent of not seeking the support of relatives beyond the immediate household. Patrick largely shared their view, and with the exception of some friends who knew but were not confided in, he was completely unidentified as a young carer:

We rely on ourselves to keep us going because they [wider family] have their own lives that they should worry about rather than worrying about us.

Patrick (I1)

While Sophie had told a few friends, her mother was keen not to attract attention and, as a result, they had not informed services:

My mum doesn't want me getting like, a lot of attention for doing these things. Like, not that it's bad or anything, but like if, like if I come in late and people just ask why I come in late.

Sophie (I2)

However, privacy was not the only reason for not seeking support. Sophie and Kirsty highlighted how they had not initially realised that they were young carers due to their perception of caring as part of their normal life. Even when Kirsty realised that she was a young carer it did not seem noteworthy enough to inform people about:

Sometimes I'm just like 'Oh it's normal'... then sometimes it's completely the other way and I'm like 'Most people don't speak for their mum, or tell their mum what other people are saying to her, like they can do that for themselves'.
Sophie (I1)

Half the time I didn't really look at it as being a young carer, I just, you know, it was, it was my way of life. And as a result it, you know, the way I saw it, it wasn't anything special.
Kirsty (I2)

10.3.2 *Self-disclosure to trusted individuals*

The reluctance of participants and their families to be widely known as young carers led to most families seeking a balance between maintaining privacy and satisfying the need for support. Self-disclosure to trusted individuals was one way to achieve this balance, and while all the participants were at least known to friends as a young carer, seven had disclosed their status to individuals. Lucy, Thea and Martin in particular had close friends that they talked to about being a young carer:

I tell my friends, like only my close friends, just so I have someone to talk to.
Lucy (I1)

Thea had admitted to being highly protective of her family and she would develop a relationship over a significant period of time before deciding to confide in the person. While this wider protectiveness maintained her privacy, she felt it gave people the wrong impression about her:

I have to properly trust a person like to tell them about my young caring role. I'm not just going to go out and be like 'Oh yeah I'm a young carer, my mum's bipolar'.
Thea (I1)

I come across as very intimidating. I do have a big mouth on me, I do like to shout at people, I can stand up for myself, but then when people actually finally get to know me, I'm actually a really nice person, and I'm very open and I care about a lot of people and I was speaking to some girl before and she just joined my school and I scared her when she first joined, because of the way I am. She got to know me, and she went, we're good friends now.

Thea (I2)

Despite having people to talk to, most participants acknowledged that their friends would struggle to give useful advice unless they also had experience of caring. Sophie in particular had found her friends' lack of knowledge and understanding frustrating. They tended to focus on her mother's deafness rather than her more serious diabetes that is often seen as an invisible illness, and therefore would underestimate her role. As a result, she admitted at times to being reluctant to talk to them (Insert 10.1).

However, many still found the support of friends beneficial with Harry appreciating people who listened, and Angela finding the differing perspectives useful:

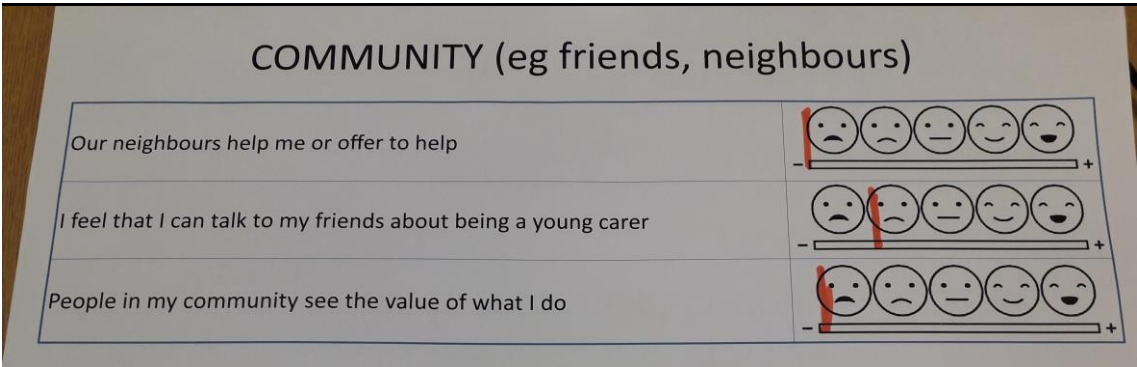
It feels good to talk to someone about things going on at home with like my brother and stuff... I don't really get advice from them, it's just so they can listen to like what's going on and stuff like that... they don't really say too much about it, but you know, they let me talk to them.

Harry (I1)

When I'm annoyed... it's good because I get an outside opinion that can change my perspectives on things, so sometimes I do.

Angela (I1)

Figure 10.1 Sophie's experience of talking to her friends about caring



They think 'Oh yeah you should just help your mum', and I don't think they realise it is a difference between like chores and stopping her dying.

Sophie (I1)

Insert 10.3 considers Martin's community support and how informal support sources are not always stable. He talked about having a close relationship with his friend Joel whose support was particularly useful when Martin first became a young carer and was struggling with the role, but their relationship fluctuated over time. He was also receiving support from neighbours though this also deteriorated over time. With the addition of support within his household and extended family, Martin was accessing a complex network of informal support rather than seeking formal assistance. While each support source varied over time, Martin felt that it largely worked for him.

Like Martin, Lyra's family had informed particular neighbours. Once informed, Lyra and Lucy felt able to talk to them, and benefitted from doing so (Figure 10.3).

10.3.3 Self-disclosure to access formal interventions

While young carers and their families disclosed their status to friends and neighbours on the basis of a trusting relationship, a second motivation concerned the five young carers who were accessing young carer projects and also more likely to have disclosed their status to health services and their schools. This disclosure to services was in order to access support that their families recognised as being needed.

Consideration of service support begins with young carer projects, which for four of the five participants connected to social services. Self-disclosure to schools and the resulting support is also considered. No participants had disclosed their status to medical professionals, though the next section on young carer identification by services considers health authorities in detail.

Young carer projects and the importance of active support

Four of the five young carer project users (Harry, Thea, Lyra and Lucy) were accessing the same service, while Richard lived in a different area and attended a separate project. The families of all five participants had disclosed their status in order for them to access the service, but there were differences in their motivations and the type of project that they chose to access.

Insert 10.3 Longitudinal Change 5: Martin's informal support

During his first interview Martin highlighted the support of his neighbours. His mother had informed them, and they had helped when she was in hospital:

I have really friendly neighbours and I do talk to them and whenever I see them... So we just normally have like a little chat, about how my mum's doing. They don't know everything, but my mums like, kind of told them about like, kind of what's happened, because like when my mum first came home Louise was outside and she was like 'Oh my god what happened?'.

Martin (I1)

Well they used to like, there they, like I said they used to come and take our bins out and stuff, so they definitely did offer to help and they did help a lot.

Martin (I1)

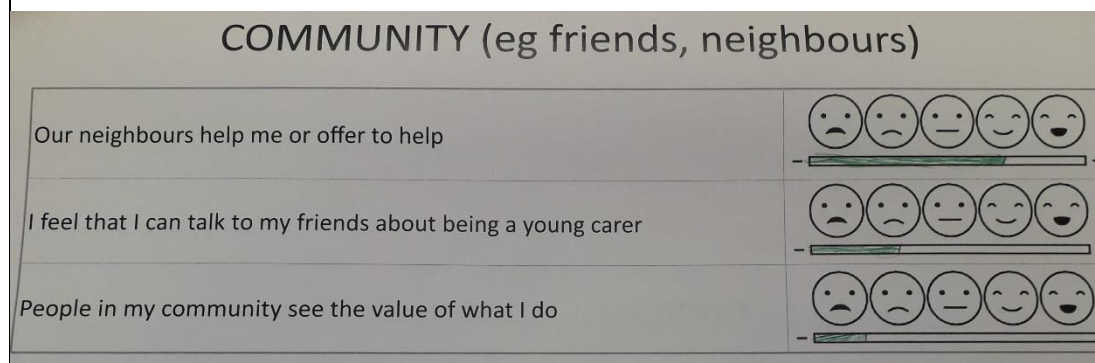
However, this relationship had unexpectedly faltered by the second interview and Martin was unsure why. Their relationship had not improved at the time of Martin's final interview:

For some reason they just abruptly stopped... I went over to take their dogs over, over the park for them, one day... I was like 'Do you want me to come over tomorrow?' and she was like 'Oh yeah that'd be nice', and when I went over the next day they didn't answer the door. I did that for a couple of days and then my mum was like 'Go and ask the neighbours if they want you to take the dogs out', and I was like 'Mum, I'm not doing it again'... I've seen them a couple of times but we haven't really mentioned it.

Martin (I2)

Martin was wary of telling lots of friends but had developed a close relationship with Joel. Joel's family had looked after him when his mother was initially hospitalised and, despite his wariness, Martin found him useful to talk to (Figure 10.2):

Figure 10.2 Martin's informal support from friends and neighbours, at the time of Interview One.



I kind of talk to [Joel]. He's my best friend and when something goes wrong I always know that I can talk to him and stuff. Like when me and my mum have an argument I... speak to him and stuff and he's very supportive.

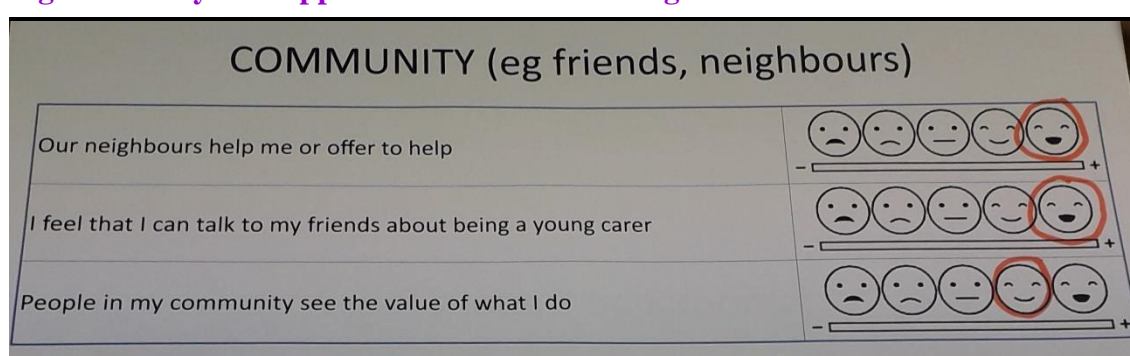
Martin (I1)

Their relationship also varied over time, and at the time of the third interview Martin and Joel had recently fallen out for a week. Martin tended to blame himself when he fell out with people and missed the support, but their friendship had been restored:

Well I've got a very guilty conscience. So when I do something wrong and then, we sort of have an argument... I'm just like I hope we talk again and stuff like that and I just overthink things a lot. My mum tends to do that a lot as well and, what's it called, it just makes me really down when we're not talking, like me and Joel didn't speak for like a week.

Martin (I3)

Figure 10.3 Lyra's support from friends and neighbours



Two of my neighbours know... they ask how my day is, like my next-door neighbour, like they grow stuff so they just like, they're nice in that they give us some stuff.

Lyra (I1)

Richard was predominantly interested in the social aspect of his project. His autism had resulted in a lack of friends and the project offered a chance to meet other children:

I was like ok, it would probably be best if I come here, talk to some more people who actually have few things in common with me, you know, helping their parents out... she's [young carer worker] helped me make a few more friends.

Richard (I2)

Richard's project was independent of the local authority, and this suited Richard and his family's privacy. The project did not assess the young carer needs of members and was predominantly a social group with this satisfying his reason for attending:

R: So some young carers have an assessment...

P: I haven't even, I haven't had anything like that.

Richard (I2)

The social aspect was also one element of a wider project attended by Harry, Thea, Lyra and Lucy, and they also appreciated the opportunity to meet other young carers. This was particularly important to Thea due to her protectiveness, and the project gave her the confidence to share her experiences with other children that were similar to her:

When I come to young carers, it like helps because other people are here... they understand like, because we all, not that we do the same thing but like it kind of is.

Lyra (I1)

Before I ever started, I was a bit of a shy person and it has given me the confidence to talk in front of people, to allow myself to actually find out who I am, to hear or talk to older people, younger people, people who have been in similar situations to me, people who have been completely different.

Thea (I2)

In contrast to the non-statutory service accessed by Richard, their project was joint run by the youth service and social services. Prior to joining all potential members had young carers assessments that gathered information about their home situation and caring responsibilities. Following the assessment young carers were invited to attend the project:

Sally our social worker now came in and did an assessment on us, see if we were eligible to be a young carer... We fill out questions like how much do we help out at home, do we like pay for any bills, do we help our carer, the person we care for in the shower. Just general questions... Yeah, we do it once or twice a year.

Thea (I1)

The assessment affected the support that was offered, and members received periodic check-ups that were individualised to them. Thea and Lyra's assessments also resulted in them being provided with appliances that reduced the potential for their mum to have accidents at home:

I think [support] is based on your assessment... they like ask me like questions about my brother and how I'm doing personally and stuff... I assume like other people, obviously they ask how they're doing and like if there's anything they can do to help.

Harry (I3)

She's developed really bad shakes, and the first time she came out, she had an accident with the kettle, she burnt all her hand. So when we first became young carers, we asked could we get a kettle which is more suitable for her and her shakes which we got, thankfully.

Thea (I2)

Thea highlighted a final element to their project, an ID card scheme for members to use in school when they were struggling with responsibilities at home:

They were just to hand out to teachers, if you've been late with your homework, because your caring roles, or being late to school, or you haven't got the right equipment or the right uniform, it's just show to them, 'I'm a young carer, I've got struggles at home, just don't have a go at me, or don't be like shouting at me in front of the class', that's pretty much what it is.

Thea (I2)

She was using her ID card regularly at the time of her first interview as her mother had recently been discharged from hospital and needed more support than usual. She used the card if she was late or had not completed her homework, and most teachers accepted the card when shown to them:

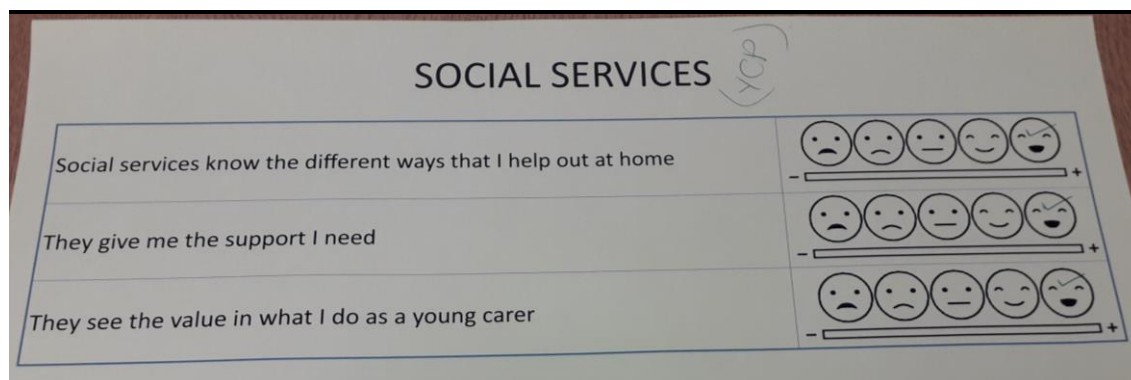
I use mine quite often to be honest... because my mum's recently come home I have to look after her a lot more, so my work gets behind a bit more, like my homework... I'm like 'I cannot do it, I could not do it last night'. I showed her, it's like 'Yeah that's fair enough, can you get it to me as soon as possible'.

Thea (I1)

The benefits of caring identified in Chapter Nine included positive feelings of usefulness and happiness from making a difference. Harry and Thea felt that the support offered by their young carers project increased their confidence, with this boosting further the initial benefits of caring (Figure 10.4). This was similar to the boost mentioned by Sophie when talking about the support of her family.

They also emphasised the active nature of the provision with the project workers engaging with them positively and interested in their lives. In considering potential improvements in the support offered by schools and health authorities, Harry and Thea often compared their provision to that offered by their young carers project:

Figure 10.4 Thea's perception of support from her young carers project



They've taught me to be more confident in myself, they've taught me new skills. They've taught me ways of how I can cope with it... I shouldn't be embarrassed about caring, which I'm not. I, honestly I love caring, it gives me a greater feeling.
Thea (I1)

They give me the support I need because, you know, they actually ask you like, you know, how's everything at home and stuff like that. And they see the value of what we do as a young carer, because you know, they actually talk to us, they give us support.

Harry (I1)

Young carer provision in schools

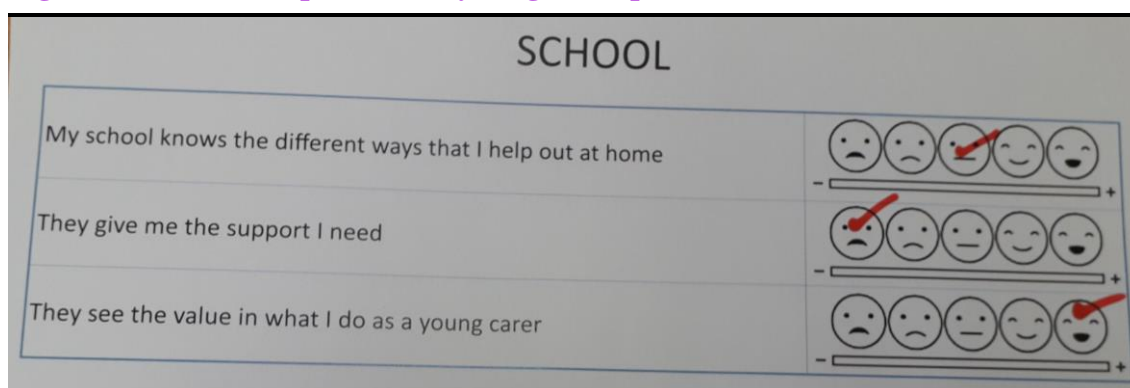
The families of four participants had informed their schools. Of these, Harry, Thea and Lyra were attending the same secondary school with Lucy transitioning from her primary school at the time of the research.

Harry reported that their school maintained a database of young carers and, according to Thea, they had designated a young carer lead. The lead's responsibilities included organising periodic support meetings with identified young carers, and informing teachers of young carers in their class, but Thea did not feel that this support had been running for some time (Figure 10.5):

They've got a list of people who they know who are young carers... and they don't really ask us too much about it... So they don't really know how we help out at home. So they don't really give any support to you, to people at my school.

Harry (I1)

Figure 10.5 Thea's experience of young carer provision in her school



We're supposed to have a person who's supposed to be there for us, when we have caring problems, but I haven't seen her in about two years. She said 'We're supposed to have a meeting every term', but she still hasn't done one, I was in year nine when I had the last one.

Thea (I2)

None of the four participants felt that their school knew the details of their caring. They had mixed opinions of whether this would be a good thing, with Lyra preferring them to have limited knowledge and to approach them if and when she needed help (Figure 10.6).

In contrast, Harry and Thea felt that greater knowledge of individual needs would improve provision, and that schools should be more proactive in supporting young carers if they expect young carers to engage with them. Thea in particular compared current school provision with the active support offered by young carer projects:

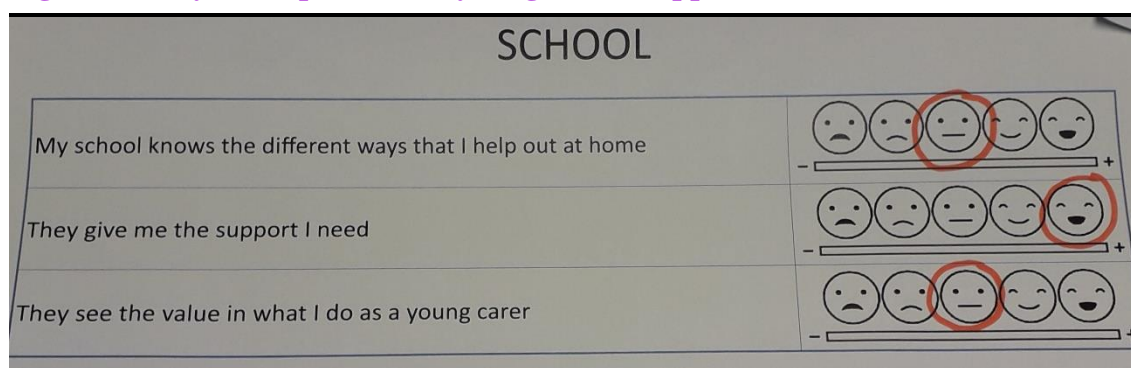
If you expect us to come to you, you should make an effort with us, because we don't know it, and she's supposed to be there, to be your own care supporter, but I haven't seen her in the new school at all.

Thea (I2)

School not as much, but the young carer project definitely because they understand what it's like for my difficulties. They understand me. They know me on a personal level... They've been speaking to me four or five years, so they know my difficulties, they know me as well. They know me at my good times, they know me at my bad times.

Thea (I1)

Figure 10.6 Lyra's experience of young carers support in her school



They know that I look after my mum and like, they, they, they kind, they know bits but they don't know 100% so I'm putting in the middle so they know and they don't... personally I don't feel that they need to know 100% what I do.

Lyra (I1)

This section has focused on disclosure of status as a joint decision with the family often deciding whether to inform services and neighbours while the child potentially tells their friends. No young carers in the sample had informed services themselves when their family had chosen not to, but there were instances where they sought support from individual teachers. This included Thea who would often sit with a teacher that she trusted on days when she was struggling:

If I ever have a breakdown in school I just go in... be like 'Oh I've had a bad day, I'm just going to sit in here'. They never really ask me a question. They ask me how am I, how's my mum, that's about it. I just don't talk to them.

Thea (I1)

Chapter Nine reported on the support that Kirsty was accessing from individual teachers following the death of her mother, but this had begun when she was still a young carer. She spoke retrospectively about this support and emphasised the importance of trust that was also key for some when informing particular friends and neighbours:

If my mum needed something or she was unwell, I had a couple of past teachers who... would be rallying round me, giving me that support I needed.

Kirsty (I1)

R: Why do you prefer having an individual person to a whole school?

P: I think it's just through sort of the, the one-on-one level of trust that can be built up.

Kirsty (I3)

10.4 Service identification of undisclosed young carers

The self-disclosure of young carer status is key to increasing awareness within services of individual young carers. Two main motivations for self-disclosure have been identified: the seeking of support of trusted individuals; and the recognition that the child needs formal support from services. At the same time this chapter has also highlighted how many remain reluctant to be identified, particularly by services.

Because of this reluctance to self-disclose status, services are increasingly expected to identify young carers, particularly those with more substantial responsibilities who are more likely to require support. However, while some are identified by specific professionals or as an indirect outcome of the care receiver accessing support, there was little evidence of services actively seeking to identify young carers. The section focuses on the barriers to identification and the opportunities missed by services, especially health services. At the same time the study highlights the experiences of one participant who was identified by health services and subsequently given the information and training that they needed, resulting in evidence of sizeable benefits.

10.4.1 Service identification of young carers

Three participants had been identified by health professionals. This included Richard who was known to his school due to his mother's substance misuse, and to the health service as a result of his mother accessing mental health support. However, while he was receiving school support for his autism, he chose not to access young carer support offered by mainstream services. Richard's reasoning was that medical professionals approved of his caring and therefore the support was not needed, but he also appeared to be guarded about services knowing further details. As a result, he was known to his school and the health services as a young carer but not receiving support:

They see the value of what I do. They do... I pick up a bit of a slack technically, or again, doing the shopping, a little bit of emotional support, and the GP and the nurses that come to see her. They agree with what I'm doing, they agree with what she's doing.

Richard (I2)

Things are just fine as it is, so is there any reason for them to know? I mean it's ok if they do, just, it won't change anything and I don't really need change, I'm doing well as it is.

Richard (I2)

Martin had also been recognised as a young carer by a doctor when accompanying his mother to a medical appointment. He was given the opportunity to go to a specific appointment and find out more about her illness but could not attend due to it being on a school day. No further opportunities to meet with the doctor were arranged:

I was really gutted because I wanted to go and speak to this lady cos I didn't know anything at this point, and I just wanted to know what was going on.

Martin (I1)

The third participant, Sophie, had been recently identified as a young carer with regular medical responsibilities by her mother's diabetic nurse. This was despite her family's privacy that was considered earlier in this chapter, and prior to this identification she had not been involved in meetings.

10.4.2 The benefits of receiving information and training

Once Sophie had been recognised, the nurse involved her more in conversations, demonstrated how to do particular tasks and recognised when something was done well:

I think it's my mum and my nan [were informing Sophie before], but then with all this new stuff like carb counting and the pump that has been the nurse.

Sophie (I1)

If I help her with carb counting... then she does always say like 'Well done for getting it back up' cos like my mum's got this app on her phone that tells her her blood sugars and then I get it as well, and yeah she always goes, like 'Well done for doing that' and stuff, because I often have to like, coach my mum in to doing things.

Sophie (I1)

While this identification led to initial benefits in terms of information and involvement, this was followed by a more substantial change for Sophie but also for her mother. The installation of a new diabetic pump helped to improve her mother's quality of life, with

this also reducing her needs. In addition, Sophie was fully informed and trained by the diabetic nurse in how to use the new equipment. Insert 10.4 details the change in their lives, from the first interview when the decision had been made but the pump not yet fitted, through the second when it has been recently fitted with some initial issues, to the third when they had become accustomed to the new equipment. The insert considers in more detail the difference that it made to Sophie and her family.

10.4.3 Gaps in health service support

While Richard, Martin and Sophie were identified by the health authorities with Sophie subsequently accessed support, other participants regularly accompanied the care receiver to medical appointments. While they did not tell the medical professional that they were a young carer, they felt that they should have been recognised as young carers and involved more in appointments. Kirsty and Patrick in particular reported wanting to understand what was being discussed and feeling able to contribute, but felt unvalued and overlooked:

When I was there I'd do my best to kind of speak up, like get a grip of what was going on but, for the, for the sole reason that I was under 18 I was just overlooked.

Kirsty (I2)

What it's like from the day to day is something that I can contribute to... but then you just sit there because they don't ask you.

Patrick (I2)

While most participants were able to attend appointments, this was not the case for Thea and her sisters. They were not allowed in the hospital where their mother was sectioned because of her illness and their age, and Thea also reported that medical professionals would not give her information about her mother's condition:

P: I don't talk to my mum's doctors.

R: You don't go to hospital?

P: No, I'm not allowed, because apparently I'm not old enough to, when it all happened a doctor told me I'm not old enough to understand what's going on.

Thea (I1)

Insert 10.4 Longitudinal Change 6: Sophie's experience of the new diabetic pump installation and being trained to use it

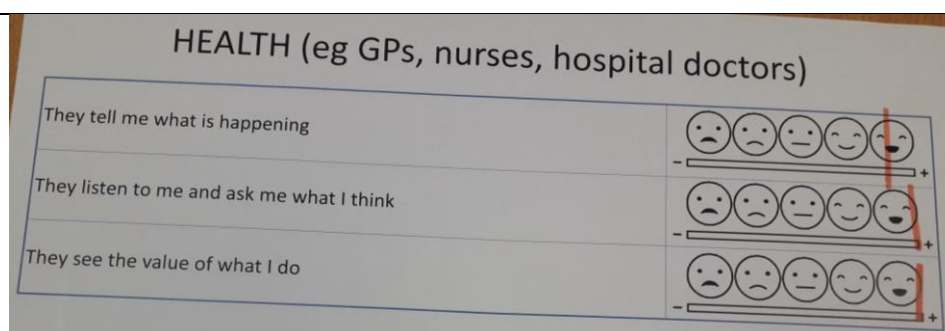
The decision to install a new pump was taken just before Sophie's first interview. It was intended that the pump would stabilise her mother's blood sugar and reduce Sophie's night-time caring. She shared how she had been involved in the decision:

They ask if I think it's a good idea, and then I say if it's practical or not really, because my mum might want it, but like if she can't practically have it... with her pump I was like 'Yeah, I think that's a good idea.

Sophie (I1)

Sophie talked in her first interview about expecting to be taught how to use the pump, and it was clear in the second interview that the nurse had worked hard to train them prior to the installation (Figure 10.7). As a result, Sophie had a detailed understanding of the equipment.

Figure 10.7 Sophie's perception of support from the health service



My mum got a book as well on like how to use it... I read it... then I went with my mum to the nurse's house and she was like explaining everything more.

Sophie (I2)

There were however initial problems with the equipment, and Sophie was concerned that the expected benefits would not happen:

When she like turned on her pump and it did it itself, on automatic, loads of things were going wrong, and her blood sugars were like, really like, really high, and it was cos all like the needles that she was trying to use were really like dodgy, and they were going in and they were bending, so the insulin wasn't going in properly, it was leaking out... They thought they'd found on that worked and then we went home and she woke up in the morning and it was all over the bed stuff and then that took ages to get sorted.

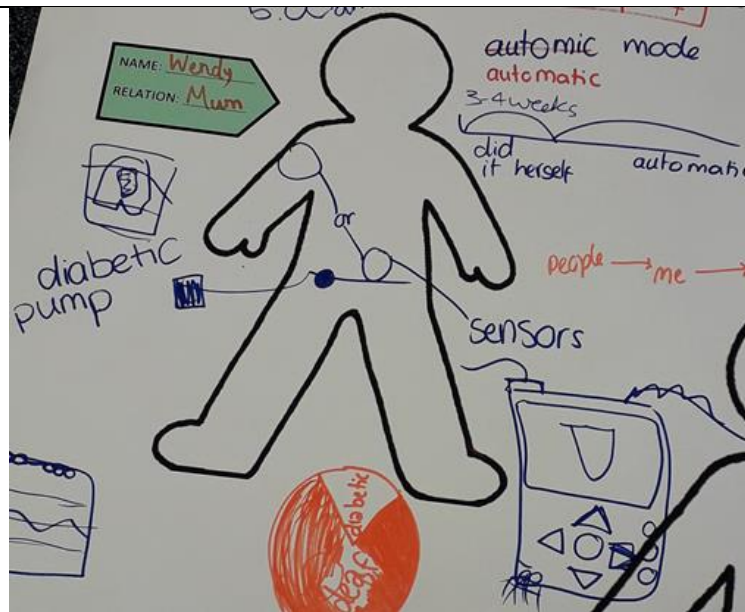
Sophie (I2)

These initial problems had been resolved by the third interview and, while it was a learning process, Sophie had become increasingly knowledgeable and confident in using the new equipment (Figure 10.8):

I don't find it that difficult anymore but at times it does get quite confusing... this like, long bit of speech thing and you had to click down and then click another button to say you'd read it... when it finally got down to the bottom it was like 'Calibrate' and then 'Give Bolus'. I ask my mum, 'What do I need to do?' and she'll like tell me, just do this, do that, and then she'll like explain it to me so that I know for like future reference.

Sophie (I3)

Figure 10.8 Sophie's knowledge of her mother's new diabetic pump



On her pump there's like a little screen, and it will say like where her blood sugars are... But they're sensors so ... [If] her blood sugars go low, then it will... recommend an amount of Bolus to put in, like the other day she had a hypo and it asked her if she wanted to insert like 1.1 units of Bolus.

Sophie (I2)

The installation of the pump stabilised her mother's blood sugar levels and improved her sleep. This reduced Sophie responsibilities as she was no longer monitoring her every night. Instead of going to bed after midnight every night and sometimes as late as 4am, Sophie was in bed several hours earlier every night, and on occasion sleeping all night:

I go to bed really early, because sometimes in the night my mum's pump goes off but obviously she can't hear it, but it will keep going and going until it's like looked at.

Sophie (I3)

Because I got like a full night sleep... I wake up in the morning less tired but then I find it really hard to get out of bed! [laughs].

Sophie (I3)

In addition, the pump also replaced the need for injections. In addition to reducing a risky responsibility, Sophie was spending less time caring during the day, resulting in a healthier balance of caring, schoolwork and hobbies:

It's normally quicker to solve now... I got home and my mum was having like problems so then I had to help her, and then we had to get my little sister from school and then go back home, get ready for dance, go to dance and then I went from dance straight to rugby, and then home, and then I had to do coursework.

Sophie (I3)

A lack of information about the care receiver's illness and how to best provide care was an issue for several participants who felt that it would improve the quality of their care. Thea argued this by comparing her knowledge at the two times her mother was discharged from hospital in 2015 and 2019. She felt better informed and able to provide the relevant care on the second time as a result of her previous experiences, and reflected that some of the substantial caring responsibilities undertaken the first time may not have been necessary:

He's my brother, I want to know what's like going on with him and stuff, and since I'm a young carer I think if I know it'll, I can like make changes or do different things, or I don't know, whatever, depending on what it was really. So I can do different things with like what they tell me.

Harry (I1)

The first time, it was keeping her company... so we was always with her twenty-four seven, but then this time we know what's happening and we don't, we don't keep on top it as much because we know she's independent.

Thea (I2)

Alternative sources of medical information

In the absence of information from professionals, most participants relied on information from the care receiver and other family members. This included Kirsty who had been shown by her parents how to treat a form of epilepsy called absence seizures, and this enabled her to remain calm when needed:

Her eyes would sort of glaze over and the way of getting out of that was just like squeezing her earlobes really tightly... there wasn't pretty much else to it... I can't remember if it was mum or dad or both told me about that. Like it was basically directed by one of them, so in the event of this do this.

Kirsty (I3)

I was quite cool about it so you know, I think, I think if I hadn't had that information especially the first time that it happened I would've just had like this great fear instilled in me and may not have been able to do much about it.

Kirsty (I3)

While the information on absence seizures was useful, Kirsty found the medical information from her father overly technical. In contrast, Richard felt his mother was best suited to informing him due to her knowledge and understanding of his autism:

I wasn't told anything by any sort of medical professional or anything, it all came as, as... slightly technical as possible for my dad.

Kirsty (I3)

They don't tell me at all, but they tell my mum, which in turn tells me... Well, my mum has a better way of phrasing things to me.

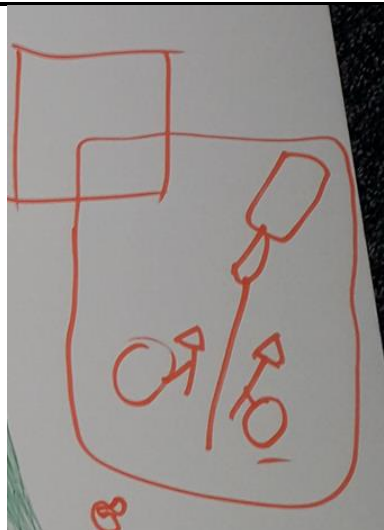
Richard (I2)

Martin's mother often talked to him about her illness, and like Sophie understanding of her mother's diabetes, he had developed a detailed understanding of aplastic anaemia and his mother's treatment (Figure 10.9):

I can talk to my mum about it and stuff. So it's not just like, talking gibberish to me so I can actually speak to her and I actually know what's going on with her, like she'll say that her nukes are down and you're like, a couple of years ago I would've been like 'What's a nuke?'.

Martin (I3)

Figure 10.9 Martin's understanding of his mother's treatment



[Solaris is] a liquid that gets put into her veins... Red blood cells, they're fighting each other but basically the Solaris, it comes down from the drip and from the bag, through the vein and basically just puts a wall between them.

Martin (I2)

There was however a risk of incorrect information from family members. Martin gave an example of a minor misunderstanding by his mother but, as a result, he preferred to be informed by medical professionals:

When she was in hospital she told me her immune system was really low... so that she couldn't leave her room... one of the nurses one day said why don't you go out and she said I just thought I can't and then she found out.

Martin (I3)

I expect to see someone who is a professional and knows exactly what's going on than someone who's going through it and doesn't know like everything about it.

Martin (I3)

10.5 Chapter summary

This second qualitative results chapter has considered the support that participants received from family and, depending on self-disclosure and identification, friends, neighbours and services.

Lyra, Lucy, Harry and Thea were accessing multiple informal sources but also formal interventions for support. While they had highlighted issues in the support offered by their schools and health services, their young carers project alongside the informal support sources helped to moderate the effects of their caring responsibilities.

Martin's support network was complex but also completely informal, with him accessing support from his mother, extended family, friends and neighbours. His experiences indicated the potential issue of a reliance on informal support sources alone, though Martin viewed these variations in informal support as temporary and felt that he had the overall support that he needed.

Participants accessing fewer sources of predominantly informal support still reported satisfaction and many did not feel they needed formal support. This included Angela who, despite taking on increasing responsibilities in comparison to other members of her immediate family, felt she had adequate support from her mother as the care receiver, relatives and friends. The same was true for Richard who was known to

multiple services but selective in accessing support due to privacy concerns. Sophie and her family were also reluctant for her to be known as a young carer but, once identified by the health service her family went on to access training, information and support. This made a real difference to their lives and demonstrated the potential difference that the health authorities can make to young carers and their families.

While nine of the ten participants accessed differing amounts of formal and informal support, enabling some moderation of the impacts of caring, Patrick was not accessing any support despite experiencing substantial negative impacts as a result of his higher-level responsibilities. This was largely due to the privacy of him and his family and served to exacerbate the impacts of his caring.

Chapter Eleven is the final results chapter and considers the development of a caring identity. This identity is informed by three factors. The first is control over the caring role as reported in Chapter Nine, and the second is support that was the focus of this chapter. The final factor, perception of choice, is introduced next chapter. These three factors affect whether the identity is based on a positive or negative perception of caring.

Chapter Eleven

Identity and self-perception of the caring role

The two previous qualitative results chapters each considered a domain from the realist model of young carers' mental health and psychosocial wellbeing. Chapter Nine focused on the *caring responsibilities* and the contextual factors that affect control of the role, and Chapter Ten concerned how *support* can moderate the initial caring impacts.

This final results chapter relates to the third domain and concerns the caring *identity*. This identity is informed by three factors, the first two of which were the central themes of Chapters Nine and Ten. The third factor, perception of choice to be a young carer is considered first, before looking at how the nature of the caring identity is affected by the three factors. When a young carer has control due to their responsibilities being manageable, or when more problematic responsibilities are mitigated by positive support, young carers are more likely to develop a positive perception of themselves as a young carer and to value the role. In contrast, if responsibilities are problematic but support either absent or of a poor quality, young carers were more likely to develop a negative identity.

This is used as the basis to explore the caring identities of the ten young carers in this study. In addition, the chapter considers the loss of Kirsty's caring identity following the death of her mother who she had cared for. While closely related to her being a young carer, this is considered as a separate additional adversity that was affecting her mental health.

11.1 Perception of choice in the caring role

Participants perceived their choice to be young carers in different ways. Some perceived a complete lack of choice, with two participants describing themselves as

being born as young carers. Others recognised an element of choice, though it involved accepting that them not providing care would impact the care receiver negatively, something that many could not do. In addition, choice was further complicated by participants perceiving it as not a single decision, but as an ongoing negotiation over time and in different circumstances.

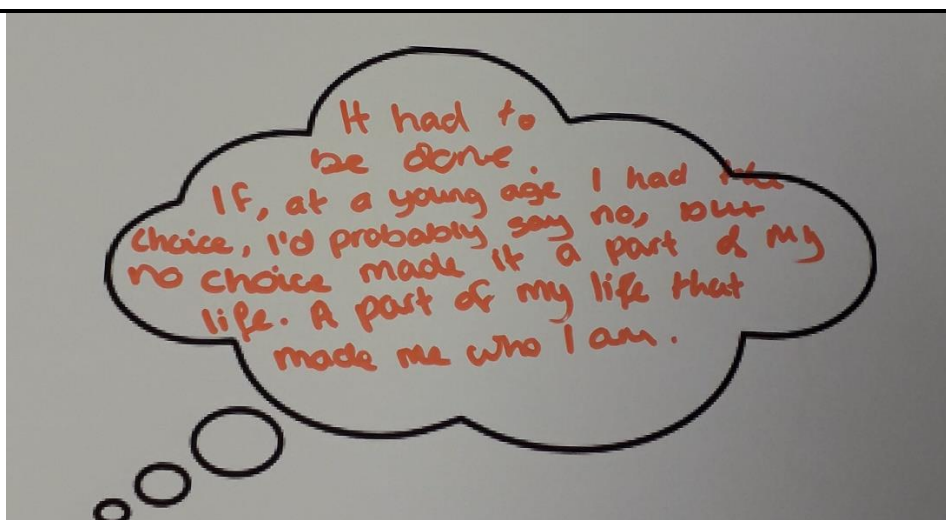
11.1.1 Absence of choice amongst young carers

Kirsty, Patrick and Angela felt strongly that they had been born as carers with no choice. Despite this, they viewed their caring differently with Kirsty viewing it as a vocation that she had been pleased to have (Figure 11.1) prior to the death of her mother. In contrast, Patrick was expecting to continue caring for his sister Sara into adulthood and eventually become her main carer. He did not view his caring positively but as something that he had come to accept:

I don't think it's a choice I think we're born into it and so we just have to deal with it and then after a while just get used to it... She's always going to need help, I'm always going to have to try and keep looking after her because it'll get to a point where there is no one else.

Patrick (I1)

Figure 11.1 Kirsty equated caring to a vocation that she was born into



I guess I was essentially born a carer... I wouldn't say choice, I'd say vocation... it had to be done. You know, there was no sort of choice about it I had to do it.

Kirsty (I1)

11.1.2 *Caring as an ongoing decision*

While Patrick and Kirsty had been carers for as long as they could remember, Angela had become a carer later in her childhood. Like them she felt that she had little choice over the provision of care but differentiated between what she saw as essential care and the optional companionship that she chose to provide. She shared her experiences of neither hating nor liking caring but, like Patrick, becoming used to it over time:

Feeding her, when she can't feed herself, helping her up the stairs, making sure she's got like drinks and stuff, helping her to the toilet, that sort of stuff. And then like, I don't need to do this stuff... taking her shoes off, keeping her company downstairs.

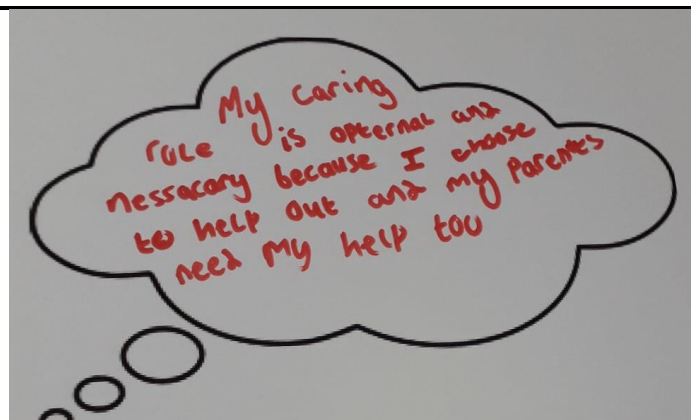
Angela (I2)

I didn't hate it then and I obviously didn't like it, I mean I've kind of become more used to it as time's gone on, ... I don't like it more now but I don't hate it as much now.

Angela (I1)

While Angela differentiated between essential and optional responsibilities, Harry and Richard reflected on how their choice changed over time. Harry shared his memories of offering to care for his brother as a young child and felt strongly that it had been his choice. At the same time but this help had become increasingly necessary due to his parent's other commitments (Figure 11.2).

Figure 11.2 Harry's view of his caring as optional but increasingly necessary



I think it's optional and necessary as one, like my parents never told me I need to help out with my brother, I just started doing it on my own, like helping him with things like that. But I sometimes also think it's necessary as my parents aren't always able to do things with him.

Harry (I1)

Conversely, Richard felt he had greater choice at the time of the research due to his mother's health improving and her needs decreasing, compared to when she was misusing substances or going through the process of withdrawal. He was willing to continue providing reduced care but recognised there was less of an obligation.

I could easily just say 'I give up. You go and do everything yourself'. I could easily go and say that, and my mother probably would panic and she probably would have a go at me. Things would get a little difficult for a bit but she would get herself around it all.

Richard (I1)

11.1.3 *Choice in the context of the care receiver's life*

The remaining participants viewed the choice as not just about whether to provide care but if they were willing to accept that the care receiver could struggle more without their support. With most finding this unacceptable this severely limited the choice, and Martin in particular talked about the closeness of his relationship with his mother and his willingness to help:

I definitely got pushed into the deep end but I, I'd rather help than my mum struggle so yeah, I would say so. Like I don't think anyone would be happy with me if I said I don't want to help her any more... It's not really a choice but I'm happy to do it, I would never say 'I can't help you anymore'.

Martin (I1)

For some participants there were additional potential repercussions, with Thea feeling that her sisters would struggle to provide care alone, resulting in their mother going into long-term care (Figure 11.3):

My sisters, I'm not saying they're not mature enough, but then yeah, I don't think they'd be mature enough to look after her, because they're still a little bit younger.

Thea (I2)

Sophie also had stressed in her first interview the nature of her mother's diabetes and the potential repercussion that she could die without her support:

I feel like I have to, sometimes... Because sometimes my mum can't handle it on her own... with a hypo you have to, like if you don't get your blood sugars

you go into a coma, a diabetic coma then, most people don't recover out of them.

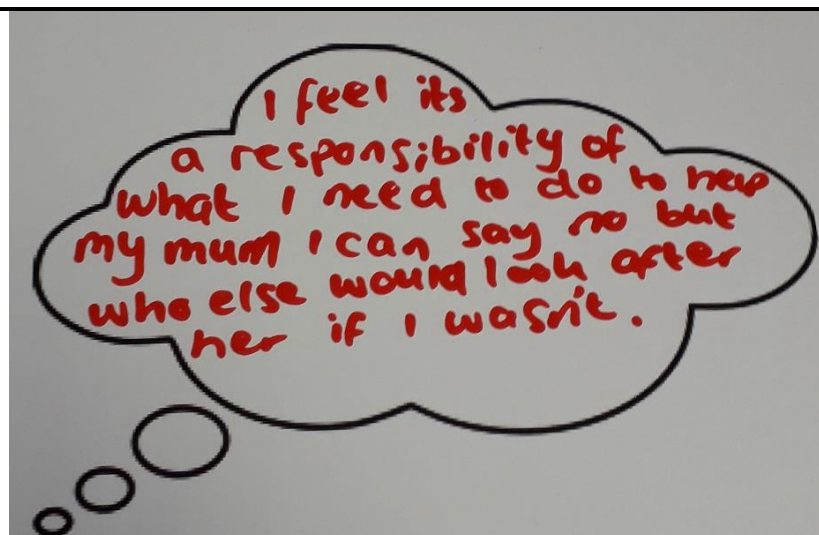
Sophie (I1)

However, this was before the subsequent installation of the new diabetic pump that was reported in Chapter Ten. While Sophie was still providing regular care, the new equipment reduced her mother's reliance, and evidenced how alternative support has the potential to improve the care receiver's life. While Sophie was keen to continue caring for her mother, her options had changed due to her mother's changed circumstances.

11.2 Identity, community and difference

The first part of this chapter focused on young carers' perception of choice. Many participants felt that they either had no choice, or that their unwillingness to accept the repercussions of them not providing care largely limited this decision. Along with the managing of responsibilities and access to support, choice informed the development of the caring identity that either aided or hampered their role.

Figure 11.3 Thea's perception of her choice to be a young carer



I don't think there is a choice, it's just purely a responsibility. Because if no one's going to look after my mum, then who is? I don't want some doctors medicating my mum again. Don't want them, I don't want other people, I don't want to be placed into a home. I want to be able to take that responsibility. So that's my mum, she's looked after me, she's not very well, it's my turn to look after her.

Thea (I1)

The remainder of the chapter frames the identity of the participants in the context of these factors. This begins with a focus on how a positive identity can be developed when responsibilities were manageable or support in place to mitigate the impacts of reduced control, and it is argued that eight of the ten participants had a positive caring identity. In contrast, when a young carer has reduced control over their caring or an absence of quality support, this has the potential to exacerbate the negative impacts of caring, resulting in a negative caring identity that affects how they see themselves as a carer. This was the case for Angela but particularly Patrick.

11.2.1 Development of a positive caring identity

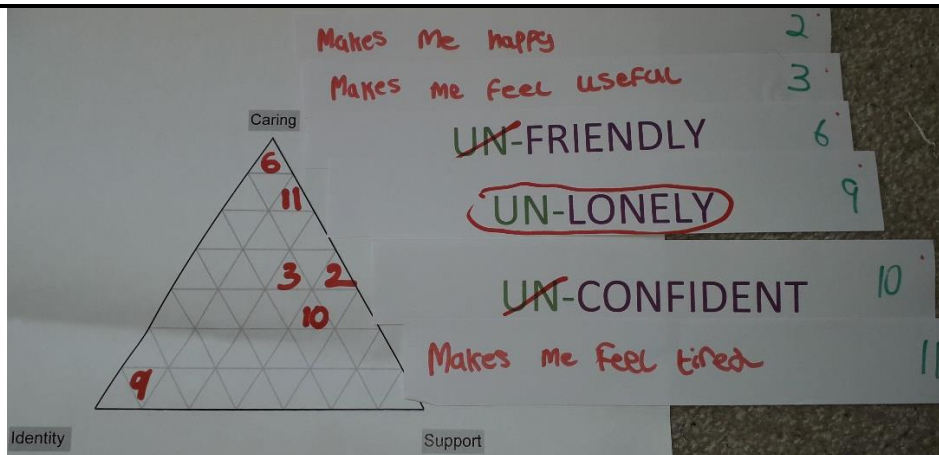
There was evidence that eight of the participants reported had a positive caring identity. This included Thea who felt that her identity had given her an emotional strength and maturity beyond the impacts of caring tasks alone. She recognised that she struggled at times with her mental health, with this partly due to her caring responsibilities but also the additional adversities of bereavement and feelings of abandonment that were reported in Chapter Nine. However, with the support of her young carers project she was able to develop a positive caring identity and valued her role:

It has given me maturity and responsibility to look after my sisters, to look after her. It's also given my own identity because I'm a lot, I'm a stronger person than I thought I would be. I'm not a goofy kid, I don't mess about in school, I don't mess about with like drugs or anything like that, I've got my head straight, got my head down, working in school.

Thea (I2)

Harry had a high level of responsibilities due to his brother Sean constantly requiring care. This included substantial responsibilities before and after school but, due to the regularity of his tasks and accessing of quality support, he was able to develop a positive routine. In addition to his family, his young carers project was a particularly important source of support, and it led to him developing an identity that was underpinned by the idea of a young carer community that he was proud to be a part of (Figure 11.4).

Figure 11.4 Harry associated his sense of community with his caring identity



The fact that I'm a young carer doesn't make me feel lonely. It makes me feel that I've got more people to be with if you get what I mean. Since knowing there's more young carers out there doesn't make me feel that I'm all alone.

Harry (I2)

My family are obviously very supportive because of you know my brother and stuff, and the young carers group is very supportive to me, because knowing about other people's problems makes me feel like we're all in the same boat.

Harry (I3)

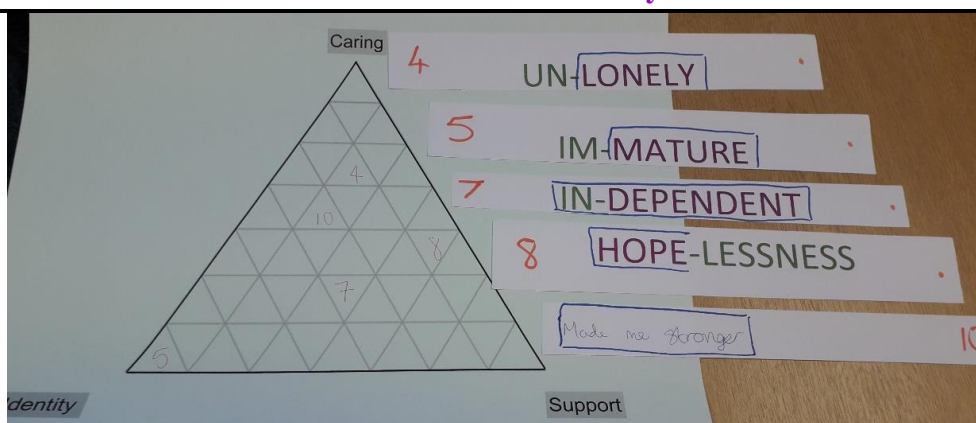
Unlike Harry and Thea, Kirsty had not accessed support beyond her family, but she still viewed caring as a way of life. In addition to her upbringing in an area for older and disabled people and the death of her mother, she felt that her caring fundamentally changed her as a person and informed different parts of her wider identity (Figure 11.5):

I think it, well it makes me who I am you know. I can say quite confidently that if I hadn't been a young carer I wouldn't be the same, the same person I am.

Kirsty (I3)

While Kirsty had a very strong caring identity, she also felt that the death of the person that she cared for effectively ended her caring role and threatened this identity. This included endangering the strengths she had gained from caring. While closely related to her role as a young carer, Insert 11.1 considers the loss of her caring role as an additional adversity.

Figure 11.5 Kirsty highlighted that her maturity was a result of her caring identity as well as the death of her mother and the community where she lived



Mature... That is 100% identity, trying to, I think, the fact that I was a young carer, it was also quite environmental so like, where I live, where I've grown up. I live, because of my mum we live in a bungalow... I know a couple of doors down there's a house for old people with CP, across the street it's all council houses and pensioners in them.

Kirsty (I2)

Insert 11.1 Additional adversity: Loss of Kirsty's caring role

In addition to bereavement following the death of her mother, the loss of the person that she cared for threatened her caring identity. Kirsty viewed this absence of caring as a void that needed to be filled and, as a result, she would help teachers arrive for school every day:

I'm kinda trying to keep it up a bit but, you know it's just, it's fading... I just kind of, I kind of crave it, you know, I still struggle to function without it.

Kirsty (I2)

I leave the house at half past, I'm here 8.40, and then 8.45 I'm in one set of doors, 8.50 the other set, 8.55 the third set... Because it, you know I always used to have to like hold, hold the doors for my mum like when we were out and stuff, on the other side of town. So it's kind of just like, a nice, a little way of being needed I suppose.

Kirsty (I1)

Kirsty recognised that caring had helped her develop skills including independence, confidence and emotional strength, but she was worried about losing these benefits:

I kind of had to be independent for the most part, because mum was dependent on me, and I was always independent but I turned around last year and sort of went 'Am I independent anymore?'. I kind of felt like I was losing my identity, I was, I felt like I was having to rely on people a lot more, and I just, I couldn't stand that.

Kirsty (I1)

It kind of fades in and out nowadays, my confidence and my strength and my independence as well, I mean, I've had times where things have just kind of crashed and I've been feeling so alone that I've kind of gone, you know, 'What's happened to me? Where, what happened to my strength?

Kirsty (I2)

10.2.2 *Negative caring identity and difference*

While manageable responsibilities, or more substantial responsibilities mitigated by positive support, had the potential to result in a positive caring identity for most participants, this was not the case for Angela and in particular Patrick. Angela viewed her responsibilities as manageable and was proud of taking on responsibilities to help her mother. However, she was not proud of the young carer identity and felt unappreciated, potentially due to her increasing responsibilities as part of an unbalanced family caring unit:

Not proud to have to take care of my parents. It's not really a thing that I'm proud of, it just is what it is.

Angela (I2)

While this negative identity had a limited impact on Angela due to her responsibilities being largely manageable, Patrick's negative identity was more pronounced. This was partly due to his substantial responsibilities and regular night-time caring that prevented the development of a positive routine. In addition, he was not accessing any support, including from his parents, largely due to his privacy, and felt unappreciated by the person he was caring for. As a result, Patrick associated his anger and sadness with a duty he did not wish for but would likely continue to have:

Sad that my life has to focus around her and then like, that will always be a title that's being put towards me. So like constantly having to care for my sister... It shows that you do something for someone, but it's also like a duty you have.

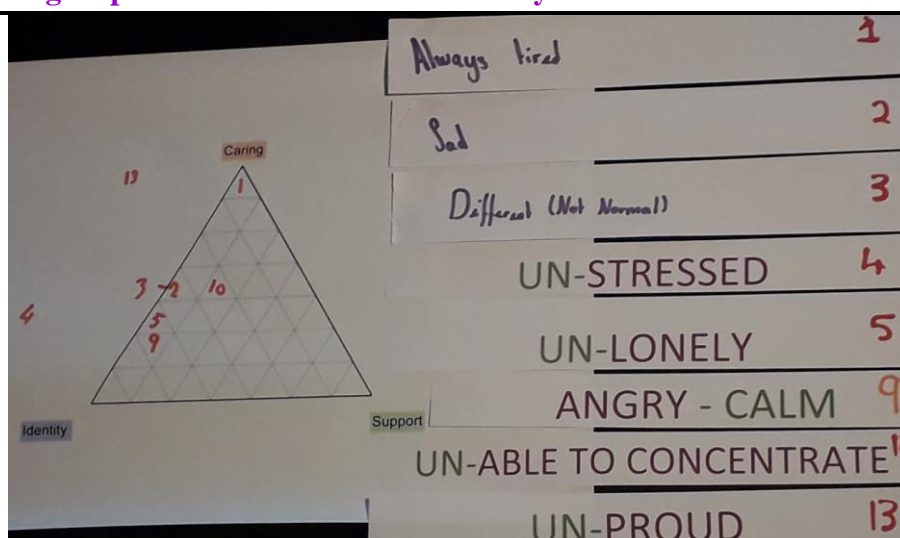
Patrick (I2)

Patrick's caring identity was underpinned by the idea of him being different. He viewed himself as different to children who were not young carers due to his responsibilities and the life he expected to have caring for Sara (Figure 11.6), but he also felt that the diversity of young carers meant he would also have little in common with them. He therefore disagreed with the idea of a community suggested by Harry:

Caring for my sister is different to somebody else caring for their mother or even their sibling or whatever because no person with a disability has the same thing... So it's like caring for different people is always going to be different and then identity I'm not the same as anyone else who lives like the normal life.

Patrick (I2)

Figure 11.6 Patrick identified difference as an additional impact, and attributed it to his caring responsibilities but also his identity



When I realised that nobody else had to do the same things as me. Like, people never had the same sort of siblings as I did ... as I did, so sort of then you're just different, and that you'll have to care for them.

Patrick (I3)

11.3 Summary

This final qualitative results chapter has demonstrated how caring responsibilities, support and choice informs the development of the caring identity. When young carers have control of their caring role, or when the provision of support mitigates the impacts of reduced control, they are often able to develop a positive identity and see the value of being a young carer. In contrast, a lack of support has the potential to reduce the benefits of manageable responsibilities, or more problematically exacerbate the negative impacts of higher-level caring.

Considered together the three qualitative chapters demonstrate the complex contextual factors that combine to impact the lives of young carers. In particular, the longitudinal focus enabled demonstration of how changing context such as transition into the caring role, deterioration in the relationship between the young carer and the care receiver, or the accessing of formal support can impact health and wellbeing.

In addition to these qualitative results, Chapter Eight reported on the quantitative results of the structural equation modeling (SEM). The next chapter integrates the mixed methods design components in order to refine the initial model of young carer mental health and psychosocial wellbeing that was reported in Chapter Five.

Chapter Twelve

Results Integration

The previous four chapters have presented the results of the mixed methods study. Chapter Eight reported the SEM (Structural Equation Modeling) findings that indicated young carers have poor mental health in comparison to their peers, but also that the impacts of caring vary with duration of care and level of responsibilities. Chapter Nine, presenting the first part of the phenomenological results, also considered the impacts of caring responsibilities with control emerging as key to positive and negative effects. Chapter Ten presented further phenomenological results on the potential for family, informal support and services to moderate caring impacts. Chapter Eleven considered the development of a caring identity that can be positive or negative depending on control of the caring role, the receiving of support, and perception of choice to be a young carer.

This chapter integrates the results of the quantitative and qualitative research components together, in order to test the realist model developed in Chapter Five. In particular, CMO configurations deemed potentially weaker due to conflicting or a comparative lack of evidence are refined, and configurations concerning identification, long-term care and higher-level responsibilities are added and strengthened. Emergent findings concerning control over the caring role, identification and disclosure are also incorporated into the refined model.

12.1 Integration of mixed methods findings

The study used a theoretically informed complex concurrent mixed methods design, with the initial realist model developed in Chapter Five informing the methods used to answer each of the study questions. In line with accepted mixed methods research practice the quantitative and qualitative components remained separate during the planning, implementation, data collection and analysis stages, in order to reduce potential bias of one component by the other.

This final integration stage brings the findings of the quantitative and qualitative components together. As detailed for each question in Chapter Six, this study used a combination of two tools for integration. Three questions used complementarity, the acceptance that a single quantitative or qualitative method can best answer particular questions, with the quantitative analysis of cohort data ideal for the study of young carer prevalence among children (Q2), and the comparison of young carers' mental health with their non-caring peers (Q3). In contrast the qualitative phenomenology was best able to consider the needs of participants (Q5).

The fourth question concerned change within the young carer population over time (Q4) and was answered through the triangulation of qualitative and quantitative data. Specifically, the two qualitative and quantitative components considered duration of care and the different levels of responsibilities, with the findings of each method used to check the other, but the qualitative study also focused on wider factors including care receiver illness, young carer responsibilities and life balance.

12.2 Model refinement

Having briefly recapped the integration process, this section details the strengthening of evidence and the emergence of original findings. While the organising construct of the realist model remains the same, there are considerable refinements throughout the model with new CMO configurations introduced in the *caring responsibilities* and *support* domains, and pre-existing configurations expanded to include additional outcomes and contextual factors.

Updated visuals of the three domains are presented with changes highlighted in red. Consideration of refinement is accompanied by references to the revised model, using the same notation (CMO; C; M) as when reporting the initial model in Chapter Five.

12.2.1 *Caring responsibilities domain*

A central finding of the realist synthesis was the need to strengthen evidence on the overall impacts of caring through studying the relative mental health of young carers in

comparison to their peers. However, as discussed in the summary of the structural equation modelling at the end of Chapter Eight, the potential of the quantitative component to refine the model was limited by the statistical significance of the findings.

While findings in relation to young carer prevalence for different demographic groups were statistically significant and therefore used to refine the model, this was not the case for consideration of relative mental health. Therefore, findings in relation to all young carers having marginal short-term impacts that deteriorated over time, and higher-level young carers having greater magnitude short-term benefits but also more substantial negative long-term impacts were not incorporated into the refined model, unless they could be triangulated with similar qualitative findings. The refined *caring responsibilities* domain is presented in Figure 12.1.

Impacts of caring

The phenomenology focused on the impacts that were shared by participants due to their carer status and unrelated to more specific circumstances. This led to the addition of three positive outcomes for the **Caregiving responsibilities** configuration [CMO⁶], with Kirsty, Martin and Harry reporting satisfaction as a result of making a difference to the person that they cared for, and Angela and Thea perceiving increased maturity and being more hardworking. More specific outcomes relating to particular contextual factors are considered in the next sections.

Stability in the lives of care receivers and young carers

The initial model considered how time spent caring was affected by the care receiver's illness or disability, and by the stability of their condition as two contextual factors. The phenomenology highlighted how these contextual factors are interlinked, and the refined model merges them into a single *care receiver stability* factor. The addition of the **Care receiver stability** configuration [CMO²] reflects the findings that their stability, and therefore the stability of the young carer's responsibilities, is dependent on three contextual factors. The first, *fluctuating condition* [C^{2a}] was highlighted by Thea and Lyra's responsibilities depending on their mother's bipolar disorder. Martin's mother's fortnightly treatments illustrated how *treatment* [C^{2b}] can create cycles in

responsibilities while, in the case of Angela's mother, care receiver *adaptation to the condition* [C^{2c}] can increase their independence and reduce their needs.

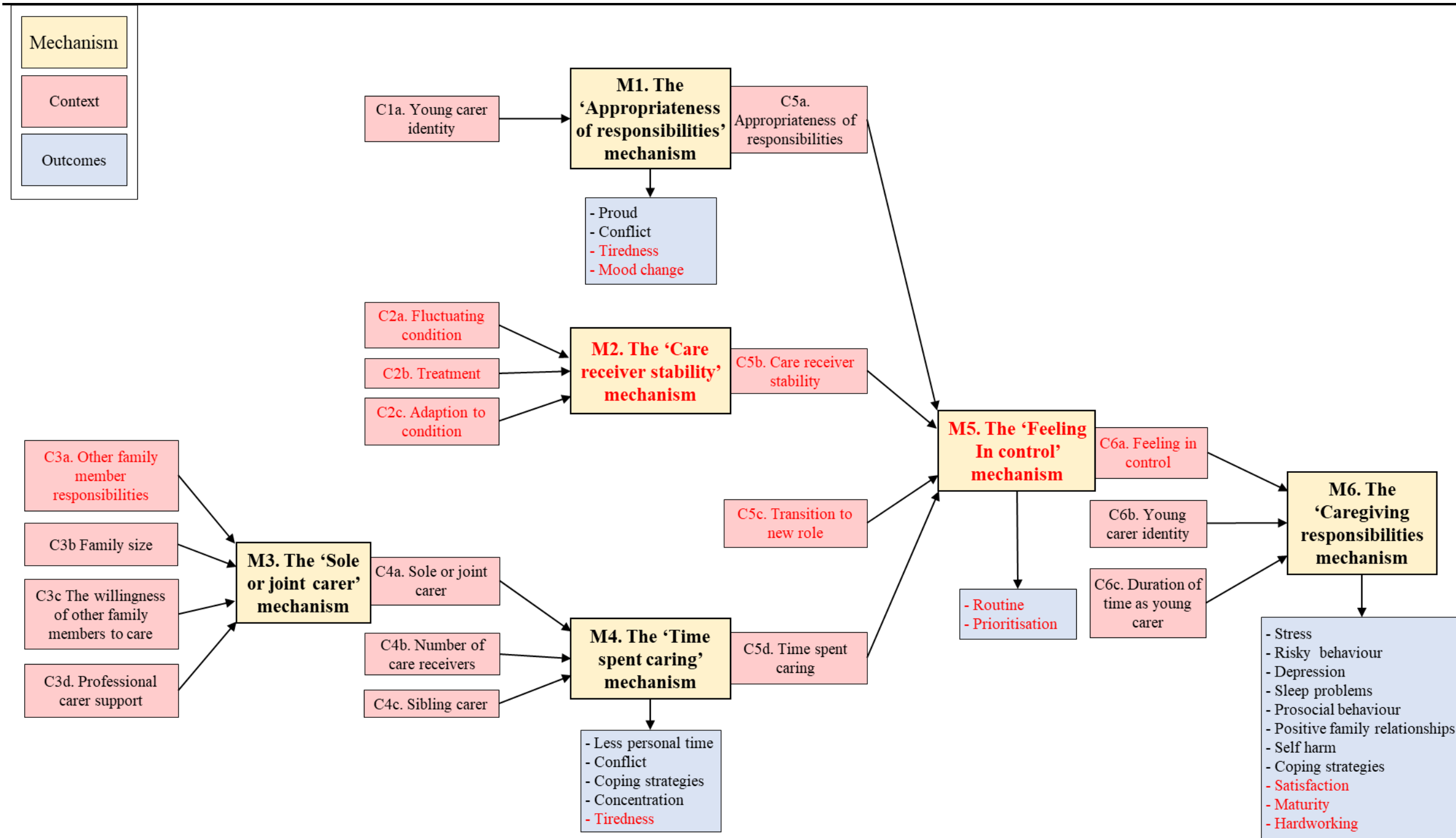
Young carer control and management of the role

The realist synthesis identified level of caregiving as a major theme in young carer research, with higher levels of responsibilities due to inappropriate responsibilities or larger amounts of time caring (Aldridge and Becker 1993b; Lane et al. 2015). As a result, level of care was included as a CMO configuration in the initial model.

However, the phenomenology recruited young carers unknown to services as well as those who were accessing projects. This enabled consideration of a wider range of experiences and the emergence of control as a key theme. As a result, the refined model includes a new **Feeling in control** configuration [CMO⁵] with four contextual factors, in place of the level of care mechanism. The first contextual factor, *appropriateness of responsibilities* [C^{5a}; M¹], remains from the previous mechanism but with tiredness and mood change as additional outcomes due to Sophie and Patrick's night-time care. *Time spent caring* [C^{5d}; M⁴] also remains as a contextual factor. *Care receiver stability* [C^{5b}], already considered as an additional configuration [CMO²], is one of two new contextual factors for the control mechanism. The final contextual factor specifically concerns new young carers and their *transition to new role* [C^{5c}]. This is an addition to the refined model, based on Martin's experiences of his initial frustration as a young carer and his increasing confidence over time.

The focus on control enabled the identification of two largely opposing outcomes. The first, routine, as experienced by Angela and Richard, is usually a positive outcome of the young carer largely feeling in control, though the experiences of Harry highlighted that routines can be imposed to fit with wider family provision of support. The second, de-prioritisation, is a negative outcome resulting from lower levels of control. This was evidenced by Thea providing care when her mother needed additional support instead of attending school and having social opportunities, and Patrick deprioritising his own needs permanently to care for his sister

Figure 12.1 Refined Caring responsibilities domain with major changes marked in red



12.2.2 *Support domain*

Substantial refinements are also included in the *support* domain (Figure 12.2). This was partly due to the recruitment of young carers that were unknown to services in the qualitative study, enabling a greater focus on self-disclosure, but other changes include a focus on the relationship with the care receiver, and the potential for improved support of the care receiver to decrease the responsibilities of young carers.

Family dynamics and the caring unit

The Supportive family configuration in the initial model is renamed the **Family caring unit** configuration [CMO⁹] with a focus not solely on supporting children to be carers but on the importance of caring as a family. The experiences of Harry and Sophie evidenced how positive family support can reinforce confidence in caring ability, while a dysfunctional family caring unit led to Angela not feeling valued. Two additional contextual factors threaten the unit, with *family tensions* [C^{9d}] affecting the support that Martin initially received from his grandmother. The second, *other family member commitments* [C^{9e}] is also a configuration and is considered next.

The **Other family member commitments** configuration [CMO⁸] is modified from the Other family members in employment mechanism that was in the initial *caregiving responsibilities* domain. While the phenomenology found evidence of participants having greater responsibilities due to family members having to work [C^{8a}], Harry and Patrick also provided care while their parents were *looking after other children* [C^{8b}]. The modified configuration is included in the Support domain to reflect the impact on the family caring unit, but *other family member commitments* also remains a contextual factor [C^{3a}] in the first domain.

Young carer – care receiver relationship

The initial model included a configuration on the relationship between the young carer and the care receiver and highlighted the potential for conflict and depression when the relationship is problematic. The phenomenological results indicated that the majority of participants had close relationships with the care receiver, and Kirsty and Angela highlighted the parenting that their mothers provided for them. As a result, *two-way*

caring [C^{7c}] is included as an additional contextual factor for the **Young carer – care receiver** configuration [CMO⁷]. In addition, Martin's responsibilities as a new carer were frustrating at times, but his improving relationship also led to better communication with his mother.

While rare, the impacts of a difficult relationship with the care receiver were problematic. This was evidenced by Patrick's experiences of caring for his sister and, as their relationship deteriorated, he felt increasingly unappreciated and impatient. These outcomes are added to the model, with *appreciation* therefore both a contextual factor [C^{7b}] for the nature of the relationship, but also an outcome.

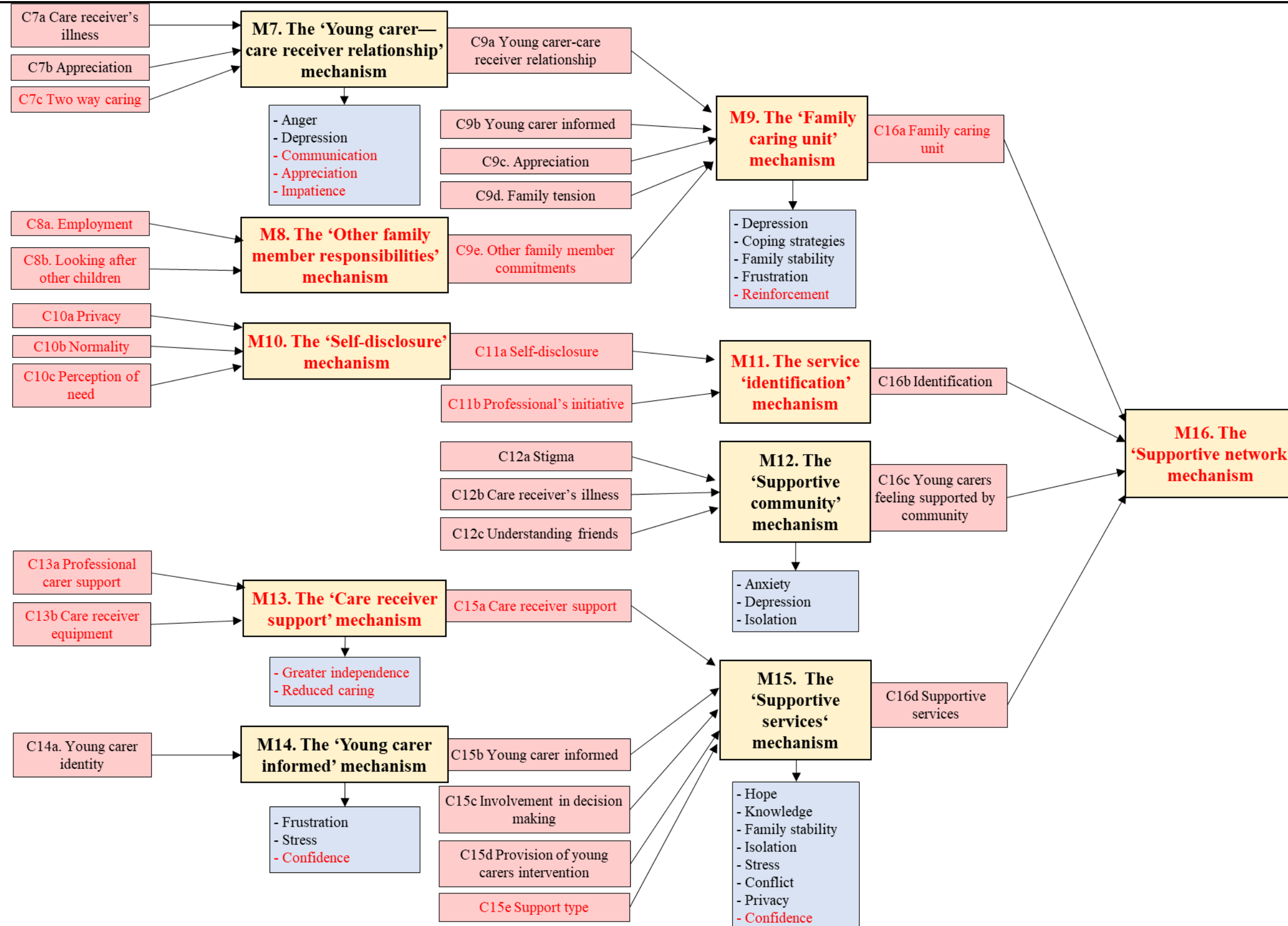
Self-disclosure and identification

The realist synthesis highlighted the need to focus on identification in the primary research. As a result of sensitising the phenomenology to this evidence gap, there are major refinements including two new CMO configurations relating to self-disclosure and identification.

The **Self-disclosure** configuration [CMO¹⁰] considers why young carers and their families disclose their status and has four contextual factors evidenced by the results from the phenomenological analysis. *Privacy* [C^{10a}] is the first contextual factor with many young carers and families selective in who they told based on trust, and Patrick and Sophie were particularly wary of telling services. However, Sophie and Kirsty also reported a perception of *normality* [C^{10b}] with their caring a regular part of their lives and not seeming noteworthy. The third contextual factor, *perception of need* [C^{10d}] was the basis of family decisions to seek support from services.

The second new CMO configuration concerns the **Service identification** [CMO¹¹] of young carers and has two contextual factors. The first contextual factor, *self-disclosure*, is also the previous CMO configuration [C^{11a}, M¹⁰]. The second, *professional's initiative* [C^{11a}] reflects how identification is often by individual professionals, for example Sophie's mother's diabetic nurse and the mental health team supporting Richard's mother. There was no evidence of schools or health authorities actively seeking to identify young carers.

Figure 12.2 Refined support domain with major changes marked in red



The importance of active support

The amended **Supportive services** configuration [CMO¹⁵] reflects participant experiences of accessing different services. The five participants who accessed a local young carers project were very positive concerning the social aspect, with Thea, Lyra, Lucy and Harry also valuing the assessments that enabled individualised support and advice. They compared the active support of projects to the lack of provision received in school, and participants including Patrick and Kirsty highlighted missed opportunities by health professionals to identify young carers. *Support type* [C^{15e}] is included as a contextual factor to reflect the differences in provision, and confidence is included as an additional outcome to reflect the positive support offered by projects.

There was however a major exception concerning Sophie's experiences of being identified, informed and trained by her mother's diabetic nurse. As a result, evidence of the potential benefits of support by health services were strengthened, and confidence is again included as an outcome for the **Young carer informed** mechanism [M¹⁴].

The initial model included the Professional carer support configuration that concerned formal support for the care receiver from outside of the family. However, Sophie's experiences highlighted the importance of supporting the care receiver in other ways, with this indirectly improving the life of the young carer. The original mechanism is expanded and renamed the **Care receiver support** configuration [CMO¹³] in the refined model, with *professional carer support* instead a contextual factor [C^{13a}]. *Care receiver equipment* [C^{13b}] is a new contextual factor, as it can potentially enable greater independence for the care receiver and reduced caring by the child.

A final change in the domain concerned the renaming of the Supported and recognised configuration in the original model. The revised **Supportive network** configuration [CMO¹⁶] reflects the myriad of potential formal and informal support sources that young carers and their families attempt to navigate and combine.

12.2.5 Identity domain

Fewer refinements were made to the third domain (Figure 12.3), but the mechanisms were modified to better reflect young carers' perception of choice. The impacts of

control that are central to the refined *caring responsibilities* domain also affected the development of a positive or negative caring identity.

Choice and unacceptable alternatives

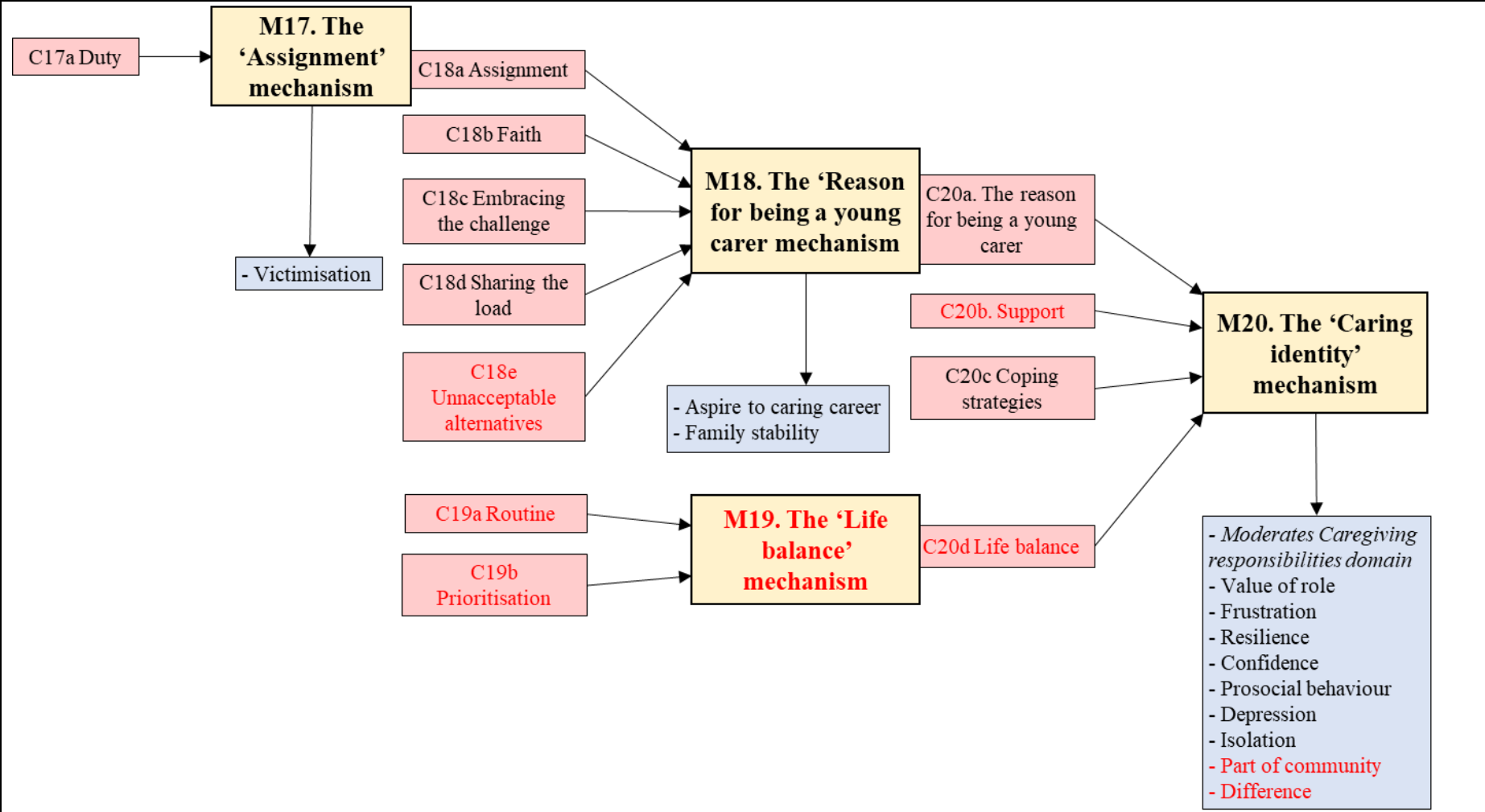
The *identity* domain of the initial model included a configuration on the reasons why children become carers, with four contextual factors: assignment concerned children being selected as carers, potentially ahead of other siblings; faith led to the feeling that they should help people; embracing the challenge was linked to an interest in caring as a possible career; and sharing the load concerned them wanting to help other family members. Assigned young carers rejected the idea of a choice to be a carer, but a common perception among the wider group was of ‘a choice but not a choice’.

The phenomenological results largely reinforced this with *assignment* [C^{18a}], *faith* [C^{18b}], *embracing the challenge* [C^{18c}] and *sharing the load* [C^{18d}] remaining as contextual factors on the **Reason for being a young carer** configuration [CMO¹⁸]. However, several participants discussed how their choice was severely limited by a lack of alternatives to them providing care, and the unacceptable repercussions of the care receiver being unsupported. This included Martin and Lyra’s unwillingness to let their mothers struggle without their help, and Thea fearing her mother would go into long-term care. This helped understand the complexity of choice, and *unacceptable alternatives* [C^{18e}] was included as an additional contextual factor.

12.2.6 Development of a caring identity

Refinements to the *caregiving responsibilities* domain included incorporating control as key to enabling a positive routine. For participants in the phenomenology, a positive routine enabled the balancing of caring with school and social lives, resulting in a positive caring identity being developed. In contrast, threats to this control, including for example Thea, Lucy and Lyra’s mother’s unstable condition, and Sophie and Patrick’s extensive and night-time caring hampered the development of a positive caring routine and led to the need to prioritise caring over education and social lives. Depending on the support that was in place, this affected their perceptions of caring.

Figure 12.3 Refined Identity domain with major changes marked in red



As a result, the identity domain has been revised with the previous life management configuration renamed **Life balance** [CMO¹⁹]. The four contextual factors in the original configuration (caring, education, personal needs and employment) have been replaced with *routine* [CMO^{19a}] and *prioritisation* [CMO^{19b}] to reflect the positive or negative balancing of caring with other aspects of their lives.

In addition, the **Life Balance** [CMO¹⁹] and **Caring identity** configurations [CMO²⁰] are reversed to reflect how a positive routine enables the balancing of care with other parts of lives, leading to a positive perception of their responsibilities.

Lastly, the original **Caring identity** configuration [CMO²⁰] included a contextual factor to reflect how social recognition can improve self-perception of carers. Social recognition is renamed *support* [C^{20b}] in the refined model to reflect how the receiving of positive or negative support can moderate the effects of caring and inform the caring identity. In particular, Harry highlighted the support of his young carers project that helped him to manage substantial responsibilities, resulting in multiple positive benefits and a strong feeling of belonging to a young carer community. In contrast, Patrick was not accessing any support, and his perception of himself as a carer was based on feelings of difference from children without caring responsibilities but also from other young carers. The refined model includes community and difference as additional outcomes.

12.3 Chapter summary

This chapter has sought to integrate the findings of the phenomenology and SEM studies, in order to refine the initial realist model of young carer mental health and psychosocial wellbeing. Considerable refinements to the initial model were made, most notably concerning the emergence of control as central to the differing outcomes for young carers, and the addition of mechanisms of self-disclosure and identification.

The final chapter returns to the research questions and consider how the study has clarified understanding of how the impacts on mental health and psychosocial wellbeing vary for young carers depending on their individual and family circumstances. The chapter also details a model of the young carer spectrum and differentiates tiers of

caring on the basis of perception of control. The needs of the whole young carer spectrum are considered, including young carers with generally manageable responsibilities, those with reduced control, and those with elevated needs due to particular aspects of their caring. Strengths, limitations and opportunities for further research are also considered.

Chapter Thirteen

Discussion and Conclusions

The primary aim of this thesis is to investigate the causal mechanisms linking child caring and mental health, and how the impacts of caring vary depending on individual circumstances and experiences. Through the use of innovative methods to increase understanding of these mechanisms, the study has considered whether the needs of all young carers are being met.

This final chapter begins with a restating of the research questions, and a summary of the study methods. The results are summarised with key findings relating to control, duration as a young carer, the young carer-care receiver relationship and the provision of mainstream services and young carer project support. A model of the young carer spectrum is presented, and recommendations for the support of the different tiers are suggested. In addition, the strengths and limitations of the overall study design and the individual components are considered.

13.1 Summary of realist model development and refinement

This thesis began with a brief review of previous research with young carers. Chapter One highlighted the strengths of early exploratory qualitative research that increased prominence in policy and legislation (Aldridge 2018; Leu and Becker 2017) but also criticism relating to the lack of involvement of young carers not known to services, and the need for large-scale quantitative research to strengthen the qualitative evidence (Newman 2003; Olsen and Clarke 2003). It was accepted that these challenges were difficult to solve during the 1990s but argued that the failure to learn from these criticisms or revisit the challenges has hampered more recent progress in impacting on policy, legislation and provision.

This initial review informed the research questions for this study as follows:

1. What are the causal mechanisms underpinning young carers' mental health and psychosocial wellbeing?
2. What is the prevalence of young carers amongst children in the UK?
3. How does the mental health of young carers compare to their non-caring peers?
4. How do the mental health and psychosocial wellbeing impacts of caring change over time and within the young carer population?
5. What are the needs of young carers and are they being met?

13.1.1 Study stages

The background literature review in Chapter One informed the selection of methods and the resulting study used a theoretically informed concurrent mixed methods research design, divided into two stages. The first stage included a concept analysis and realist synthesis that resulted in the development of an initial model concerning young carers' mental health and psychosocial wellbeing. The second stage used structural equation modeling (SEM) and a longitudinal phenomenology to refine the initial model further. Each component is summarised next.

Model development

Due to the lack of consensus over the definition of young carers, the study treated the phenomenon as a contested term. A concept analysis enabled the analysis of 55 definitions from studies spanning a 25-year period, with a focus on how the concept had evolved over time. This enabled the identification of key attributes, and the development of the definition that is used in this study.

A realist synthesis of 44 studies identified CMO (Context-Mechanism-Outcome) configurations in relation to the mental health and psychosocial wellbeing of young carers. Through identifying these mechanisms and considering the contextual factors that produced different outcomes for individual young carers, the synthesis increased the clarity of previous research. The resulting initial model, reported in Chapter Five, identified 17 CMO configurations that were divided into three domains concerning the

impact of the *caring responsibilities* themselves, the provision (or absence) of *support*, and the development of a caring *identity*.

Assessment of the overall model and individual CMO configurations resulted in the identification of evidence gaps for refinement through mixed methods research. The most prominent evidence gap concerned the lack of representation of young carers not known to services in the model, due to research being predominantly qualitative and conducted through young carer projects. Evidence on the impacts of caring over time, and on the relative health and wellbeing of young carers in comparison to children without caring responsibilities also needed strengthening.

Model refinement

While large-scale quantitative data concerning young carer status were not available during the 1990s, more recent cohort studies have collected this information at multiple timepoints. This enabled a SEM study of the longitudinal mental health of young carers in comparison to children without caring responsibilities.

The qualitative component was a longitudinal phenomenology that studied the health and wellbeing of ten young carers in the context of changing family circumstances. A school-based phenomenology was developed in an attempt to recruit young carers who were unknown to services, and therefore ensure a wider range of participants.

13.2 Review of key findings

The previous section summarised the limitations of past research and the resulting evidence gaps. This informed the innovative use of methods in this study, and resulted in a range of original findings, most notably concerning the extent to which young carers have control over their role. A model is presented of young carers as a spectrum of children with different experiences and impacts, and perception of control enables the differentiation between the majority of young carers who have largely manageable responsibilities, and the minority whose caring is more problematic, often due to particular circumstances that were identified as threats. For young carers with reduced

control, positive support can mitigate against the negative impacts of caring, but poor-quality support can also exacerbate these effects further.

13.2.1 Caring as a spectrum of responsibilities and impacts

Current perception of young carers is often of a small group of children taking on large amounts of responsibilities. This perception has been shaped by the early definition of young carers as having significant responsibilities, and early prevalence studies that used alternative methods due to a lack of quantitative data. This resulted in maximum prevalence estimates well below 1% (Becker et al. 1998; Office of National Statistics 1996) with this informing the young carer provision that has largely remained unchanged since.

More recent prevalence estimates have been sourced from confidential cohort studies with children as the respondents. That includes this study which estimated three annual prevalence figures for the same cohort of children in England, ranging from 5.1% to 6.2%, with 0.8% to 1.0% taking on greater amounts of care. While far greater than the early estimates, other cohort study estimates are higher still, including 12% (Lloyd 2013) and 17% (Hewitt et al. 2019). These increasing prevalence estimates reflect the improvement in methods, but also the move towards defining young carers as any child providing care due to a family illness or disability, rather than only those with ‘substantial’ responsibilities.

The increasing prevalence estimates have also led to a growing recognition of a broader spectrum of young carers with differing experiences, impacts and support needs. Chapter One considered a descriptive model of young carers (Joseph et al. 2020) as concerning three concentric circles of young carers with minimal responsibilities, manageable responsibilities that do not impact on their wider life, and responsibilities that limit educational and social opportunities. This model is returned to when considering the emergence of control as a potential way to differentiate between levels of care.

Between-group comparison of young carers and non-caring peers

The SEM study enabled a large-scale study of the relative mental health of young carers in comparison to children without caring responsibilities. This was an area of the realist model that needed refinement due to limited and conflicting evidence over whether the negative impacts of caring increase over time or peak in the middle term. However, in contrast to these previous studies that focused on how the detrimental effects changed over time (Aldridge 2006; Cree 2003), the results of the longitudinal analysis suggested that initial impacts on mental health were marginal, before becoming more negative over time.

Within-group comparison of young carer mental health

The second SEM model compared higher-level young carers (those spending at least 11 hours a week caring) with all other respondents. The results reinforced the idea of young carers as a heterogeneous group, with substantial short-term benefits but also increasing long-term detrimental effects for higher-level young carers.

Control as a way to differentiate manageable and unmanageable responsibilities

The phenomenology recruited a sample of ten young carers, five of whom were recruited through schools as young carers that were unknown to services. Following the expansion to include young carer projects, an additional five were recruited who were all accessing support. This ensured that the sample had a wider range of experiences of caring responsibilities and accessing support compared to previous studies, and this enabled the study of higher-level young carers alongside those with lesser responsibilities. As a result, perception of control over the caring role emerged as a key factor in understanding how their caring experiences affected their wider lives.

Those who largely felt in control tended to have relatively stable responsibilities that were not excessive in hours and did not include inappropriate responsibilities such as regular medical responsibilities. This led to them being able to develop a positive routine that balanced caring alongside their social lives and education. Therefore, while

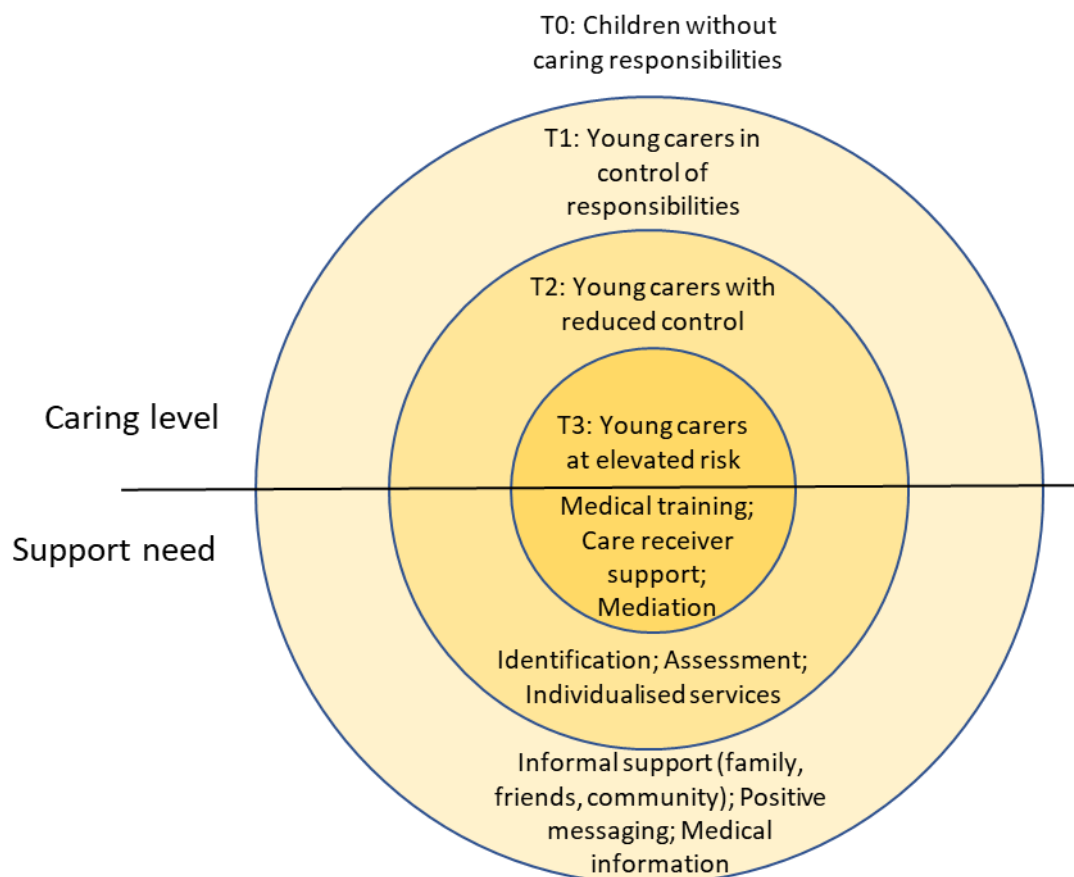
they are not able to control the illness or disability of the care receiver and their family circumstances, these young carers could control their caring.

In contrast, those with a self-perceived lack of control often had to deprioritise school or social activities to provide care. A number of threats to control were found, with many having been identified as challenges in previous research and therefore included in the initial realist model. This included the inappropriateness of particularly responsibilities and particularly medical care (Aldridge and Becker 1993b; Assaf et al. 2016), the amount of time spent caring (Bauman et al. 2007; Skovdal 2011), and an instability in the young carers responsibilities as a result of the fluctuation in the care receiver's condition (Andersen 2012). Transition into the young carer role was a new threat identified in this study, with evidence that control increases as young carers become accustomed to the role.

Chapter One introduced a descriptive model (Joseph et al. 2020) of a young carer spectrum of responsibilities. The model required further specification, but three tiers were detailed with the first containing young carers with lower-level responsibilities for care receivers that may be equivalent to the chores of non-caring children. The second tier concerned young carers who have greater but manageable responsibilities that do not impact on their wider life, while the third tier included young carers with responsibilities that limit educational or social opportunities.

Based on the findings of this study and, in particular the emergence of control as a key factor, Figure 13.1 suggests an alternative model. The model includes children without caring responsibilities (T_0) who may have chores as part of a healthy development to adulthood, therefore recognising the continuum of dependence that changes with the age of children., but the actual spectrum contains three tiers of young carers. T_1 concerns young carers who are largely in control of their responsibilities, and therefore likely to have a positive routine. T_2 contains young carers who struggle to manage due to reduced control, potentially as a result of the threats detailed earlier in this chapter. T_3 concerns young carers who are at an elevated risk due to particular aspects of their caring role, particularly those who have regular medical responsibilities or problematic relationships with the person that they care for. The support needs for young carers in each tier are also included in the model and considered later in this chapter.

Figure 13.1 Model of young care levels and support needs



There is potential for further studies on control and the threats to it, particularly concerning the highest tier of the model and whether other aspects of care result in elevated need. This is partly due the limitations of the study, particularly concerning the limited sample, and none of the ten participants in the phenomenology had regular personal care responsibilities such as toileting or bathing the person that they provided care for. It has been extensively argued in previous research that these are inappropriate responsibilities for children to be undertaking, but further longitudinal research needs to include these young carers to assess the control that these young carers have.

Transition is another area that needs further research, due to it being identified as a threat to control in this study despite little consideration in previous research. Based on the experiences of Martin alone, children transitioning into the young carer role initially struggle to manage their responsibilities (T₂), before developing increased control over

time (T_1), but the lives of other recently transitioned young carers need to be considered to strengthen this evidence. In particular it is possible that the Tier Two is the entry point for new young carers, but that various circumstances combine to affect trajectory.

13.2.2 Support as a moderator for caring impacts

The initial realist model developed in Chapter Five included a *support* domain with CMO configurations concerning the family, informal sources including friends and neighbours, education, health and social care services, and specialist young carer projects. However, there were knowledge gaps due to a lack of evaluation studies or research concerning education or health services. This informed the phenomenological focus on self-disclosure among young carers and their families, as well as how services identify undisclosed young carers.

Family support and the relationship with the care receiver

Irrespective of the barriers affecting identification outside the home, most families were aware if a child in their household was providing support to a family member with an illness or disability. The study results reflected this with all ten participants known to be young carers within the household, nine receiving family support, and most being part of a caring unit comprised of multiple family members.

The relationship between the young carer and the care receiver was particularly important and the study looked at the twin dynamics of the young carer providing support for the care receiver and (when the care receiver was a parent) the disabled parent raising the child. The majority of these relationships were positive with the parents potentially limited in specific tasks but active in others, and most participants were close to the person that they cared for. This positive support from the family and the care receiver increased the benefits and mitigated the negative effects of caring responsibilities in these families.

In contrast, Patrick had a problematic relationship with his sister. His substantial responsibilities included regular night-time care that resulted in reduced control, and the de-prioritisation of school and social opportunities, resulting in a range of negative

impacts. The study evidenced how the coronavirus changed their circumstances and caused further deterioration in their relationship. This difficult relationship, potentially exacerbated by an unwillingness to discuss the problem with his parents, caused additional anger and sadness. As a result, the model includes young carers with problematic relationships in the highest tier of young carers who have elevated needs and need urgent support.

Self-disclosure and identification of young carers

Similarly to the findings of early studies (Aldridge and Becker 1993a, 1993b) and reviews of young carers research (Rose and Cohen 2010, Sahoo and Suar 2009), this study identified high levels of privacy relating to service identification and community stigma. However, a perception of normality was also highlighted as a second reason why young carers and families do not disclose their status.

For those who did not inform services, there was little evidence of progress in identifying them, with opportunities particularly being missed by medical professionals. This lack of progress is despite guidance in (The Carers Strategy for Wales 2013) and the (Children and Families Act 2014) that health professionals are trained to identify young carers, and schools raise awareness.

The importance of individualised, active support

As a result of the lack of self-disclosure and identification by services, many participants were unknown to health services and therefore not accessing medical training or information. In addition, none of the ten participants were receiving support from schools despite five of them being known to the setting as young carers.

In contrast, the study reinforced the findings of previous research concerning the benefits of young carer projects (Aldridge 2006; Kavanaugh 2013). Those accessing projects emphasised the active nature of the services in offering social opportunities, with many also reporting how assessments enabled advice and guidance to be individualised to their needs.

Support and training for young carers with medical responsibilities and their families

While medical information is important for all young carers, previous research (Aldridge and Becker 1993b; Coles et al. 2007; Trondsen 2012) has recommended that those with substantial medical responsibilities receive specialist training. Of the three, the recommendation by Coles was the result of a six-day intervention for children of parents with MS, and benefits included increased knowledge of the care receiver's illness, lower stress and decreased distress. This is the only other study to assess the health and wellbeing of a young carer (Sophie) before and after the accessing of medical training and information, with highlighted benefits including reduced stress, as well as decreased tiredness and greater confidence.

Also central to this support was the installation of a new diabetic pump for her mother. With early young carers research criticised for focusing on supporting the child rather improving the life of the care receiver (Olsen and Clarke 2003), this new equipment improved her mother's life and reduced her needs, indirectly easing Sophie's responsibilities. Further studies of young carers and their families before, during and after accessing services would strengthen the case for training young carers but also meeting the needs of the care receiver.

13.2.3 Identity and self-perception of the caring role

The final key findings consider the development of a caring identity relating to how a young carer perceives themselves and their role. The *identity* domain in the initial realist model concerned how the impacts of caring, moderated by their perceptions of support and choice, affects the development of the caring identity. The refined model reflected how control over caring responsibilities is key to this identity.

The complexities of choice

The study sought to increase clarity over young carers' perception of choice. Whereas previous studies have highlighted the different motivations for a particular child

becoming a young carer (Aldridge 2006; Kain 2009; Skovdal 2011), young carers often struggle with the idea of choice and whether it was their decision to be a carer. This study found that the repercussions of them not providing care, for example the care receiver's condition worsening or them entering long-term care, were unacceptable to the young carer with this largely limiting any choice that they had.

Caring control, support and identity

In considering the three elements of the realist model together, the carer identity is developed as the result of a young carer attempting to control the responsibilities that result from a family member's illness or disability. A number of negative circumstances can be viewed as potential threats to this control, while the positive perception of support and recognition from individuals and services can help young carers to manage their responsibilities.

The nature of the caring identity, and the child's perception of themselves as a young carer can be positive or negative. Those in control tended to view their caring positively and reported fewer negative impacts and more benefits, compared those who were struggling to manage their responsibilities. Support was also crucial in mitigating or reinforcing negative impacts of caring and therefore affecting the development of the identity. This was most notable for Harry who had substantial responsibilities, but the support of family and his young carers project resulted in multiple benefits and a positive identity based on the idea of community. In contrast, Patrick also had greater responsibilities but his extreme privacy, combined with a difficult relationship with his sister, impacted on his perception of support. In addition to numerous negative impacts including anger, sadness and loneliness, his identity was based on difference.

These findings can be considered in the context of work by White (2008) on the formation of identities as a result of adversity. White theorised that young children initially develop an identity from watching others around them, and over time develop multiple identities for the different social groups that they belong to and expect to remain a part of. However, adverse events create unexpected challenges and attempts to control these events can also result in additional identities.

13.2.4 The needs of young carers

The final research question concerned the support needs of young carers. All young carers require support but, as detailed in the model (Figure 13.1), their needs are likely to vary depending on their control of the situation. This is considered briefly below, and then in more detail when considering recommendations.

Most young carers are in the first tier (T_1) and are largely supported by family and informal sources. They are largely in control of their caring but should be provided with support from schools and health authorities if and when needed. With the increasing prevalence estimations, expecting services to identify the larger population is unlikely, but a move towards positive messaging in policy and education has the potential to reduce stigma and increase self-disclosure.

The second tier (T_2) largely contains those who struggle to manage their caring due to the threats identified in this study. Young carers in this tier are likely to require regular support but, while some access young carer projects. Many are reluctant to seek this support and therefore remain unidentified by services. Greater consideration of how schools and medical professionals can identify and support this group remains key.

Finally, young carers in T_3 require specialist services beyond young carer projects. This includes training for young carers with medical caring responsibilities, and mediation for young carer and care receivers who have problematic relationships.

13.3 Study strengths and limitations

This study has reported findings including increased clarity over how the impacts of caring vary depending on individual family circumstances. In addition to control emerging as a central factor, the study has also strengthened evidence relating to the impacts of long-term and higher-level caring, the relationship between the young carer and care receiver, and the benefits of accessing information and training from medical professionals.

Part of the reasons for the original knowledge in relation to control, and the strengthened evidence was the intentional focus on innovative methods, and the

strengths and limitations of the mixed methods approach and the individual components are considered next.

13.3.1 Mixed methods approach

The study used a theoretically informed concurrent mixed methods design, with the development of an initial realist model informing the primary research. This design ensured that the individual methods stand alone, but also link together with a logical flow through the thesis.

The mixed methods approach enabled the researcher to move beyond the traditional qualitative - quantitative divide that places one approach as superior to the other. Instead, methods were chosen that best enabled investigation of each individual question (Creswell et al. 2008), with research quality based on the justification of the methods used and the standard of implementation (Teddlie and Tashakkori 2009). The justification of methods for each study question was detailed in Chapter Six but is briefly restated when considering the individual components.

13.3.2 Concept analysis

The concept analysis technique enabled consideration of how the phenomenon had evolved from an early definition that focused on ‘substantial’ care, to the increasing inclusion of any level of care for a family member with an illness or disability. The technique also enabled identification of related but different concepts including young adult carers as a separate older group, and language brokers as providing cultural support rather than care. This analysis enabled a theoretically based definition that was crucial to the realist synthesis.

13.3.3 Realist synthesis

A realist synthesis of previous research studies informed the development of the initial model of young carers’ mental health and psychosocial wellbeing. The method was selected due to the large amount of exploratory research that had resulted in an

accumulation of knowledge but a lack of clarity on how and why the impacts of caring vary for different children. The approach enabled the identification of key mechanisms that, when triggered by various contextual factors, produce specific outcomes (Pawson and Tilley 1997). The resulting model included 17 CMO configuration in three domains: *caregiving responsibilities*, *support* and *identity*. In addition to clarifying the impacts of caring, the model considered how support moderates these effects and assists in the development of a caring identity.

The model also highlighted a number of knowledge gaps due to limited or contested evidence. The initial model but also the knowledge gaps theoretically informed the questions that were asked in the primary research and the methods used to answer them.

13.3.4 *Structural equation modeling*

This thesis has accepted that the lack of large-scale quantitative analysis during the 1990s was due to a lack of suitable data, but also argued that more recent research has failed to utilise now-available datasets. With several cohort studies publishing multiple waves of suitable data, the use of SEM was justified to strengthen and test the evidence that the mental health of young carers is poor compared to children without caring responsibilities.

SEM enables the analysis of multiple variable relationships simultaneously and is widely used in longitudinal and cross-sectional studies (Biesanz 2012; Kline 2016). In particular the analysis of multiple waves of data enabled consideration of causal explanations, and the models developed in this study were *a priori*, fully theoretically informed by the realist model. The Longitudinal Study of Young People in England (LSYPE1: What Next) dataset contained over 700 young carers, far higher than in previous research, and 11,000 respondents overall, ensuring confidence in the results of the comparative study. Confidence was lower for the second model, due to the small proportion of higher-level young carers in the sample (under 120 in each wave).

Other limitations included the researcher having a lack of control as a result of utilising secondary data. In particular, the LSYPE1 young carer status question did not explicitly include people with substance misuse issues as care receivers, contrasting with the

definition developed for this study. The lack of control also relates to the data collected, with no data available concerning type of responsibilities and inappropriate tasks. With the MACA-YC18 measure on type of responsibilities (Joseph et al. 2009) being developed and utilised in quantitative research with young carer project users, there is considerable potential for the measure to be integrated into cohort studies. Finally, with the intention to study longitudinal change, LSYPE1 was the best cohort study to utilise at the time of the quantitative analysis in Autumn 2020, but the data is from 2004 to 2007. With LSYPE2 (Our Future) continuing to collect and periodically release data, there is potential for further modeling when additional waves are released.

13.3.5 The longitudinal phenomenology

The study recognised the strength of previous qualitative research that has increased understanding of the in-depth experiences of identified young carers. At the same time the need remains to involve young carers that are not known to services in research, in order to ensure that our knowledge reflects the wider spectrum. This informing the justification for the development of a school-based longitudinal phenomenology.

The interview design enabled the researcher and each young carer to develop a shared understanding of their caring through conversation and the ‘fusion of horizons’ (Gadamer 2004). Informal methods and conversation ensured that participants felt empowered to take control over the direction that the interviews took, and the later interviews were increasingly individualised with questions based on the content of their previous meetings. This led to discussions of additional adversities including bereavement and familial substance misuse, and attempts to differentiate these effects from the impacts of caring.

Another related strength was the treatment of time as a variable (Bartolini 1993; Pennings et al. 2006). Detailed contextual information was collected in the first meeting and revisited in subsequent interviews, enabling the potential for health and wellbeing impacts to be considered as a result of changing circumstances. This was particularly useful when considering impacts during transition into the caring role, the effects of a deteriorating relationship, and the benefits of being trained by health authorities.

Challenges related to the retention of participants, with six of the ten participants completing all three interviews. Despite all participants finding it beneficial to talk to an external person, two did not participate after the first interview due to the sensitivity of the topic, preventing longitudinal consideration of their experiences. Another two did not participate beyond the second interview due to a loss of contact caused by the coronavirus pandemic. While Chapter Nine considered the challenges of the limited sample of ten participants including three siblings from the same family, the study was still able to consider the differences between them and how this affected their perceptions of caring.

The recruitment of young carers who were not known to services

Central to the phenomenology was the recruitment of young carers who were not known to services. The decision to do this reflected the intention to assess whether the initial realist model was representative of all young carers, rather than those who were accessing projects and participating in research.

The involvement of identified and unidentified young carers in the study ensured a greater range of experiences in terms of the amount and type of responsibilities undertaken, the needs of the care receiver and the support that they received. The emergence of control as a key factor can largely be attributed to the more diverse sample.

However, while recruitment was expected to be challenging, the magnitude of the problem was underestimated. The flexible approach to working with individual schools to develop a suitable procedure for disseminating information, obtaining consent, and hosting the interviews was time-consuming and, despite high interest from schools, several did not go on to participate. The multiple levels of consent (i.e., schools signing up, young carers engaging and taking information home, and families giving consent) also served to erode the number of participants. As a result of the time taken to recruit, the number of participants were reduced from 15 to ten, and while the original intention was for all participants to be unknown to services, the challenges of recruitment resulted in the expansion to include young carer projects. This turned out to be a benefit as the

comparison of young carers that were unknown to services with those who were accessing support led to the findings in relation to control.

Despite these recruitment issues, the findings of the phenomenological study justified the approach taken. There is definite value in further research on methods to recruit young carers as a hard-to-reach population, therefore enabling further qualitative research on the whole young carer spectrum and full range of their experiences.

13.4 Lessons learnt

This study has contributed to our understanding of how children are affected differently by caring responsibilities depending on their individual circumstances. In particular, control has emerged as a key contextual factor for differentiating between the experiences and impacts of a larger population. Recognising this spectrum of experiences and impacts also means accepting that support needs will vary but there is little evidence of tiered support for young carers currently. The main support source, young carer projects, typically support those in Tier Two who struggle to manage their caring but are unable to offer the more specialist support needed by those in Tier Three. There is also a lack of support for the Tier One, possibly due to their lower needs, and they usually access support from families and informal sources. Recommendations of potential service provision for each tier, and then future policy and legislation, are considered below.

13.4.1 T₁: Positive messaging and information

Education and health services have long been seen as a place to identify young carers that are not known to services. However, there is often a tension with them desiring support but remaining reluctant to be identified and, at the same time, identified young carers continue to report a lack of awareness, understanding and recognition by educational and health professionals. The tension was most visible when participants shared their frustration of not being identified despite visibly supporting care receivers at medical appointments, but they did not feel able to disclose their status to the medical

professional. This potentially reflected the fact that many young carers do not see the benefit of disclosing their status.

In considering how to resolve this tension, there is a fundamental need to revisit the messaging on young carers. While caring at a young age is not necessarily desirable it is also not inherently negative, yet awareness raising in schools often reflects the incorrect perception of a small number of young carers providing large amounts of care. Messaging in schools should instead reflect the fact that increasing numbers of children are thought to have some level of caring responsibilities at home and that, if the responsibilities are reasonable and the child supported within in the family, caring is not normally problematic. This has the potential to reduce concern among pupils who have manageable responsibilities but are told that their caring is problematic, and in the long term this more balanced message has the potential to reduce the stigma around caring and increase self-disclosure, with schools then better placed to offer support if and when needed.

This study has differentiated between the information that all young carers need concerning the care receiver's illness and how to provide support, and the regular medical responsibilities of a minority that are considered in T₃. Health services have obvious opportunities to identify young carers who accompany family members to appointments, and it is manageable for them to answer the questions of young carers and provide them with suitable information to increase their confidence in their caring abilities.

13.4.2 T₂: Support to manage responsibilities

The previous section considered the potential for a more positive young carer message that is reflective of the larger population. This can be the foundation for highlighting the presence of a minority who need more regular support. One specific recommendation of this study is for the development of awareness raising materials that are reflective of the whole young carer spectrum. These materials can then be trialled in participating schools with evaluation of impacts including young carer self-disclosure rates and accessing of support, as well as changing perceptions of young carers within all pupils.

Schools should already be central to the support of young carers and view this as part of the holistic responsibilities that they have towards students, but there is evidence that this is not the case. Replicating the active and individual approach to respite and support developed by young carer projects is one possible way forward, with schools being more informed about each young carer so they are better able to support them individually on the basis of how their caring affects their education. The evidence suggests that this tier is a comparatively small proportion of young carers, but the development of school-based interventions would improve knowledge of the type and amount of resources needed.

Young carer projects remain a vital source of support for those in Tier Two (as well as Tier Three). In line with previous research (Aldridge 2006; Kavanaugh 2013), this study found that young carers value the social opportunities, respite and the assessment-informed advice and guidance. However, while there are limited examples of young carer project evaluations, few focus on the specific reasons why some work better than others. A second specific recommendation is for a realist evaluation of young carer projects that could include services with, for example, a purely social remit, respite provision, and assessments that inform individual support. This improved understanding of the specific components of projects that work, as well as those that are ineffective, could then inform the development of future interventions.

13.4.3 T₃: Additional support for those with elevated needs

The study identified two particular aspects of caring that elevate the needs of particular children. The first is regular medical responsibilities, where there is a risk for the young carer and care receiver should there be a problem. The support requirements of this group from health services are beyond the information needs of the wider young carer population, and training by medical professionals is required. However, despite this being identified as a key issue previously, there has been little success in implementation. The catch-22 situation identified by Aldridge and Becker (1993b), where health professionals refuse to train young carers with medical responsibilities for safety reasons, despite the fact that they will continue to undertake the task regardless, appears to endure. Support for this group should be a high priority, especially given the benefits evidenced for one participant who accessed support in this study, but further

study of young carers before and after receiving medical information and training is needed.

The second factor concerns problematic relationships between the young carer and the care receiver. This issue also affects a minority of young carers, but the effects were again notable in terms of exacerbating the impacts of the caring responsibilities themselves. While previous studies (Bauman et al. 2007; Kavanaugh 2014) have identified the potential for problematic relationships and conflict, there is no evidence of mediation or other interventions being developed to change their situations and improve their outcomes.

This chapter has argued the need for further research concerning the experiences of young carers, and specifically how transition and personal responsibilities affect control. There are also further questions in relation to support, with the model referencing multiple possible interventions including awareness raising of positive messages (T₁), assessments and individualised provision (T₂), and relationship mediation and medical training (T₃). It is also unclear at what point more serious child protection action becomes appropriate for those in the third tier, with this potentially due to there being little research into young carers in the care system, despite the widespread fear among families that young carers can be taken into care. This is another avenue for future research.

13.4.4 Young carer policy and legislation

The lessons learnt up to this point have focused on service provision for the different tiers of the model, but governments continue to have a key role in legislating for improved support and holding services to account. Whereas past provision has been largely aimed at those with greater needs (usually T₂ in the model), it is increasingly evident that there is also a larger population that need occasional assistance, and a small group who need specialist support beyond that which young carer projects currently offer.

Considering the positive message concerning the spectrum needed in schools, policy and legislation should also be framing young carers as a larger and more heterogenous

population. However, despite policy (Children and Families Act 2014; Social Services and Wellbeing Act 2014) defining young carers as children that provide any level of care, there is little indication that they recognise the diverse experiences and impacts of this wider population.

Finally, further investigation is needed into why the support of young carers in schools and health authorities remains a challenge despite repeated legislation (Children and Families Act 2014; The Carers Strategy for Wales 2013; Social Services and Well-Being Act 2014). There are a number of possible reasons for this, but the evidence is limited due to the continuing focus on the experiences of young carers, potentially at the expense of research with professionals on the barriers of implementing provision. Reasons may include the absence of research-informed good practice, which is notably lacking for young carer support, as well as professionals having a lack of time, capacity or financial resources. While engagement with professionals was outside the remit of this research, a final specific recommendation is for an increased focus on working with policy makers and professionals (including education and health professionals) to explore the challenges of identifying, recognising and supporting young carers.

13.5 The future of young carer provision and research

The thesis has charted the progress of young carers research and evidenced how the UK has led the way, predominantly through the use of explorative qualitative research. While this remains the case, there is a growing recognition of the need for a change in direction. Most notably this includes viewing young carers as a spectrum of children with different experiences, comparing young carers to children without caring responsibilities, and improving causation between caring and impacts. This became the starting point for this study and the result is an innovative approach that assessed and utilised methods that were not possible in early research and not revisited since.

In offering final thoughts for the future of young carer research and provision, two ideas stand out. First, with young carers increasingly being defined as any child providing care for a family member with an illness, research should be working with the whole

population. This study set out to study the wider spectrum and, while further research is needed, the inclusion of a broader range of participants in this study enabled original findings concerning control as a way to differentiate between young carers, their experiences and needs. Specifically, problematic caring among children is best conducted in the context of the larger population who have manageable responsibilities.

At the same time challenges remain over how to do this. In terms of quantitative research, multiple cohort studies now include variables on young carer status and amount of caring, enabling comparison of young carers with differing amounts of responsibilities. This is a big step forward but the majority of cohort studies collect data on the same few young carer indicators (status; time spent caring; impacts on school absence). Based on the focus on threats to control identified in this study, additional data is also needed considering duration of time as a young carer, type of responsibilities, family relationships, support being accessed, and perception of control.

While quantitative research is arguably now better placed to identify the wider spectrum of young carers but does not currently collect enough data, qualitative studies continue to struggle with identity and recruitment. This study has highlighted again the longstanding need to identify, recruit and involve young carers not known to services as a hard-to-reach group. This should be a priority going forward.

Second, research needs to become increasingly focused on solutions, meaning the support and interventions that can minimise the negative effects of caring while maximising the benefits. Past research has produced evidence and made recommendations concerning the support services that young carers feel they need. In the case of young carer projects, they have been developed and become a staple for young carers with greater support needs, though further studies of their success are needed. Outside of young carer projects, implementation of research findings has been limited, and evaluations rarer still.

The phenomenological approach used in this study enabled the tracking of a single study participant as they progressed from having been recently identified by the health services, through the accessing of information, training and new equipment for the care receiver, to the identification of substantial benefits. The experience of a single young carer is unlikely to result in widespread change in provision, but it does highlight a

future direction for research that, with the exception of young carer projects, is missing. Evidence is needed not only on the experiences of young carers and the support and interventions that they think they need, but also on the interventions that are developed and whether they benefit young carers. In terms of the best approach to enable this, the longitudinal phenomenology in this study was sensitised to track the changing circumstances of participants, but even so, the following of a participant through the accessing of support was opportunistic. Evaluations of services or, given the lack of current provision, the development and then evaluation of new interventions is the way forward in terms of evidencing the benefits of intervention and improving good practice.

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Appendix A

Glossary of methodological terms

CMO configuration	Diagrammatic representation of the relationship between each mechanism and its context and outcome components. In developing configurations Pawson and Tilley (1997) argued that they can be used in any intervention type.
Concept analysis	A technique developed for the analysis of contested terms by considering definitions in past research. The original technique developed by Walker and Avant (1983) viewed concepts as static and having rigid boundaries, but this study utilises the evolutionary cycle of concept analysis developed by Rodgers (1989). The evolutionary approach analyses how the concept of interest evolves over time, in addition to identifying antecedents that can cause the concept of interest, and consequences of it.
Context; contextual factors	The multiple conditional factors that interact together to affect a mechanism (Pawson and Tilley 2006). If the conditions are favourable the mechanism is triggered, with this affecting the resulting outcomes. Interventions aim to change the context to trigger particular mechanisms.
Critical realism	Philosophy of science developed by Bhaskar (2010). Critical realism concerns the co-evolution of social structures and human agency. This two-way relationship is the result of society governing the behaviour of individuals through rules and meaning, and individuals largely reinforcing but occasionally transforming these rules. The result of this relationship is knowledge that changes over time and space.
Embedded CMO configurations	Embedded configurations are the result of evidence informing different components in multiple configurations. For example, the same data informs the outcome in one configuration and the context for another. Jagosh (2012, 2014) theorised that targeting the first configuration can produce the positive outcome that is then the contextual needed to trigger the subsequent embedded configuration. Therefore, careful targeting of a mechanism can improve the outcome for that configuration but also enable wider system change.
Estimation	The fourth of the SEM steps detailed by Kline (2016). Estimation determines how well the model fits the data. A good fit leads to the model being accepted, while a poor fit leads to respecification or the SEM being aborted.
Fusion of horizon	Phenomenological term developed by Gadamer (2004) and building on the work of Husserl. Gadamer argued that a researcher and participant have their own horizon, a view of the world and phenomena that is shaped by their experiences and beliefs. This can affect the researcher's ability to accurately describe the participant's experience, but a fusion is possible through open and respectful conversation. This enables the development of a shared understanding.

Identification	The second of the basic SEM steps detailed by Kline (2016). Identification concerns the theoretical fitting of the data to the hypotheses. The visual representation developed in the specification stage is transformed into a statistical model with parameters denoting relationships between pairs of variables.
Measurement selection (SEM)	The third of the SEM steps detailed by Kline (2016). Based on the previous identification step, measures are selected for inclusion in the model. Depending on how the data is being sourced, this can inform the content in a survey, or inform which pre-existing dataset that is selected for analysis.
Mechanism	<p>Naturally existing but unobservable phenomena that are under the surface of the social world, mechanisms can be studied through the impacts that they have on people and social structures. They are the causal force in a social system and, depending on contextual factors, produce specific outcomes</p> <p>Interventions aim to target particular mechanisms, in order to improve the outcomes for particular groups. This is done by changing the contextual factors in order to trigger the chosen mechanism (Pawson and Tilley 1996).</p> <p>De Souza (2013) has argued that the focus on the potential of interventions to trigger mechanisms should be elaborated to include the study of pre-existing mechanisms. This enables realist studies of natural systems to inform intervention development, in addition to traditional evaluations.</p>
Mixed methods research	A third approach to research alongside the traditional qualitative and quantitative approaches, mixed methods researchers argue that methods should be selected that best enable the research question to be answered. Mixed methods research has grown in prominence due to a greater focus on rigor, in particular concerning the justification of which methods to use.
Outcomes	The result of a mechanism interacting with specific context (Pawson and Tulley 1996). The outcomes of a mechanism can be positive or negative but interventions target mechanisms with detrimental outcomes in order to enable social change.
Path diagram	Standard approach to visually display SEM models, as developed by Wright (Ho et al. 2012).
Phenomenology	Phenomenology was developed initially by Husserl and is the study of how we experience the physical world. Central to phenomenology is the horizon that is informed by our experiences and affects our view of the world. This has raised questions over how researchers can provide unbiased descriptions of the experiences of others.

Realist evaluation	A form of evaluation research, a family of approaches that assess the success of interventions against their objectives. Realist evaluation is based on critical realist principles and was developed by Pawson and Tilley (1997) to study the success of interventions in triggering mechanisms and enabling positive social change. A key part of realist evaluation is the recognition that interventions affect individuals differently, resulting in the central question: 'What works for whom in what circumstances and what respects?'
Realist synthesis	A form of systematic literature review developed by Pawson and Tilley (2006). The traditional approach synthesises information by comparing the context of different studies when considering the effects. This enables the development of a model for the intervention type, that includes the identification of mechanisms, as well as the consideration of context and resulting outcomes.
Retroductive research strategy	The retroductive research strategy is used in critical realist studies to identify the presence of non-observable mechanisms by witnessing change in phenomena. The two-stage approach involves the initial development of a model hypothesising mechanisms, and the testing of these hypotheses to refine the model (Blaikie 2000).
Specification	The first step of a SEM study (Kline 2016) concerns the visual representation of study hypotheses, with the hypotheses based on the researcher's understanding of the research area.
Structural equation modeling (SEM)	Collection of statistical techniques that were developed to move beyond traditional statistical techniques (Kline 2016). SEM offers the potential for simultaneous calculation of multiple relationships in a designed model, and offers versatility in terms of cross-sectional and longitudinal data. Basics steps have been detailed by Kline as applicable for all studies.

Appendix B

Initial theory building

Mechanisms		Context	
M1	Young people could be pressurised to become a young carer	C1	The size of the family, i.e., the presence of both parents but also grandparents, siblings, aunts, uncles who can take on caring role
		C2	The willingness of other family members to care
		C3	Other family members having time to care alongside study, job, etc
		C4	Child's reason for being a young carer (choice, duty or forced)
		C5	Age of the young carer
		C6	Gender of the young carer
		C7	Ethnicity of the young carer, and their culture's attitude towards family care
M2	Young carers could be exposed to increased responsibilities compared to other young people	C8	The nature of the care-receiver's illness (including disability, mental health, substance misuse)
		C9	The severity of their illness
		C10	Care requirements of the care receiver
		C11	Formal support provided by the local authority
		C12	Family paying for additional support
M3	Young carers could take on inappropriate responsibilities (e.g., manual handling, personal care)	C8	The nature of the care-receiver's illness (including disability, mental health, substance misuse)
		C9	The severity of their illness
		C10	Care requirements of the care receiver
		C11	Formal support provided by the local authority
		C12	Family paying for additional support
		C1	The size of the family, i.e., the presence of both parents but also grandparents, siblings, aunts, uncles who can take on caring role
		C5	Age of the young carer
		C6	Gender of the young carer
		C7	Ethnicity of the young carer, and their culture's attitude towards family care
		C13	Relation of young carer to care-recipient (e.g., mother-son, sibling)
M4	Being a young carer could result in a changed relationships with the person being cared for	C14	Extent of role reversal between the child and the person they care for
		C15	Care-receivers attitude towards the young person being their carer

M5	Young carers could have less time available for other parts of their lives (e.g., education, recreation)	C10	Care requirements of the care receiver
		C10	The size of the family, i.e., the presence of both parents but also grandparents, siblings, aunts, uncles who can take on caring role
		C2	The willingness of other family members to care
		C3	Other family members having time to care alongside study, job, etc
		C16	How time-consuming the care activities are

M6	Family could hide the fact that have disabled person/young carer	C5	Age of the young carer
		C17	Feeling of stigmatisation

Appendix C

Systematic literature search strategy and results

The initial search strategy was divided into two strands due to the varied terminology in young carers and disability studies research.

The initial search was developed in PsychInfo and tested to ensure it was identifying key papers. This was then used as the basis of searches in Medline, Embase, ASSIA, IBSS, Sociological Abstracts and JSTOR, plus the Web of Science citation index.

Search developed and carried out in May 2018.

Summary of results

Database	Results
PsycINFO	4262
Medline	4933
EMBASE	4616
ASSIA	714
Sociological Abstracts	424
IBSS	199
JSTOR	85
Web of Science	285
Total	15518

With duplicates removed: 12391

Source: PsycINFO

Young carers strand

Field 1: Young carer

Subject term	Text word (tw) search
Caregivers	Young carer* Young caregiver* Child

Notes

- 'Caregivers' AND 'Child' terms combined.
- 'Teenage' and 'Adolescent' surrogate terms removed as reduced accuracy.

Field 2: Health effect

Subject term	Text word (tw) search
Mental health Child abuse Child welfare Childhood development Caregiver burden	Mental Emotional Psychosocial Abuse Neglect Parentification

Disability studies strand

Field 1: Disabled person

Subject term	Text word (tw) search
Parenting Parents Disabilities	Disabled parent* Parental disability Parents with disabilities Impaired parent* Parental impairment

Notes

- 'Disabilities' AND 'Parenting', and 'Disabilities' AND 'Parents' terms combined.

Field 2: Health effect on child

Subject term	Text word (tw) search
Child abuse Child welfare Child development	Abuse Neglect Parentification Child welfare Child health Child well-being Child wellbeing

Combining the 2 strands of the search: 4262 results

Source: Medline

Young carers strand

Field 1: Young carer

Subject term	Text word (tw) search
Caregivers Child Child of impaired parents	Young carer* Young caregiver*

Notes

- 'Caregivers' AND 'Child' terms combined.
- 'Teenage' and 'Adolescent' surrogate terms removed as reduced accuracy.

Field 2: Health effect

Subject term	Text word (tw) search
Mental health Child abuse Child welfare Childhood development Child health	Mental Emotional Psychosocial Abuse Neglect Parentification

Disability studies strand

Field 1: Disabled person

Subject term	Text word (tw) search
Parenting Parents Disabled persons	Disabled parent* Parental disability Parents with disabilities Impaired parent* Parental impairment

Notes

- Disabled persons' AND 'Parenting', and 'Disabled persons' AND 'Parents' terms combined.

Field 2: Health effect on child

Subject term	Text word (tw) search
Child abuse Child welfare Child development Child health	Abuse Neglect Parentification Child welfare Child health Child well-being Child wellbeing

Combining the 2 strands of the search: 4933 results

Source: EMBASE

Young carers strand

Field 1: Young carer

Subject term	Text word (tw) search
Caregivers Child of impaired parents Child	Young carer* Young caregiver*

Notes

- 'Caregivers' AND 'Child' terms combined.
- 'Teenage' and 'Adolescent' surrogate terms removed as reduced accuracy.

Field 2: Health effect

Subject term	Text word (tw) search
Mental health Child abuse Child welfare Childhood development Caregiver burden Child health	Mental Emotional Psychosocial Abuse Neglect Parentification

Disability studies strand

Field 1: Disabled person

Subject term	Text word (tw) search
Parent Disability Disabled person	Disabled parent* Parental disability Parents with disabilities Impaired parent* Parental impairment

Notes

- Parents' AND 'Disabilities', and 'Parents' AND 'Disabled person' terms combined

Field 2: Health effect on child

Subject term	Text word (tw) search
Child abuse Child welfare Child development Child health	Abuse Neglect Parentification Child welfare Child health Child well-being Child wellbeing Child development

Combining the 2 strands of the search: 4616 results

Source: ASSIA

Young carers strand

Field 1: Young carer

Subject term	Text word (tw) search
Caregivers Carers Child Children Child of impaired parent	Young carer* Young caregiver*

Notes

- 'Caregivers' AND 'Child' terms combined.
- 'Teenage' and 'Adolescent' surrogate terms removed as reduced accuracy.

Field 2: Health effect

Subject term	Text word (tw) search
Mental health Child abuse Child welfare Childhood development Child abuse and neglect	Mental Emotional Psychosocial Abuse Neglect Parentification Child health

Disability studies strand

Field 1: Disabled person

Subject term	Text word (tw) search
Disabled people Disabled persons Parenting Parents Disabled parents	Disabled parent* Parental disability Parents with disabilities Impaired parent* Parental impairment

Notes

- 'Disabled people' AND 'Disabled persons', and 'Parenting' AND 'Parents' terms combined.

Field 2: Health effect on child

Subject term	Text word (tw) search
Child abuse Child welfare Child development Child health	Abuse Neglect Parentification Child welfare Child health Child well-being Child wellbeing Child development

Combining the 2 strands of the search: 714

Source: IBSS

Young carers strand

Field 1: Young carer

Subject term	Text word (tw) search
Caregivers Carers Child Children Child of impaired parents	Young carer* Young caregiver* Child

Notes

- 'Caregivers' AND 'Child' terms combined.
- 'Teenage' and 'Adolescent' surrogate terms removed as reduced accuracy.

Field 2: Health effect

Subject term	Text word (tw) search
Mental health Child abuse Child welfare Childhood development Child health Child abuse and neglect	Mental Emotional Psychosocial Abuse Neglect Parentification

Disability studies strand

Field 1: Disabled person

Subject term	Text word (tw) search
Disabled persons Disabled people Parenting Parents	Disabled parent* Parental disability Parents with disabilities Impaired parent* Parental impairment

Notes

- 'Disabled persons' AND 'Disabled people', and 'Parenting' and 'Parents' terms combined.

Field 2: Health effect on child

Subject term	Text word (tw) search
Child abuse Child welfare Childhood development Child health	Abuse Neglect Parentification Child welfare Child health Child well-being Child wellbeing Child development

Combining the 2 strands of the search: 199 results

Source: Sociological Abstracts

Young carers strand

Field 1: Young carer

Subject term	Text word (tw) search
Caregivers Carer Child Children Combined Child of impaired parents	Young carer* Young caregiver*

Notes

- 'Caregivers' AND 'Child' terms combined.
- 'Teenage' and 'Adolescent' surrogate terms removed as reduced accuracy.

Field 2: Health effect

Subject term	Text word (tw) search
Mental health Child abuse Child welfare Child development Caregiver burden Child abuse and neglect Child neglect	Mental Emotional Psychosocial Abuse Neglect Parentification Child health

- There were large numbers of low scoring subject areas so only higher scoring terms were used

Disability studies strand

Field 1: Disabled person

Subject term	Text word (tw) search
Disabled persons Disabled people Parenting Parents	Disabled parent* Parental disability Parents with disabilities Impaired parent* Parental impairment

Notes

- 'Disabled persons' AND 'Disabled people', and 'Parenting' and 'Parents' terms combined.

Field 2: Health effect on child

Subject term	Text word (tw) search
Child abuse Child welfare Child development Child health	Abuse Neglect Parentification Child welfare Child health Child well-being Child wellbeing Child development

Combining the 2 strands of the search: 424 results

Source: JSTOR

Young carers strand

Field 1: Young carer

Subject term	Text word (tw) search
	Young carer* Young caregiver*

Notes

- No subject terms/MeSH field
- 'Teenage', 'Adolescent', 'Child carer' and 'Child caregiver' surrogate terms removed as reduced accuracy.

Field 2: Health effect

Subject term	Text word (tw) search
	Mental Emotional Psychosocial Abuse Neglect Parentification

Disability studies strand

Field 1: Disabled person

Subject term	Text word (tw) search
	Disabled parent* Parental disability Parents with disabilities Impaired parent* Parental impairment

Notes

- 'Disabled persons' AND 'Disabled people', and 'Parenting' and 'Parents' terms combined.

Field 2: Health effect on child

Subject term	Text word (tw) search
	Abuse Neglect Parentification Child welfare Child health Child well-being

Combining the 2 strands of the search: 85 results

Source: Web of Science

Young carers strand

Field 1: Young carer

Subject term	Topic search
	Young carer* Young caregiver* Child carer* Child caregiver* Children of disabled parents

Notes

- No subject terms/MeSH field
- 'Teenage' and 'Adolescent' surrogate terms removed as reduced accuracy.

Field 2: Health effect

Subject term	Text word (tw) search
	Mental Emotional Psychosocial Abuse Neglect Parentification Child abuse Child welfare Child development

Disability studies strand

Field 1: Disabled person

Subject term	Text word (tw) search
	Disabled parent* Parental disability Parents with disabilities Impaired parent* Parental impairment

Field 2: Health effect on child

Subject term	Text word (tw) search
	Child abuse Child neglect Parentification Child welfare Child health Child well-being Child wellbeing Child development

Combining the 2 strands of the search: 285 results

Appendix D

Surplus realist synthesis papers

Author	Year	Author	Year
Banks et al.	2002	Smyth et al.	2011
Orel & Dupuy	2002	Griffiths et al.	2012
Pakenham et al.	2006	Kennan et al.	2012
Bauman et al.	2007	Partovi	2012
Pakenham et al.	2007	Andreouli et al.	2013
Stein et al.	2007	Collins & Bayless	2013
van de Port et al.	2007	Sieh et al.	2013
Grant et al.	2008	van Parys & Rober	2013
Thastum et al.	2008	Harrison et al.	2014
Turpin et al.	2008	Kavanaugh et al.	2015
Zhang et al.	2009	Acton & Carter	2016
Ireland & Pakenham	2010	Aeyelts et al.	2016
Ireland & Pakenham	2010	Cunningham et al.	2017
Svanberg et al.	2010	Redmond et al.	2018

Appendix E

CMO configuration component guide

Component	Codes	Evidence	Source
Appreciation	C15b; C16c	There is a suggestive trend that having a parent who does not appreciate them or having too much responsibility might be associated with higher depression, but further research is needed.	Bauman, L.J. et al. (2007)
Appropriateness of responsibilities	M1; C5a	Conversely, conflict arising out of the parent's incontinence might stem from the child or adolescents frustration in dealing with something that does not feel right, or is developmentally out of synch with what a child is supposed to do.	Kavanaugh, M. (2014)
Aspiration to caring career	O8	Participants in this group anticipated using the skills learned in the future or adult life. Several mentioned careers as a doctor. These participants demonstrated a self-driven desire and pride in learning and using these supportive indirect and direct skills.	Kain, C.A. (2009)
Assignment	M7; C8a	One adult said that a first-born child "does all the duties, he/she is not viewed as either a boy or a girl, but can do any duty". Once the first-born child moved away from home, the second born sibling typically took over the caring responsibilities, but with continued support from the older sibling who could send back money or food.	Skovdal, M. et al. (2009)
Care receiver illness	C4c; C15a	The amount of care they provide is directly related to need as defined by the extent of the parent's illness and disability and does not appear to be related to the child's age or gender or the presence of other adults or older siblings.	Bauman, L.J. et al. (2007)
Caregiving responsibilities	M6	The types of responsibilities children undertake when they care vary depending on the nature of parents' illness or disability and the availability of other informal and formal support and assistance.	Aldridge, J. (2006)
Caring identity	M9; C10a	The participants fought hard to marry their roles as carers, the lack of understanding of others, and the perceived negative opinion of caring held by others into an integrated whole. They achieved this by deriving a sense of pride and self esteem from caring, and used this to combat feelings of uncertainty and isolation.	Bolas, H. et al. (2007)
Concentration	O4	I take my siblings to creche (30 mins) and then I go to school. Sometimes I miss school if I have to take her to the clinic - I can't concentrate at school.	Lane, T. et al. (2015)

Confidence	O9	As predicted secondary control engagement was related to greater life satisfaction and primary control engagement was related to greater caregiving confidence and prosocial behaviour.	Fraser, E. & Pakenham, K.I. (2009)
Conflict	O1; O4; O14; O15	Often the person gets angry and shouts at them and the children do not understand why and do not know what they have done wrong. This in turn led the children to argue with their parents or shout back.	Martin, R. (2006)
Coping strategies	O4; O6; C9c; O16	Even marginal differences in children's access to support can have a major impact on whether their active response to adversity enables them to cope or compromises their own safety and wellbeing.	Andersen, L.B. (2012)
Depression	O6; O9; O11; O16	The relationship between parent-child conflict, low emotional support and depression is important in understanding the lives of HD young carers who exist in families where it is not uncommon to experience stigma, shame, embarrassment, and isolation (Vamos, Hambridge, Edwards, and Conaghan, 2007; Aubeeluck and Moskowitz, 2008). These issues may leave the HD family, and the young carer specifically, without many outside resources or support, thus heightening the potential for conflict within the isolated family, leading to depression in the young carer.	Kavanaugh, M. (2013)
Duration of time as young carer	C6c	What is clear is that children's development and childhood experiences can be adversely affected when caring becomes long term and disproportionate, that is, where the onset of practical and emotional responsibility is not congruent with a child's age and level of maturity and understanding.	Aldridge, J. (2006)
Duty	C7a	Children's notion of duty was especially interesting when explored within the context of the 'generational bargain', which posits that parents provide care for children with the understanding that the child, when she/he is an adult and their parent older or elderly, will reciprocate this care (Collard, 2001).	Lane, T. et al. (2015)
Education	C10b	Participants ordered school related tasks as less important than caregiving tasks. For example, homework was considered something to be done between other activities that the young caregivers were involved in.	Kain, C.A. (2009)
Embracing the challenge	C8c	Some of the participants saw the manipulation of the devices, procedures and medications that offer information, comfort or pain relief as interesting, fun and a useful thing to know about and do. They learned to be a caregiver by taking an interest in what was going on around them and embraced the opportunity or challenge to learn new things.	Kain, C.A. (2009)
Employment	C10d	While responsibilities differed according to the circumstances of each household, all the children in our study contributed significantly to wider household subsistence efforts.	Skovdal, M. et al. (2009)

Faith	C8b		Emotional attachments, reciprocity, faith, and the meaning attached to caregiving all helped the children perceive their role positively and thereby cope better psychosocially.	Andersen, L.B. (2012)
Family size	C3b		It also appears that the children of single parents are consistently reported by both themselves and their parents to be involved in greater amounts of domestic and caring work than the children of dual-parent families.	Olsen, R. & Clarke, H. (2003)
Family stability	O8; O16	O14;	The majority of participants identified their healthy parent as the chief means of family support, followed by siblings and extended family. Important aspects of the healthy parent's role include providing information, emotional support, and a sense of stability.	Nichols, K. et al. (2013)
Fluctuating carer role	C4d		it is especially important to recognise how the fluctuating dynamics of the parent's health becomes reflected in the child's caregiving activities; therefore, during periods when the parent's condition has strengthened, the vulnerability of the caregiving child may be hidden.	Andersen, L.B. (2012)
Frustration	O9; O16	O13;	The adolescents in the online self-help group expressed their need to be informed early enough about their parent's mental illness and to be involved in important conditions and decisions that affected them. However, they experienced a lack of information and openness about the mental illness both inside and outside their family, which was emphasized as a source of concern, fear, and frustration.	Trondsen, M.V. (2012)
Hope	O14		In addition, school was also identified as a place of hope, helping children to believe in themselves and to construct hopeful representations of their futures.	Skovdal, M. et al. (2009)
Identification	C14c		In most cases, even where health and social care professionals were visiting the family home, children's contributions and needs were overlooked or discounted. This was not necessarily a deliberate oversight, but appeared to be due to a lack of recognition of the triggers for the contexts in which young caring occurs.	Aldridge, J. (2006)
Involvement in decision making	C14d		As such they will generally not be consulted in decisions such as who will care for the sick person and, once caring, may not be consulted or even told about a change of plan or new treatments.	Martin, R. (2006)
Isolation	O9; O14	O11;	The perceived stigma attached to caring and the lack of understanding in others left the participants feeling vulnerable to being misjudged or rejected. The fear of negative reaction and attribution led them to withdraw from others, and in each case they felt the need to conceal and deny an important and consuming part of their lives and identity; being a carer.	Bolas, H. et al. (2007)
Knowledge	O14		The most frequently reported form of assistance gained from the camp by children was increased knowledge and understanding of MS (79%).	Coles, A.R. et al. (2007)
Less personal time	O4		Continuous caregiving made them unmindful and they were unable to pay attention to their own activities.	Sahoo, R. & Suar, D. (2010)

Level of care	M5; C6a	Since my grandmother became sick I now have to take on more responsibilities and I am always worried and sometimes lose my mind. If she's sick I'm not even going to play. I just want to stay at home and look after her.	Lane, T. et al. (2015)
Life management	M10	They struggled each day to manage complexities related to adolescence and social life, school, and caregiving that were constantly changing.	Kain, C.A. (2009)
Number of care receivers	C4b	As the disease took stronghold, reducing the number of active adult members within her household, Beryl's caring responsibilities intensified.	Skovdal, M. (2011)
Other family members in employment	M2; C3a	Another 16-year-old girl described how her responsibilities were dependent on the availability of people willing and able to help: 'If there is a shortage of people in my home, for example my mother is at work, I must help.	Lane, T. et al. (2015)
Personal needs	C10c	Despite being a major developmental task, making friends and maintaining friendships often took a low priority for the young caregivers in this study.	Kain, C.A. (2009)
Positive family relationship	O6	Emotional parentification was associated with predominantly negative outcomes among European Americans (e.g., increased externalizing behavior problems), yet with positive outcomes among African Americans (e.g., increased parent– child relationship quality).	Khafi, T.Y. et al. (2014)
Professional carer support	C3d; M12; C14a	The child caregivers received only occasional support from CHWs. Only 10 of the care recipients were linked with a CHW, who might help to bathe and feed the care recipient, clean bedsores or carry food.	Olang'o, C.O. et al. (2012)
Prosocial behaviour	O9	Going through stressful events in the family was positively associated with pro-social behavior by adolescents growing up with a sick family member.	De Roos, S.A. et al. (2017)
Proud	O1	Even though he may not recognize us at first, if we start to play with him, or we start cracking jokes, or we do stuff that's familiar to him, he'll smile and laugh a bit. And that makes it worth it.	Nichols, K. et al. (2013)
Provision of young carer intervention	C14e	Often, the needs of children in these contexts can be accommodated by, for example, referral to dedicated services such as those provided by young carers projects. Both children and parents alike value services such as those offered by young carers projects.	Aldridge, J. (2006)
Reason for becoming a young carer	M8; C9a	Conceptualizing the critical event of becoming a young adolescent caregiver as following the three distinct paths of embracing a challenge, sharing the load and being assigned offers new ways of thinking about the experience from the perspective of the young adolescent caregiver.	Kain, C.A. (2009)

Resilience	O9	They suggested that resilience in young carers was enhanced through a positive identity as a carer based on social recognition of the value of the caring role.	Cassidy, T. & Giles, M. (2013)
Risk of family poverty	C2a	Eventually Juan had to stop working and was no longer able to manage the family's bills and finances... As a result, the family's finances decreased drastically.	Gelman, C.R. & Greer, C. (2011)
Risky behaviour	O6	Girls were more likely to report sleeping difficulties and eating difficulties, problems at school and higher levels of truancy... Girls were much more likely to state that they had used drugs or alcohol 'to shut off', and had self-harmed.	Cree, V.E. (2003)
Self-harm	O6	Disturbingly, almost 50% of girls had self-harmed at some time, and 19% (almost one in five) had 'often self-harmed'. The fact that 20% of boys admitted to self-harming is also noteworthy.	Cree, V.E. (2003)
Sharing the load	C8d	Yes, I think so. Things just need doing so I help. I want to help because if I take some of the work off my dad, then my mum and dad will be more relaxed and happy'.	Olsen, R. & Clarke, H. (2003)
Sibling carer	C4e	One 18-year-old girl explained: 'Since my mom got sick [HIV/AIDS] I've had to take on more responsibilities and be a mother to my sister and brothers'.	Lane, T. et al. (2015)
Sleep problems	O6	Further investigation demonstrated that some kinds of problems increased with age, including sleeping difficulties, eating problems, truancy, trouble with the police, substance abuse, self-harm and worries about not having friends.	Cree, V.E. (2003)
Social recognition	C9b; C11c	This strong community ethic which often made support available to children during times of hardship also shaped the way children themselves articulated a strong ethic of responsibility to care for those in need of support.	Skovdal, M. et al. (2009)
Social services capacity	C12a	Enhancing the coordination of home-based care workers and strengthening the supply of resources would improve the effectiveness of community health services. Regular visits from community health workers and better supplies would create a far more supportive context in which caregiving children navigate as they seek resources and support.	Andersen, L.B. (2012)
Sole or joint carer	M3; C4a	Each of these young people in the sample felt they were the only ones available to provide all of the care that was required by their family member.	Moore, T. et al. (2011)
Stigma	C11a	Children felt that caring for a sick relative affects their relationships with friends and neighbours. They talked of negative comments and stigma associated with looking after a sick person, being referred to for example as a "son of an HIV-mother".	Olang'o, C.O. et al. (2012)

Stress	O6; O11; O13; O14	Just as with age, some problems and worries had specific gender significance. Girls... worried about their school work more than boys. Relationships with peers were another particular source of anxiety for girls: 72% recorded problems in falling out with friends (vs. 52% of boys) and 58% worried about not having friends (vs. 20% of boys).	Cree, V.E. (2003)
Supported and recognised	M17	The types of responsibilities children undertake when they care vary depending on the nature of parents' illness or disability and the availability of other informal and formal support and assistance.	Aldridge, J. (2006)
Supportive community	M11; C17a	Immediate family members tended to work together in providing care and support, and extended family members could provide resources and extra support when required. Neighbours, schools and community groups, some initiated by the children themselves, could also be significant coping resources.	Skovdal, M. et al. (2009)
Supportive family	M16; C17c	The majority of participants identified their healthy parent as the chief means of family support, followed by siblings and extended family. Important aspects of the healthy parent's role include providing information, emotional support, and a sense of stability.	Nichols, K. et al. (2013)
Supportive services	M14; C17b	A critical factor that influences the onset and extent of care responsibility among children is the type and adequacy of health and social care interventions.	Aldridge, J. (2006)
Time spent caring	M4; C5b	When Julie was 10 years old, her mother and father fell seriously ill and spent nearly a year continuously bedridden and going in and out of the hospital. They both lost a great deal of weight. During this time Julie provided close care for both her mother and father, carried out most of the household duties, and looked after her two younger sisters.	Andersen, L.B. (2012)
Understanding friends	C11b	Thus, there is the need for friends "to get" what they do and to understand the caregiving experience. These understanding friends would allow the young carer to feel as though they were accepted, they belong, and less "othered" in their social sphere.	Kavanaugh, M. (2014)
Value of role	O9	That is, caring is a relentless task misunderstood by others who underestimate its impact and conceptualize it as 'helping'. The carers themselves maintain this invisibility by being secretive about their roles as carers, motivated by perceived stigma. This creates a dilemma that these young people are unable to resolve; wanting to be understood and recognized for their caring roles, and feeling forced into being secretive about these roles.	Bolas, H. et al. (2007)
Victimisation	O7	"I have other brothers, but they have given up on caring for her. I sometimes feel that I should not have been born. For this reason, I curse the day I was born, like I curse the job of caring."	Skovdal, M. et al. (2009)

Willingness of other family members to care	C3c	In some cases we found that another adult in the home or even another parent and/or sibling exacerbated the child carer's feelings of being punished by failing to support them, failing to take on caring duties themselves and by directly electing them into the caring role.	Aldridge, J. & Becker, S. (1993)
Young carer - care receiver relationship	M15; C16a	Participants talked about specific symptoms of FTD and the impact on the relationship with the patient and others... The discussion centered on symptoms such as personality and behavioral changes, and difficulties with communication, judgment, memory and emotion.	Nichols, K. et al. (2013)
Young carer identity	C1a; C6b; C13a	Analysis suggested that there were age and gender factors associated with the reporting of problems and worries in relation to well-being.	Cree, V.E. (2003)
Young carer informed	M13; C14b; C16b	The adolescents in the online self-help group expressed their need to be informed early enough about their parent's mental illness and to be involved in important conditions and decisions that affected them. However, they experienced a lack of information and openness about the mental illness both inside and outside their family, which was emphasized as a source of concern, fear, and frustration.	Trondsen, M.V. (2012)

Appendix F

LSYPE1 variables, including response options

Variable	Question	Response options
CareStatus	Some people your age may have to look after other people. This could be a brother or sister, a relative or someone else who is disabled or sick. Is there anyone like this who lives here with you that you have to look after on a regular basis?	1. Yes - in this household 2. No Don't know
CareStatus1	Do you regularly look after any ill, disabled or elderly relatives or friends aged 15 or more and in need of care, without being paid? This includes both people who live here with you and those who live elsewhere	1. Yes - in this household 2. No Don't know
CareWho	Who do you look after?	1.Father/mother 2.Grandfather/mother 3.Brother/sister 4.Another adult – related 5.Another adult - not related 6.Another child – related 7.Another child - not related Don't know Multicoded: up to 3 codes
CareHours	About how many hours a week would you say that you usually spend looking after this person (these people) or doing things for them?	Numeric: 1..168 Don't know
MissSchool	Do you ever have to miss going to school because you have to look after them?	1. Yes 2. No Don't know Refused
MissSchool1	How often do you have to miss school to do this?	1. Once a week or more often 2. Once or twice a month 3. Less often than this Don't know Refused
SleepLoss	Have you recently lost much sleep over worry?	1. Not at all 2. No more than usual 3. Rather more than usual 4. Much more than usual 5. Don't know 6. Don't want to answer
UnderStrain	Have you recently felt constantly under strain?	1. Not at all 2. No more than usual 3. Rather more than usual 4. Much more than usual 5. Don't know 6. Don't want to answer
Difficulties	Have you recently felt you couldn't overcome your difficulties?	1. Not at all 2. No more than usual 3. Rather more than usual 4. Much more than usual 5. Don't know 6. Don't want to answer

EnjoyActivities	Have you recently been able to enjoy your normal day-to-day activities?	1. More so than usual 2. Same as usual 3. Less useful than usual 4. Much less useful 5. Don't know 6. Don't want to answer
FaceProblems	Have you recently been able to face up to your problems?	1. More so than usual 2. Same as usual 3. Less useful than usual 4. Much less useful 5. Don't know 6. Don't want to answer
Depressed	Have you recently been feeling unhappy and depressed?	1. Not at all 2. No more than usual 3. Rather more than usual 4. Much more than usual 5. Don't know 6. Don't want to answer
LowConfidence	Have you recently been losing confidence in yourself?	1. Not at all 2. No more than usual 3. Rather more than usual 4. Much more than usual 5. Don't know 6. Don't want to answer
Happy	Have you recently been feeling reasonably happy, all things considered?	1. More so than usual 2. Same as usual 3. Less useful than usual 4. Much less useful 5. Don't know 6. Don't want to answer
Concentration	Have you recently been able to concentrate on whatever you're doing?	1. Better than usual 2. Same as usual 3. Less than usual 4. Much less than usual 5. Don't know 6. Don't want to answer
Useful	Have you recently felt you were playing a useful part in things?	1. More so than usual 2. Same as usual 3. Less useful than usual 4. Much less useful 5. Don't know 6. Don't want to answer
Decisive	Have you recently felt capable of making decisions about things?	1. More so than usual 2. Same as usual 3. Less useful than usual 4. Much less useful 5. Don't know 6. Don't want to answer
Worthless	Have you recently been thinking of yourself as a worthless person?	1. Not at all 2. No more than usual 3. Rather more than usual 4. Much more than usual 5. Don't know 6. Don't want to answer

Sex	Respondent is...:	Male Female
DoB	What is your date of birth?	DATETIME Refused
Ethnic	To which of the groups on this card would you say you belong?	White 1. White – British 2. White - Irish 3. Any other White background (specify) Mixed 4. White and Black Caribbean 5. White and Black African 6. White and Asian 7. Any other mixed background (specify) Asian or Asian British 8. Indian 9. Pakistani 10. Bangladeshi 11. Any other Asian background (specify) Black or Black British 12. Caribbean 13. African 14. Any other Black background (specify) Chinese or Other ethnic group 15. Chinese 16. Any other (specify) Don't know Refused

Appendix G

School information sheet

DECIPHER

Development and Evaluation of Complex
Interventions for Public Health Improvement
A UKCRC Public Health Research Centre of Excellence



CASCADe

Children's Social Care
Research and Development Centre
Candïan Ymchwili a Datblygu
Gofel Cymdeithasol Plant

Caring Lives: What do young people who care for members of their families need to thrive? School information sheet

Project summary

Caring Lives is an innovative research project seeking to build and test a theory of the relationship between young carers and their mental health. Unlike the majority of young carer research the project will be school based, with the final stage to consider the potential for positive support interventions in schools.

The researcher

Ed Janes is a doctoral student in Cardiff University. With a background in children's rights, participation and youth work, Ed has extensive experience of developing and facilitating engaging research in schools.

Background

Research into the lives of children and young people who care for someone at home due to a chronic illness or disability has identified a range of impacts. These have been predominantly negative with impacts on their education and aspiration, social lives, mental and physical health, though benefits have included increased independence, resilience and empathy.

The profile of young carers is continuing to rise in both the mass media and government policy, with increasing responsibilities on education, health and social care professionals to identify and support young carers. However research to date on the nature of this support is limited.

Project aims

The project concerns the development of a theory of the links between young carer status and mental health. The school-based research will then be used to refine this theory, leading to consideration of how future interventions could be school-based and with a focus on positive support of young carers in their role.

What are the ethical considerations for this research?

The majority of research with this group has been conducted in young carers projects due to a reluctance of families to disclose that their child is a carer. However in working with known and supported young carers they are not representative of the wider young carer population.

In designing a school-based project ensuring the confidential status of unknown young carers is paramount. Confidentiality will be kept through a flexible approach that will depend on the individual schools involved and their processes. While the project will be for any young carers of secondary school age (including sixth form where appropriate) it will also seek the consent of all parents as well as participants.

This approach has been approved by the School of Social Science's Ethics Committee in Cardiff University.

How will schools be involved?

1. A meeting to discuss the project with the relevant staff member(s) in interested schools.
2. Information dissemination to all pupils, potentially through email, poster or presentation
3. Information dissemination to parents to raise awareness of the project and seek informed consent.
4. Up to three creative interviews will be held with individual participants over the course of a year. The confidentiality of participant carer status will be a key factor in where the interviews are held.

Relevance to schools

Schools are increasingly required to support young carers despite the absence of research in the setting. This is an opportunity to be involved in a school-based young carer research project that in addition will have a focus on positive support.

The identity of participants will remain confidential but the results from the individual schools will be shared as well as the overall themes.

The research will consider potential school-based interventions, with participating schools having the potential to be involved in further opportunities.

For further information, or to arrange a meeting please contact Ed Janes:

Email: JanesE3@cardiff.ac.uk

Tel: 029 2087 0285

Mobile: 07941614432

Appendix H

School procedure (template)

DECIPHER

Development and Evaluation of Complex
Interventions for Public Health Improvement
A UKCRC Public Health Research Centre of Excellence



Caring Lives: What do young people who care for family members need to thrive?

Individual school procedure: [School name]

[School name] lead contact:	[POC]
[School name] additional contacts	[POC]
Cardiff University researcher	Ed Janes

Project summary

[School name] is involved in Caring Lives, a Cardiff University research project with the central aim to develop and refine a theory on the relationship between young carers and mental health. This will enable the consideration of potential future interventions with a focus on positive support of the group.

The project will include interviews with individual young carers in the school setting, with the use of creative methods to help them discuss their family situation, caring responsibilities and their health and well-being.

As a participating school involvement includes supporting the recruitment of young carers through initial information dissemination to all pupils. Once consent has been gained from both young people and parents, the school will provide a space for confidential interviews between the researcher and the individual participants.

Procedure for [school name]

The Ethics Committee in Cardiff University's School of Social Sciences have approved a flexible approach to suit the processes of the individual schools. The additional information below relates to how the project will run in [School name].

Information dissemination

Ed will be giving a short (maximum 10 minutes) assembly presentation that will suit the age of the pupils as a whole. The presentation will include an introduction of what young carers are, what the research is about and why it is important. We will then look at how pupils can be involved and focus briefly on the ideas of consent and confidentiality.

Ed will also let them know that all pupils will receive an email with information about the project following the assembly. This email will reinforce information for the presentation and include Ed's contact details for pupils to contact.

Parental consent

Parental consent will be sought for all interested pupils irrespective of age, with them sharing the contact details for their parents. Parents will receive separate information with additional detail, and will be able to contact Ed with queries before deciding whether their child can be involved.

The consent for this is opt-in. A child will not be involved unless explicit consent from parents is received.

Young person consent

The first meeting with the young person will include a reminder of what the research is about. They will be able to ask questions and will then be asked to give informed consent by completing a form.

Ensuring confidentiality of young carer status

A central aim of the research is to work with both supported and unsupported young carers to see how support affects their lives. This means that the young carer status of some participants may not be known by their school. While the research can stress the benefits of young carers being known in their school the research can not disclose the status of unknown carers.

[School name] have a confidential advisory service for pupils. The research will run through the same processes to set up meetings during the Spring and Summer terms. With the future of the school uncertain meetings in the Autumn will potentially happen in the community.

School-specific report

While the confidential nature of the research will prevent discussion of individual participants feedback will be produced for each school, reporting on key issues relevant to that school and the support of young carers.

Appendix I

Pupil information sheet (template)

DECIPHER

Development and Evaluation of Complex
Interventions for Public Health Improvement
A UKCRC Public Health Research Centre of Excellence



Caring Lives: Young person's information sheet

IN BRIEF

The project: Caring Lives is a research project looking at the link between young carers and mental health. If you think you might be a young carer you can read on for more information on how you can be involved, plus information on how this is a confidential project for young carers who do not wish to be known.

The researcher: Ed Janes has worked with young people on research projects on young carers, children's rights and poverty. He has a background in youth work, and young person friendly methods will be central to the project.

JanesE3@cardiff.ac.uk



What makes someone a young carer?

A young carer is a child or young people (under 18) who takes on extra responsibilities at home because someone in their family is unwell. This can include an illness or disability, mental health issue, or a substance misuse problem.

We know from a Cardiff University survey last year that 1 in 6 young people see themselves as a young carer.

What is Caring Lives about?

Researchers have been studying young carers for about 25 years, and we know that being a young carer can affect education, social lives, physical health and mental health. BUT it is not all negative – research has also found that young carers can be more independent and develop extra skills for later in life.

Caring Lives is focusing on young carers and their mental health (this includes areas like confidence, stress and mood). It will build a bigger picture of why caring affects young carers differently which has not been looked at before.

Why is this research important?

This bigger picture will help us move from a focus on the effects of caring to thinking about possible solutions. It has the potential to change how young carers are supported by schools and other groups.

What does being involved mean?

Taking part will mean meeting with Ed 2-3 times in the next year. The first meeting will be in this term.

All the meetings will be activity-based and informal. We will chat about your family, the caring that you do, and if you feel affected by it.

This project has an incentive of a £10 gift voucher in the first meeting, and another £10 voucher in the last. This is to thank you for your time and knowledge.

What else do you need to know?

- This research is **confidential**: Ed will be working with [POC] who leads your Well-Being in your school. Other teachers and school staff will not know that you are involved.
- The sound from the meetings will be **audio-recorded**. This is to make sure that information is not lost. Your name and any names mentioned in the recordings will be removed.
- This project will need **parental consent** for everyone (including over 16s).
- The project will also need **your consent** that you knew all the details of the project. This will be sorted at the first meeting.

Want to know more?

If you want to know more you can speak to [POC]. If you then decide that you are interested some information and a consent form will be sent to your parents or guardians.



Appendix J

Parent information sheet and consent form (template)

DECIPHER

Development and Evaluation of Complex
Interventions for Public Health Improvement
A UKCRC Public Health Research Centre of Excellence



Caring Lives: Parent and guardian's information sheet

IN BRIEF

The project: Caring Lives is a research project looking at the link between young carers and mental health. Your child attended an assembly in [school name] on the project, and you are receiving this because they are interested in taking part. Please read on for more information about how we are working with schools and how pupils will be involved. This sheet also includes further information about how the project is confidential, the need for parental consent and how data from the project will be stored.

The researcher: Ed Janes has been working with young people for over 15 years as a youth worker and facilitator. He has worked with young people on topics including young carers, children's rights and poverty. He is now a 2nd year postgraduate student and is studying to be a doctor.

As the research is with under 18s Ed has had a recent criminal record check and has been cleared to work with young people.



JanesE3@cardiff.ac.uk

What makes someone a young carer?

A young carer is a child or young people (under 18) who takes on extra responsibilities at home because someone in their family is unwell. This can include an illness or disability, mental health issue, or a substance misuse problem.

We know from a Cardiff University survey last year that 1 in 6 young people in Wales see themselves as a young carer.

Young carers research?

Past research has found that being a young carer can impact on education, social lives, physical health and mental health. We call these outcomes BUT they are not all negative – there is also evidence that young carers can be more independent and develop extra skills for later in life.

However there is a lot that we still don't know and this includes why the outcomes vary for different young carers. Some researchers think that it may be to do with the different circumstances of each young carer and their families but this has not been mapped in detail.

What is Caring Lives about?

Caring Lives is focusing on young carers and their mental health (for example confidence, stress and mood). It will map out why the outcomes vary for different young people.

This research is important as a more detailed picture will increase our knowledge of what different carers need, and potentially change how young carers are supported in the future.

What has happened already?

The project is working with schools across South Wales, and we recently delivered a whole school assembly in [school name] that raised awareness of young carers and introduced the project. This was followed by a letter that pupils took home.

How will young carers be involved?

Young people who take part will meet with Ed 2-3 times in 2019 with the first meeting in the spring term, and additional meetings in the summer and/or Autumn.

The first meeting will begin with a reminder of the project and the chance to ask questions. We will also talk about their right to not answer particular questions and to stop taking part in the project at any time. If they are happy to proceed they will give their consent to continue. We will then be using creative methods to discuss topics like their caring responsibilities, their wider family situation and their health.

The second and third meetings will return to parts of the previous meeting and look at any change in their life.

Some of the meeting will test ideas from previous research. It is recognised that some of the content is sensitive, and we will only discuss what the young carer is happy to talk about.

Confidentiality

We know that this is a sensitive topic and that some families don't want their school to know that their child is a young carer. If your child is not known as a young carer we will maintain their confidentiality. This means that the school will not know the names of the individual young people taking part or what they say.

This will be achieved through working with the school's Well-Being Team who regularly advise and support pupils confidentially. Meetings will be arranged through the Well-Being Team and held in their meeting space.

If you would prefer the meetings to be held outside of the school this can also be arranged. These would be held in the evening or on the weekend.

The only exception to confidentiality is if a young person indicates that they, or someone they know, is being abused or at risk of abuse.

How will my child's data be secure?

The storage and use of data will be in line with data protection law:

- Audio from the meetings will be recorded for accuracy, and will be stored on a password protected university network drive. The recordings will be transcribed and anonymized, with references to names of particular people removed.
- Any paper transcriptions and materials from the meetings will be kept in a secure locked cupboard. The DECIPHer office and building also has security.
- Recordings will be retained for at least 5 years, or at least 2 years post-publication. They will then be destroyed as required by the Data Protection Act.

Can I refuse consent?

Yes, you have complete control over whether your child takes part. This project has opt-in parental consent so your child can only participate with your permission. Not responding to this request will be treated as a refusal, and means that they will not be involved.

Ethical approval

Universities have ethics to ensure the safety and well-being of people taking part in research. This project, including the method for working with young carers, has been approved by Cardiff University School of Social Sciences Research Ethics Committee.

For more details about the ethics for this project please contact the Ethics Committee (socsi-ethics@cardiff.ac.uk), using the reference no: 2869

What's next?

If you have any additional questions about your child's involvement or the wider research you can contact Ed Janes by email (JanesE3@cardiff.ac.uk), or phone (029 2087 0285).

If you're happy for your child to take part please complete the consent form on the next page, and return it to Ed. He will then be in touch with your child about the first meeting.

Researcher details

Ed Janes
DECIPHer, School of Social Sciences, Cardiff University, 1-3 Museum Place, Cardiff, CF10 3BD
JanesE3@cardiff.ac.uk
07941614432 / 029 2087 0285

Caring Lives: What do young people who care for family members need to thrive?

Parent/guardian consent form (December 2018)

I have read and understood the parent/guardian information sheet and have had the chance to ask questions about the study via e-mail and telephone

Please initial

I confirm that I am happy for my child to take part in the research study

Your name:

Address:

.....

Child's name Email/Tel:

School:

Signature:

Date:

Please return this form by post or email to:

Ed Janes

DECIPHer, School of Social Sciences, Cardiff University, 1-3 Museum Place, Cardiff, CF10 3BD

JanesE3@cardiff.ac.uk

07941614432 / 029 2087 0285

Appendix K

Participant assent form



Consent form

The first meeting will include a reminder of the project and the chance to ask questions. Please tick the boxes below as we go through the information and sign at the bottom.

Name: _____

I have been told all about the project, and had any questions answered. ☐

I know that the meetings are being recorded for accuracy, and that all names will be removed. ☐

I have been given a support sheet with contact details for advice organisations ☐

I know that my involvement is voluntary, and that I don't have to answer questions ☐

Signature: _____ Date: _____

Appendix L

Participant support sheet (template)



Caring Lives: Support sheet

The project is about the lives of young carers, the people that young carers support and the wider family, and some of the questions are personal. If you have a question after we meet or want some advice about something that we talked about please contact me. My details are as follows:

Tel: 02920 870285

Email: JanesE3@cardiff.ac.uk

If you want to talk to someone outside of the research there are several places that you can go. Some are people that you know, while others will give you confidential advice:

[local project name]: As you are already a member of this project and know both the other young carers and the people who work there, they would be a good group to speak to for advice.

Your family: You can speak to a parent, sibling or someone else in your family. They will also know about the caring that you do so will be a good person to give you advice.

Your School: All schools support pupils differently but most have a person (or team of people) who give extra support to pupils when needed. This support is often confidential which means the information will not be shared with the wider school.

You could also speak to a teacher that you trust or get on well with. This may not be the best person if you don't want to be known as a young carer.

Carers Trust: A UK wide group for carers of all ages, but with a focus on young carers. Visit their website for information and links to a range of groups and resources.

www.carers.org

Meic: This is an information and advice group for all young people in Wales including young carers. You can contact their confidential helpline by phone or online.

Tel: 08088 023456.

Web: www.meiccymru.org

Appendix M

Interview One: Topic guide

Interview 1 schedule

Interview length: 60 minutes

Date:

Interviewee name:

School:

Introduction

Thanks

Aim of meeting

- Reminder and questions
- Consent
- Recording for accuracy (removal of name)

Check

Project aims

- Young carers and mental health
- Why the effects vary – particularly interested in positives as well as negative
- How the interviews will work – today and in future
- Confidentiality for yp projects

Check / Consent for information/audio

Support sheet

Check/Consent

Voluntary

Check/Consent

Thanks

Section 1: About you.

First sheet to think about you and person you care for

- Encourage to use all the time
- Let me know if really don't like writing
- Good to get to know you a little better.

Can you tell me a few things about yourself?

- And if you had a day where you could do anything you want (can be caring or not caring), what would you do?

Section 2: Care receiver

- Talk about person you care for

First of all who is it that you help to care for?

Can you tell me a little bit about their illness?

- How long have they been unwell?
- Can you give me an idea of how it affects their daily life

Section 3: Caring responsibilities

- Talk about you as a young carer

Could you tell me a little about the type of things you do to help at home?

- Of these, are there any particular tasks that you find easy or difficult. Why is this?

Roughly how long have you been a young carer?

- So you've cared for them since they became unwell?
- So you were not caring for them when they first became unwell?

How much time do you think you spend caring?

- How has this changed over time?

How do you balance caring around other areas of your life?

- What about school / social stuff?

We've talked a lot about the support that you give them. Can you tell me a little bit about how they support you as a parent?

Do you feel overall that you have a good relationship with [x]?

- Has your relationship changed since you have begun caring for them.

Do you feel that they appreciate the support that you give them?

Section 4: Wider family

- Want to know a little about wider family

Can you draw/write the other members of your family, and a little about them

- And how old are your siblings?
- So is your mum/dad in work?

Do other family members help with caring too?

- And how do you decide who takes on what responsibilities?
- Is there any reason why other family members are not helping with caring?

Just before we move on can I ask whether your family has any support from a professional carer? Again can you draw them

- Ok great. Can you give me an idea of how often they come and the ways in which they help.
- Is this because your family does not want support, or have you not been able to get the help?

Section 5: Choice

- Finish section with some questions about why you are a young carer.

So do you feel that is your own choice to be a young carer?

- Can you write why you do it on the sheet
- Do you feel that you could stop being a young carer if you wanted to? How would you do this?

Section 6: Support from services

- Like to ask you about support you and family receive (eg school, social services, young carer group, health)
- Smaller sheet for each

Just to check first of all, who knows that you're a young carer?

- And is that because you or members of your family told them?

- So does that mean that these groups don't know you're a young carer? (Shows particular cards)
- Is there a reason why you and your family have not told these groups?

Thinking about the school card first, can you rate your school for the areas on the sheet

And there is one for health services – these are about [x]'s GP, doctor nurse etc

Can you now do the same for social services

Can I also ask you about this service?

- Will you tell me a bit about it and what you do here?
- How long have you been coming?
- And does it link in with social services

Overall, do you feel that you are supported to be a young carer?

- Why is this?
- An example of this would be really useful
- Do you feel that you can request extra help, and that you will get it?

Section 7: Community support

- Whether feel supported by people in the area you live in too.

Do people in your community know that you care for someone in your family?

- Can you fill in this final sheet on whether you feel supported by them.
- Is there a reason why they don't know?

Have you told any of your friends?

- Has this been a benefit?
- Is there a reason why you haven't told them?

So overall you've said that you do/not feel valued for what you do as a young carer. Is that correct?

So if you ever needed more help and asked for it, do you think you would get it?

Section 8: Impacts

- Define mental health as broad topic
- How we feel about ourselves, our emotions and our relationships with other people.
- Someone's mental health can be both good and bad - again I'm interested in both sides.

I have a number of areas of health that young carers have spoken about but before we do that I'd like to ask you to write down 3 words about how you feel about being a young carer.

Can you explain the three words you've written down.

This is a set of good and bad impacts from other young carers. Not all will be relevant to you but can you pick out those that are

- So why have you picked out each of these?

Section 9: Perception of young carers

- Lastly, 2 questions on young carers more broadly.

Do you think young carers have an important job?

And do you value being a young carer

- Why/Why not?

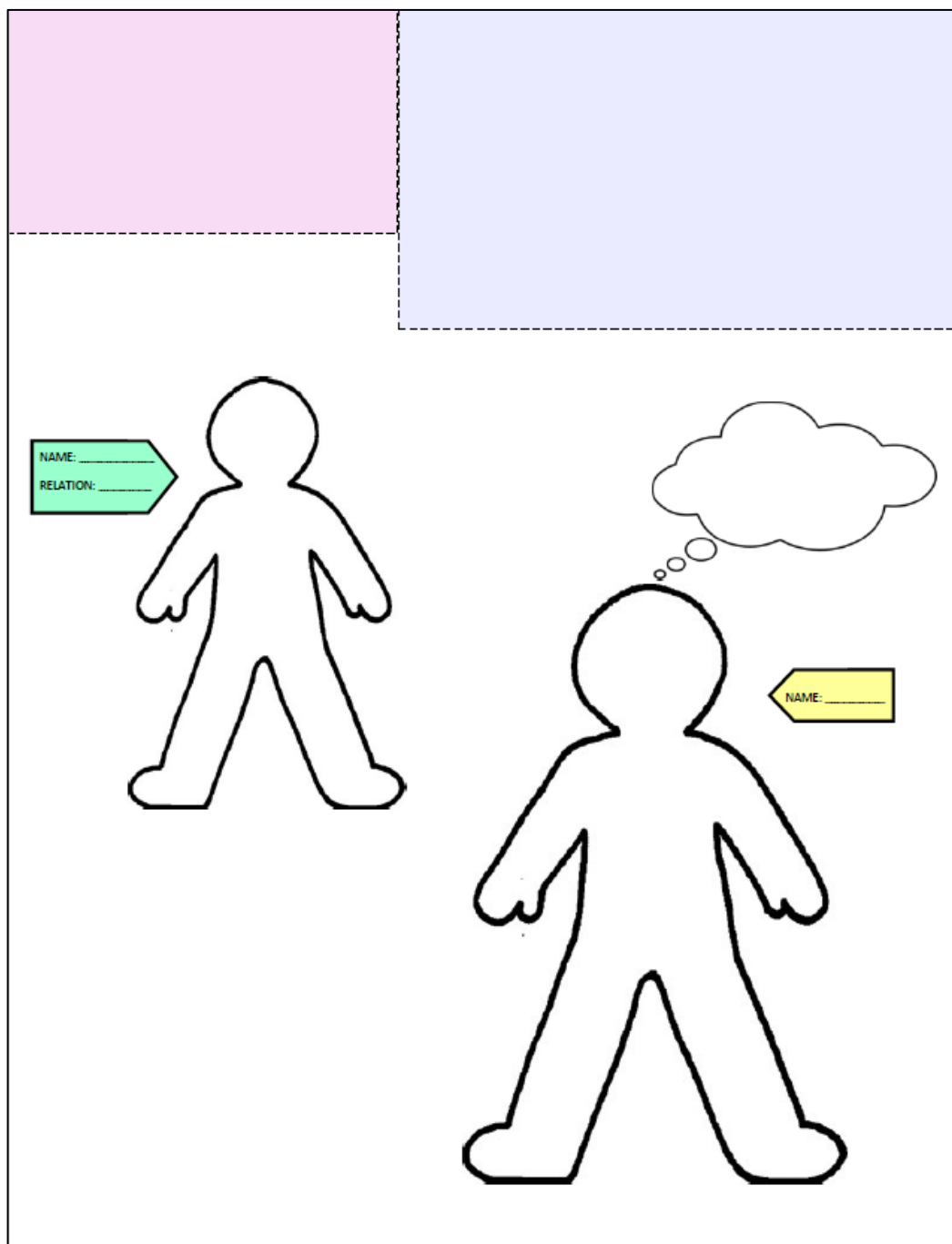
End

- It for today
- Realised covered a lot and that sensitive
- Thanks again

CHECK






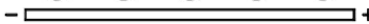
- Will be in touch in Summer / Autumn term
- Meet again to look at any change
- Check somethings with you
- Welcome to contact me in meantime with any questions


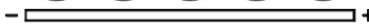




Appendix N
Interview One resource: Two-person body in a box activity






Appendix O

Interview One: Service support scales




SCHOOL	
My school knows the different ways that I help out at home	 -  +
They give me the support I need	 -  +
They see the value in what I do as a young carer	 -  +

SOCIAL SERVICES	
Social services know the different ways that I help out at home	 -  +
They give me the support I need	 -  +
They see the value in what I do as a young carer	 -  +

HEALTH (eg GPs, nurses, hospital doctors)

They tell me what is happening	
They listen to me and ask me what I think	
They see the value of what I do	

COMMUNITY (eg friends, neighbours)

Our neighbours help me or offer to help	
I feel that I can talk to my friends about being a young carer	
People in my community see the value of what I do	

Appendix P
Interview One resource: Mental health impacts

IM-MATURE
UN-STRESSED
UN-FRIENDLY
IN-DEPENDENT
IM-PATIENT
LISTENING TO-IGNORING OTHERS
UN-CONFIDENT

NOT – HARDWORKING
UN-REBELLIOUS
TIRED-ENERGISED
SLEEP
EATING
HELPLESS – EMPOWERED
SAD – HAPPY
ANGRY – CALM

UN-ABLE TO CONCENTRATE

HOPE-LESSNESS

UN-LONELY

NOT – PROTECTIVE

UN-PROUD

UN-SKILLED

Appendix Q

Interview Two: Topic guide (Sophie)

Interview 2 schedule

Interview length: 60 minutes

Date:

Interviewee name:

School:

Introduction

Greet.

Remind that voluntary

Check

Incentive

- Why
- What

So before we start is there anything that you wanted to ask?

Check

Plan for today

- Reminder of last time
- If anything changed
- A few extra questions
- Thinking about effects in more detail

I'll explain that more when we get there but does that sound ok?

Check

Reminder

About you

- Disneyland
- Rugby and dance

- So when we met before you said that you were filling in but looking to join a girls team. Has this happened?

Caring

- Care for Mum
 - Born deaf
 - Can struggle with the phone, and understanding people in noisy environments
 - Diabetes
 - Has problems with blood sugar levels (hyper where high, hypo where low)
- Been a carer for 10 years (since 3)
 - At first answering the phone for mum
 - Increased over time
 - Go out with and support her in talking to others when busy
 - Stay up late to watch blood sugars, and help if too high/low (often 2/3pm)
 - Are there some tasks that you find easier than others?
- Live with mum and sister but grandparents nearby
 - Nan sorts out hospital appointments and is backup if need help
 - Bampf drives everyone
 - Work together to look after sister (not sibling carer)
- No professional support
 - Is there a reason why not?
- Good relationship with Mum
 - Often talk etc
 - We've talked quite a lot about how you care for her but can you tell me a little more about how she cares for you?

Support

- Not involved in young carers project or social services
 - [POC] know in WB team but not school
- Family not told people as no reason to but few people realised (teachers, diabetic nurse)
- Told friends outside of school
 - What about friends in school, or most of your friends not in Bedwas High School?
- Mum told you how best to care
 - Nurse taught you to carb count
 - When we met before you were possibly going to be trained in using a diabetic pump?
- People in community, friends, etc know but not how much (invisible illness)

Identity

- Balancing caring can be hard and prioritise caring and school over dance/rugby
 - Struggle if have lots of homework
 - Late to school if up late caring
- Choice but no choice as mum can't manage diabetes on own and no one else
- As mentioned been a carer for 10 years
 - How has your feelings about being a carer changed over time?
- Sometimes see caring as normal, sometimes as unusual in terms of how you help mum
- See caring as important job as young people helping with quite serious things
 - How serious do you feel your caring is?

Effects

Did you have any more comments about any of that?

Check

Effects

Explain triangle

- Caring: The person that you care for and the kind of things you help them with
- Identity: Choice and how you balance caring with other parts of your life
- Support: Whether feel recognised and supported by range of groups

I have here the different effects you chose when we last met, starting with the ones you wrote yourself. I'd like you to place these one by one on the triangle and explain why you've placed it where you have. [Gives example].

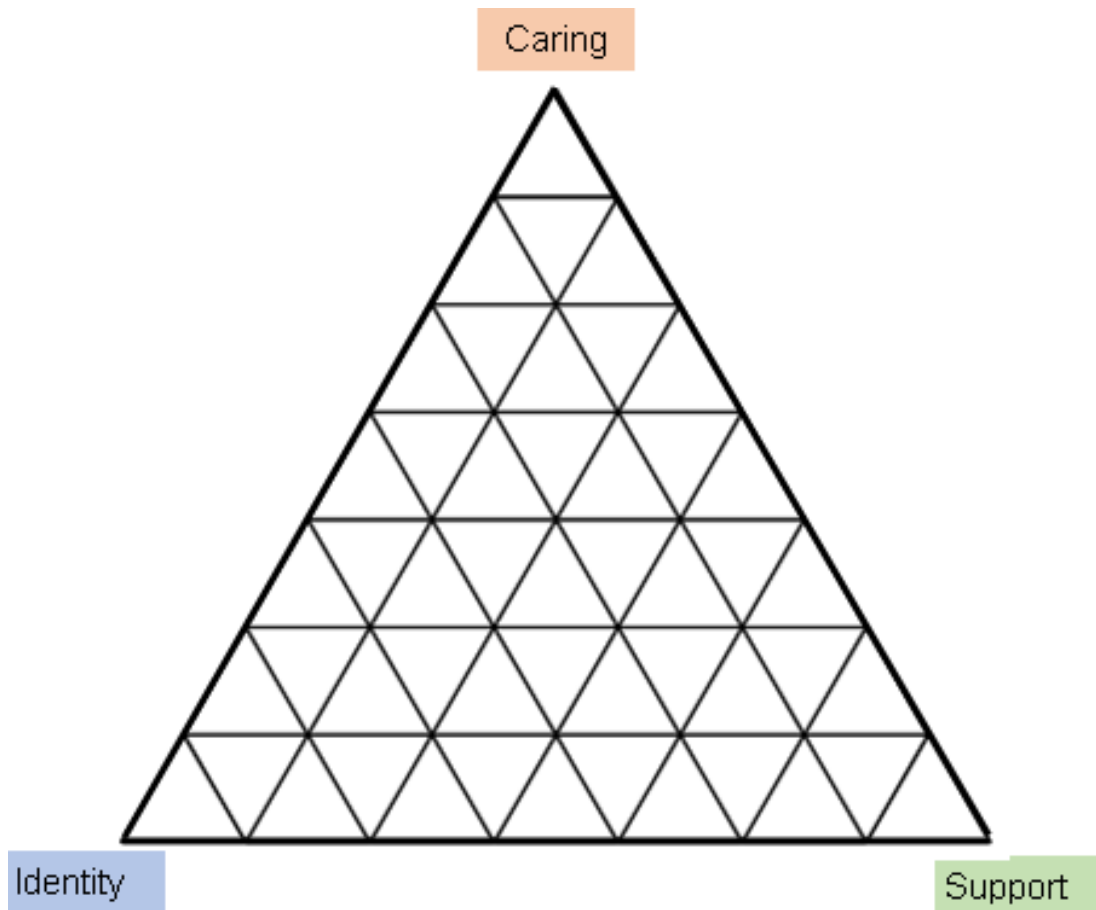
Did you have any questions before we finish?

Check

Wrap up

- Final meeting once school starts again.
- Best for summer

Appendix R
Interview Two resource: Impact triangle



Appendix S

Interview Three: Topic guide (Sophie)

Interview 3 schedule

Interview length: 60 minutes

Date:

Interviewee name:

School:

Introduction

Greet.

Remind that voluntary

Incentive

Plan for today

- Again a reminder of last time
 - If anything changed
 - A few extra questions
- The third section will focus in a little bit on particular area
 - For you the difference that your mums pumps makes, and how you have people that have trained you/supported you in it.

Does that sound ok?

Check

Initial questions

How was the coders camp?

Can you tell me about the first caring that you remember doing?

And can you tell me about when you first realised you were a young carer?

Reminder

- The caring that you do (answering phone, translating, blood sugar levels
 - What you find easier and harder

Do you feel that you have a routine?

- o Ie do you know what caring you will do most days, or does it vary a lot?

- o Mum' caring for you includes
 - o Dancing and rugby
 - o Allergies
 - o Someone to talk to

Reintroduce impact triangle

- o Last time though about impact triangle and whether effects were due to
 - o Caring responsibilities
 - o Identity (choice, and life balance)
 - o Support
- o You chose impacts and talked through where they sat on the triangle.

Friendliness due to all three

- o Caring makes you friendly as you are supported by friends and family
- o Can see that it could make someone unfriendly if
 - o Bad life balance,
 - o Lack of support
 - o Depending how become young carer

Mature depends on support

- o Immature if lack of support
- o If not told how good you are (may think you're doing badly)

Do you think caring has affected your maturity?

Stress due to caring but also identity

- o Balance is key
 - o Lots of caring make you tired

- Homework all can make you stressed (therefore balance is key)
- Generally not stressed, but difficult if something not working (also makes you impatient)
- Also stressed about missing school when in GCSE years

So have you started your GCSEs now?

- How are they going?

Feeled skilled from the caring role

- Because know what to do if mum has hypo
- And also from being supported/told doing good job
- Also skilled from being
- Would feel unskilled if something goes wrong and thought it was your fault

The pump

As I said at the beginning I'd like to focus on the new pump more

- Really interested in what's happened since we last met
- The difference that it's made, both to you but also your mum

When was the pump fitted?

Problems when first started using pump

- Bad needles that made the pump painful to use
- Needles not working with insulin leaking
- Things were starting to get better

Are these problems fixed now?

Also had problems with prescription, so had to go to multiple pharmacies with mum to get medication

Did you ever go into a pharmacist on your own to pick up a prescription?

- How did this go?
- Did you have any problems with the chemist give you the prescription?

We talked quite a lot about how the pump works

- You told me about the pump in more detail
 - How the plasters work
 - How they are also sensors
 - How they need to be changed
- Also how the pump measures your mums reading every 3 hours during the night
- New role includes filling vials with insulin
- Is complicated to use pump

How do you find using it now?

Has it made a difference your mum's life?

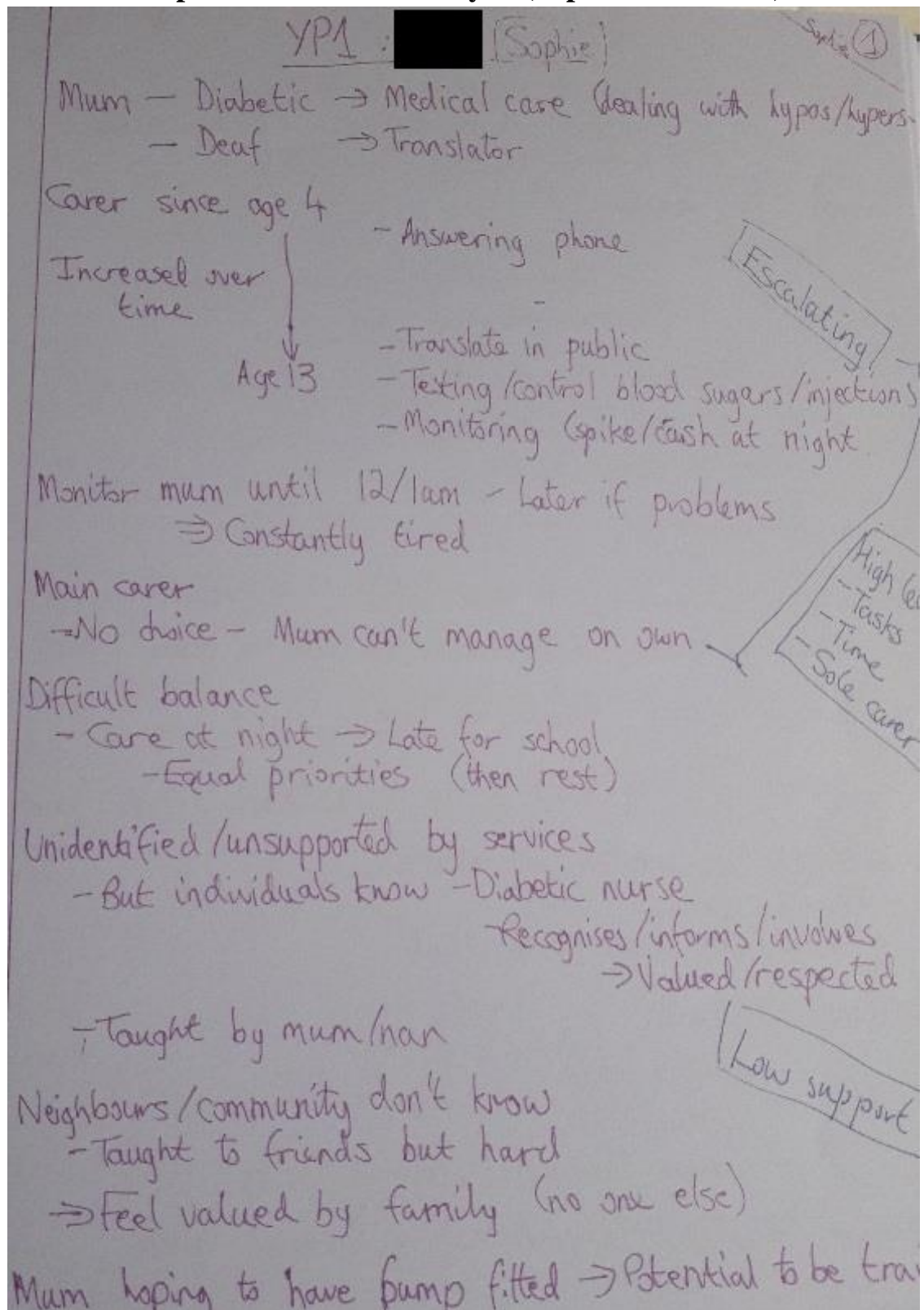
Know about diabetes and how to care for mum from listening to meetings and asking questions

- Shown how to use pump by the nurse and also the pump specialist

What would you do if you hadn't been taught how to care for your mum (both before and after pump)

Has the pump made a difference to your life?

Appendix T
Paper-based holistic analysis (Sophie interview 1)



Appendix U

Mplus SEM script: Standard young carer model

SUMMARY OF ANALYSIS

Number of groups	1
Number of observations	15923
Number of dependent variables	19
Number of independent variables	2
Number of continuous latent variables	2

Observed dependent variables

Continuous

W2SLEEPLOS	W2UNDERSTR	W2DIFFICUL	W2ENJOYACT	W2FACEPROB	W2DEPRESSE
W2LOWCONFI	W2HAPPY	W4SLEEPLOS	W4UNDERSTR	W4DIFFICUL	W4ENJOYACT
W4FACEPROB	W4DEPRESSE	W4LOWCONFI	W4HAPPY		

Binary and ordered categorical (ordinal)

W1CARESTAT	W2CARESTAT	W3CARESTAT
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Observed independent variables

SEXMERGE	ETHNICME
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Continuous latent variables

MH2	MH4
-----	-----

Estimator	MLR
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Information matrix	OBSERVED
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Optimization Specifications for the Quasi-Newton Algorithm for

Continuous Outcomes

Maximum number of iterations	100
Convergence criterion	0.100D-05

Optimization Specifications for the EM Algorithm

Maximum number of iterations	500
Convergence criteria	
Loglikelihood change	0.100D-02
Relative loglikelihood change	0.100D-05
Derivative	0.100D-02

Optimization Specifications for the M step of the EM Algorithm for

Categorical Latent variables

Number of M step iterations	1
M step convergence criterion	0.100D-02
Basis for M step termination	ITERATION

Optimization Specifications for the M step of the EM Algorithm for Censored, Binary or Ordered Categorical (Ordinal), Unordered

Categorical (Nominal) and Count Outcomes

Number of M step iterations	1
M step convergence criterion	0.100D-02
Basis for M step termination	ITERATION
Maximum value for logit thresholds	15
Minimum value for logit thresholds	-15
Minimum expected cell size for chi-square	0.100D-01

Maximum number of iterations for H1	2000
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Convergence criterion for H1	0.100D-03
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Optimization algorithm	EMA
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Integration Specifications

Type	MONTECARLO
Number of integration points	750
Dimensions of numerical integration	3
Adaptive quadrature	ON
Monte Carlo integration seed	0

Link	LOGIT
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Cholesky	OFF
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Input data file(s)

G:\modelvariables.dta.dat

Input data format FREE

SUMMARY OF DATA

Number of missing data patterns	689
Number of y missing data patterns	550
Number of u missing data patterns	8

COVARIANCE COVERAGE OF DATA

Minimum covariance coverage value 0.100

PROPORTION OF DATA PRESENT

	Covariance Coverage				
	W1CAREST	W2CAREST	W3CAREST	W2SLEEPL	W2UNDERS
W1CAREST	0.968				
W2CAREST	0.823	0.834			
W3CAREST	0.762	0.761	0.771		
W2SLEEPL	0.789	0.797	0.730	0.799	
W2UNDERS	0.761	0.769	0.705	0.755	0.770
W2DIFFIC	0.758	0.766	0.704	0.752	0.741
W2ENJOYA	0.790	0.799	0.733	0.779	0.759
W2FACEPR	0.787	0.795	0.729	0.776	0.754
W2DEPRES	0.782	0.790	0.724	0.773	0.753
W2LOWCON	0.787	0.795	0.729	0.777	0.756
W2HAPPY	0.765	0.774	0.710	0.758	0.740
W4SLEEPL	0.686	0.686	0.687	0.659	0.638
W4UNDERS	0.683	0.683	0.684	0.658	0.637
W4DIFFIC	0.682	0.682	0.684	0.657	0.636
W4ENJOYA	0.689	0.689	0.690	0.663	0.641
W4FACEPR	0.687	0.687	0.688	0.661	0.640
W4DEPRES	0.683	0.683	0.684	0.657	0.636
W4LOWCON	0.686	0.686	0.687	0.660	0.639
W4HAPPY	0.683	0.683	0.684	0.657	0.637
SEXMERGE	0.968	0.834	0.771	0.799	0.770
ETHNICME	0.968	0.834	0.771	0.799	0.770

	Covariance Coverage				
	W2DIFFIC	W2ENJOYA	W2FACEPR	W2DEPRES	W2LOWCON
W2DIFFIC	0.768				
W2ENJOYA	0.757	0.800			
W2FACEPR	0.755	0.784	0.797		
W2DEPRES	0.751	0.777	0.774	0.792	
W2LOWCON	0.756	0.780	0.779	0.780	0.797
W2HAPPY	0.739	0.764	0.760	0.756	0.762
W4SLEEPL	0.637	0.662	0.659	0.655	0.659
W4UNDERS	0.636	0.661	0.657	0.654	0.658
W4DIFFIC	0.634	0.660	0.657	0.653	0.657
W4ENJOYA	0.640	0.666	0.662	0.659	0.662
W4FACEPR	0.638	0.664	0.661	0.657	0.661
W4DEPRES	0.634	0.660	0.657	0.654	0.657
W4LOWCON	0.637	0.662	0.659	0.656	0.660
W4HAPPY	0.635	0.660	0.657	0.654	0.657
SEXMERGE	0.768	0.800	0.797	0.792	0.797
ETHNICME	0.768	0.800	0.797	0.792	0.797

	Covariance Coverage				
	W2HAPPY	W4SLEEPL	W4UNDERS	W4DIFFIC	W4ENJOYA
W2HAPPY	0.775				
W4SLEEPL	0.643	0.713			
W4UNDERS	0.641	0.705	0.711		
W4DIFFIC	0.640	0.704	0.703	0.710	
W4ENJOYA	0.646	0.710	0.708	0.708	0.717
W4FACEPR	0.644	0.709	0.707	0.706	0.713
W4DEPRES	0.640	0.705	0.703	0.702	0.708
W4LOWCON	0.643	0.707	0.705	0.705	0.711
W4HAPPY	0.642	0.704	0.702	0.702	0.708
SEXMERGE	0.775	0.713	0.711	0.710	0.717
ETHNICME	0.775	0.713	0.711	0.710	0.717

	Covariance Coverage				
	W4FACEPR	W4DEPRES	W4LOWCON	W4HAPPY	SEXMERGE
W4FACEPR	0.715				
W4DEPRES	0.707	0.710			
W4LOWCON	0.710	0.707	0.714		
W4HAPPY	0.707	0.702	0.705	0.710	
SEXMERGE	0.715	0.710	0.714	0.710	1.000
ETHNICME	0.715	0.710	0.714	0.710	1.000

	Covariance Coverage
	ETHNICME
ETHNICME	1.000

PROPORTION OF DATA PRESENT FOR U

	Covariance Coverage		
	W1CAREST	W2CAREST	W3CAREST
W1CAREST	0.968		
W2CAREST	0.823	0.834	
W3CAREST	0.762	0.761	0.771

PROPORTION OF DATA PRESENT FOR Y

	Covariance Coverage				
	W2SLEEPL	W2UNDERS	W2DIFFIC	W2ENJOYA	W2FACEPR
W2SLEEPL	0.799				
W2UNDERS	0.755	0.770			
W2DIFFIC	0.752	0.741	0.768		
W2ENJOYA	0.779	0.759	0.757	0.800	
W2FACEPR	0.776	0.754	0.755	0.784	0.797
W2DEPRES	0.773	0.753	0.751	0.777	0.774
W2LOWCON	0.777	0.756	0.756	0.780	0.779
W2HAPPY	0.758	0.740	0.739	0.764	0.760
W4SLEEPL	0.659	0.638	0.637	0.662	0.659
W4UNDERS	0.658	0.637	0.636	0.661	0.657
W4DIFFIC	0.657	0.636	0.634	0.660	0.657
W4ENJOYA	0.663	0.641	0.640	0.666	0.662
W4FACEPR	0.661	0.640	0.638	0.664	0.661
W4DEPRES	0.657	0.636	0.634	0.660	0.657
W4LOWCON	0.660	0.639	0.637	0.662	0.659
W4HAPPY	0.657	0.637	0.635	0.660	0.657
SEXMERGE	0.799	0.770	0.768	0.800	0.797
ETHNICME	0.799	0.770	0.768	0.800	0.797

	Covariance Coverage				
	W2DEPRES	W2LOWCON	W2HAPPY	W4SLEEPL	W4UNDERS
W2DEPRES	0.792				
W2LOWCON	0.780	0.797			
W2HAPPY	0.756	0.762	0.775		
W4SLEEPL	0.655	0.659	0.643	0.713	
W4UNDERS	0.654	0.658	0.641	0.705	0.711
W4DIFFIC	0.653	0.657	0.640	0.704	0.703
W4ENJOYA	0.659	0.662	0.646	0.710	0.708
W4FACEPR	0.657	0.661	0.644	0.709	0.707
W4DEPRES	0.654	0.657	0.640	0.705	0.703
W4LOWCON	0.656	0.660	0.643	0.707	0.705
W4HAPPY	0.654	0.657	0.642	0.704	0.702
SEXMERGE	0.792	0.797	0.775	0.713	0.711
ETHNICME	0.792	0.797	0.775	0.713	0.711

	Covariance Coverage				
	W4DIFFIC	W4ENJOYA	W4FACEPR	W4DEPRES	W4LOWCON
W4DIFFIC	0.710				
W4ENJOYA	0.708	0.717			
W4FACEPR	0.706	0.713	0.715		
W4DEPRES	0.702	0.708	0.707	0.710	
W4LOWCON	0.705	0.711	0.710	0.707	0.714
W4HAPPY	0.702	0.708	0.707	0.702	0.705
SEXMERGE	0.710	0.717	0.715	0.710	0.714
ETHNICME	0.710	0.717	0.715	0.710	0.714

	Covariance Coverage		
	W4HAPPY	SEXMERGE	ETHNICME
W4HAPPY	0.710		
SEXMERGE	0.710	1.000	
ETHNICME	0.710	1.000	1.000

UNIVARIATE PROPORTIONS AND COUNTS FOR CATEGORICAL VARIABLES

W1CAREST		
Category 1	0.949	14618.000
Category 2	0.051	791.000
W2CAREST		
Category 1	0.942	12508.000
Category 2	0.058	764.000
W3CAREST		
Category 1	0.938	11512.000
Category 2	0.062	762.000

UNIVARIATE SAMPLE STATISTICS

UNIVARIATE HIGHER-ORDER MOMENT DESCRIPTIVE STATISTICS

Variable/ Sample Size	Mean/ Variance	Skewness/ Kurtosis	Minimum/ Maximum	% with Min/Max	20%/60%	Percentiles 40%/80%	Median
W2SLEEPLOS	1.773	0.954	1.000	47.54%	1.000	1.000	2.000
12718.000	0.786	0.048	4.000	5.74%	2.000	2.000	
W2UNDERSTR	1.965	0.663	1.000	37.96%	1.000	2.000	2.000
12262.000	0.890	-0.525	4.000	8.31%	2.000	3.000	
W2DIFFICUL	1.850	0.871	1.000	41.61%	1.000	1.000	2.000
12227.000	0.796	-0.007	4.000	6.79%	2.000	2.000	
W2ENJOYACT	1.898	0.721	1.000	23.68%	1.000	2.000	2.000
12742.000	0.417	1.690	4.000	2.79%	2.000	2.000	
W2FACEPROB	1.826	0.746	1.000	28.61%	1.000	2.000	2.000
12690.000	0.419	1.661	4.000	2.54%	2.000	2.000	
W2DEPRESSE	1.878	0.832	1.000	44.48%	1.000	1.000	2.000
12612.000	0.927	-0.362	4.000	8.71%	2.000	3.000	
W2LOWCONFI	1.704	1.137	1.000	54.07%	1.000	1.000	1.000
12693.000	0.829	0.308	4.000	6.53%	2.000	2.000	
W2HAPPY	1.868	0.781	1.000	27.70%	1.000	2.000	2.000
12341.000	0.470	1.352	4.000	3.26%	2.000	2.000	
W4SLEEPLOS	1.921	0.693	1.000	39.45%	1.000	2.000	2.000
11361.000	0.843	-0.442	4.000	6.93%	2.000	3.000	
W4UNDERSTR	2.136	0.383	1.000	29.74%	1.000	2.000	2.000
11319.000	0.899	-0.824	4.000	9.33%	2.000	3.000	
W4DIFFICUL	1.883	0.750	1.000	39.52%	1.000	2.000	2.000
11304.000	0.778	-0.221	4.000	5.94%	2.000	3.000	
W4ENJOYACT	1.954	0.617	1.000	23.85%	1.000	2.000	2.000
11420.000	0.492	0.753	4.000	3.18%	2.000	2.000	
W4FACEPROB	1.862	0.655	1.000	26.43%	1.000	2.000	2.000
11384.000	0.418	1.385	4.000	2.32%	2.000	2.000	
W4DEPRESSE	1.905	0.734	1.000	44.80%	1.000	1.000	2.000
11312.000	0.962	-0.616	4.000	8.54%	2.000	3.000	
W4LOWCONFI	1.690	1.120	1.000	55.56%	1.000	1.000	1.000
11362.000	0.822	0.214	4.000	5.85%	2.000	2.000	
W4HAPPY	1.902	0.619	1.000	25.82%	1.000	2.000	2.000
11311.000	0.460	0.915	4.000	2.58%	2.000	2.000	
SEXMERGE	0.508	-0.033	0.000	49.18%	0.000	0.000	1.000
15923.000	0.250	-1.999	1.000	50.82%	1.000	1.000	
ETHNICMERGE	0.656	-0.656	0.000	34.42%	0.000	1.000	1.000
15923.000	0.226	-1.570	1.000	65.58%	1.000	1.000	

THE MODEL ESTIMATION TERMINATED NORMALLY

MODEL FIT INFORMATION

Number of Free Parameters 50

Loglikelihood

H0 Value -210919.821
H0 Scaling Correction Factor 1.2381
for MLR

Information Criteria

Akaike (AIC) 421939.641
Bayesian (BIC) 422323.417
Sample-Size Adjusted BIC 422164.521
(n* = (n + 2) / 24)

MODEL RESULTS

		Estimate	S.E.	Est./S.E.	Two-Tailed P-Value
MH2	BY				
	W2SLEEPLOS	1.000	0.000	999.000	999.000
	W2UNDERSTR	1.092	0.012	90.390	0.000
	W2DIFFICUL	1.026	0.013	78.384	0.000
	W2ENJOYACT	0.567	0.011	53.066	0.000
	W2FACEPROB	0.472	0.011	41.208	0.000
	W2DEPRESSE	1.331	0.015	90.847	0.000
	W2LOWCONFI	1.144	0.015	75.372	0.000
	W2HAPPY	0.645	0.011	56.610	0.000
MH4	BY				
	W4SLEEPLOS	1.000	0.000	999.000	999.000
	W4UNDERSTR	1.092	0.012	90.390	0.000
	W4DIFFICUL	1.026	0.013	78.384	0.000
	W4ENJOYACT	0.567	0.011	53.066	0.000
	W4FACEPROB	0.472	0.011	41.208	0.000
	W4DEPRESSE	1.331	0.015	90.847	0.000
	W4LOWCONFI	1.144	0.015	75.372	0.000
	W4HAPPY	0.645	0.011	56.610	0.000
MH4	ON				
	MH2	0.521	0.011	45.963	0.000
MH4	ON				
	W1CAREST	0.043	0.028	1.551	0.121
	W2CAREST	0.026	0.027	0.956	0.339
	W3CAREST	0.076	0.027	2.842	0.004
MH2	ON				
	W1CAREST	-0.009	0.027	-0.334	0.738
	W2CAREST	0.043	0.027	1.629	0.103
W2CAREST	ON				
	W1CAREST	2.429	0.095	25.688	0.000
	SEXMERGE	-0.136	0.078	-1.731	0.083
	ETHNICMERG	-0.431	0.080	-5.371	0.000
W3CAREST	ON				
	W2CAREST	2.829	0.092	30.868	0.000
	SEXMERGE	-0.098	0.081	-1.206	0.228
	ETHNICMERG	-0.231	0.085	-2.706	0.007
W1CAREST	ON				
	SEXMERGE	-0.097	0.073	-1.325	0.185
	ETHNICMERG	-0.533	0.074	-7.240	0.000

Intercepts				
W2SLEEPLOS	1.836	0.007	269.319	0.000
W2UNDERSTR	2.038	0.007	281.448	0.000
W2DIFFICUL	1.859	0.007	282.507	0.000
W2ENJOYACT	1.921	0.005	412.788	0.000
W2FACEPROB	1.840	0.004	411.956	0.000
W2DEPRESSE	1.882	0.007	255.120	0.000
W2LOWCONFI	1.692	0.007	248.384	0.000
W2HAPPY	1.883	0.005	389.364	0.000
W4SLEEPLOS	1.836	0.007	269.319	0.000
W4UNDERSTR	2.038	0.007	281.448	0.000
W4DIFFICUL	1.859	0.007	282.507	0.000
W4ENJOYACT	1.921	0.005	412.788	0.000
W4FACEPROB	1.840	0.004	411.956	0.000
W4DEPRESSE	1.882	0.007	255.120	0.000
W4LOWCONFI	1.692	0.007	248.384	0.000
W4HAPPY	1.883	0.005	389.364	0.000
Thresholds				
W1CAREST\$1	2.541	0.066	38.792	0.000
W2CAREST\$1	2.778	0.076	36.337	0.000
W3CAREST\$1	2.965	0.083	35.528	0.000
Residual Variances				
W2SLEEPLOS	0.458	0.008	56.335	0.000
W2UNDERSTR	0.481	0.009	54.888	0.000
W2DIFFICUL	0.425	0.009	47.745	0.000
W2ENJOYACT	0.319	0.005	61.703	0.000
W2FACEPROB	0.343	0.005	67.479	0.000
W2DEPRESSE	0.324	0.007	43.244	0.000
W2LOWCONFI	0.366	0.008	48.140	0.000
W2HAPPY	0.333	0.005	60.824	0.000
W4SLEEPLOS	0.495	0.009	56.697	0.000
W4UNDERSTR	0.505	0.008	59.706	0.000
W4DIFFICUL	0.429	0.008	52.037	0.000
W4ENJOYACT	0.370	0.006	64.443	0.000
W4FACEPROB	0.342	0.005	66.855	0.000
W4DEPRESSE	0.347	0.007	46.457	0.000
W4LOWCONFI	0.388	0.008	51.574	0.000
W4HAPPY	0.316	0.005	61.727	0.000
MH2	0.344	0.008	42.371	0.000
MH4	0.251	0.007	38.325	0.000

LOGISTIC REGRESSION ODDS RATIO RESULTS

	Estimate	S.E.	(Est. - 1) / S.E.	Two-Tailed P-Value
W2CAREST ON				
W1CAREST	11.348	1.073	9.643	0.000
SEXMERGE	0.873	0.068	-1.854	0.064
ETHNICMERG	0.650	0.052	-6.713	0.000
W3CAREST ON				
W2CAREST	16.924	1.551	10.268	0.000
SEXMERGE	0.907	0.073	-1.266	0.205
ETHNICMERG	0.794	0.068	-3.044	0.002
W1CAREST ON				
SEXMERGE	0.907	0.067	-1.391	0.164
ETHNICMERG	0.587	0.043	-9.562	0.000

QUALITY OF NUMERICAL RESULTS

Condition Number for the Information Matrix 0.223E-04
(ratio of smallest to largest eigenvalue)

DIAGRAM INFORMATION

Use View Diagram under the Diagram menu in the Mplus Editor to view the diagram.
If running Mplus from the Mplus Diagrammer, the diagram opens automatically.

Diagram output
d:\standardmodel.dgm

Appendix V

Mplus SEM script: Higher-level young carer model script

SUMMARY OF ANALYSIS

Number of groups	1
Number of observations	15906

Number of dependent variables	19
Number of independent variables	2
Number of continuous latent variables	2

Observed dependent variables

Continuous

W2SLEEPLOS	W2UNDERSTR	W2DIFFICUL	W2ENJOYACT	W2FACEPROB	W2DEPRESSE
W2LOWCONFI	W2HAPPY	W4SLEEPLOS	W4UNDERSTR	W4DIFFICUL	W4ENJOYACT
W4FACEPROB	W4DEPRESSE	W4LOWCONFI	W4HAPPY		

Binary and ordered categorical (ordinal)

W1CAREHO	W2CAREHO	W3CAREHO
----------	----------	----------

Observed independent variables

SEXMERGE	ETHNICME
----------	----------

Continuous latent variables

MH2	MH4
-----	-----

Estimator	MLR
Information matrix	OBSERVED

Optimization Specifications for the Quasi-Newton Algorithm for

Continuous Outcomes

Maximum number of iterations	100
Convergence criterion	0.100D-05

Optimization Specifications for the EM Algorithm

Maximum number of iterations	500
Convergence criteria	
Loglikelihood change	0.100D-02
Relative loglikelihood change	0.100D-05
Derivative	0.100D-02

Optimization Specifications for the M step of the EM Algorithm for

Categorical Latent variables

Number of M step iterations	1
M step convergence criterion	0.100D-02
Basis for M step termination	ITERATION

Optimization Specifications for the M step of the EM Algorithm for

Censored, Binary or Ordered Categorical (Ordinal), Unordered

Number of M step iterations	1
M step convergence criterion	0.100D-02
Basis for M step termination	ITERATION
Maximum value for logit thresholds	15
Minimum value for logit thresholds	-15
Minimum expected cell size for chi-square	0.100D-01

Maximum number of iterations for H1	2000
-------------------------------------	------

Convergence criterion for H1	0.100D-03
------------------------------	-----------

Optimization algorithm	EMA
------------------------	-----

Integration Specifications

Type	MONTECARLO
Number of integration points	750
Dimensions of numerical integration	3
Adaptive quadrature	ON
Monte Carlo integration seed	0

Link	LOGIT
------	-------

Cholesky	OFF
----------	-----

Input data file(s)

G:\modelvariables\high.dta.dat

Input data format FREE

SUMMARY OF DATA

Number of missing data patterns	713
Number of y missing data patterns	550
Number of u missing data patterns	8

COVARIANCE COVERAGE OF DATA

Minimum covariance coverage value 0.100

PROPORTION OF DATA PRESENT

	Covariance Coverage				
	W1CAREHO	W2CAREHO	W3CAREHO	W2SLEEPL	W2UNDERS
W1CAREHO	0.965				
W2CAREHO	0.817	0.831			
W3CAREHO	0.757	0.756	0.769		
W2SLEEPL	0.787	0.794	0.729	0.800	
W2UNDERS	0.759	0.766	0.703	0.756	0.771
W2DIFFIC	0.757	0.764	0.702	0.753	0.742
W2ENJOYA	0.788	0.796	0.731	0.780	0.759
W2FACEPR	0.785	0.793	0.728	0.777	0.755
W2DEPRES	0.780	0.788	0.723	0.774	0.754
W2LOWCON	0.785	0.793	0.728	0.778	0.756
W2HAPPY	0.764	0.771	0.709	0.759	0.741
W4SLEEPL	0.684	0.683	0.685	0.660	0.639
W4UNDERS	0.681	0.681	0.683	0.659	0.638
W4DIFFIC	0.681	0.680	0.682	0.657	0.637
W4ENJOYA	0.687	0.687	0.689	0.663	0.642
W4FACEPR	0.685	0.684	0.687	0.662	0.641
W4DEPRES	0.681	0.680	0.682	0.658	0.637
W4LOWCON	0.684	0.683	0.685	0.661	0.640
W4HAPPY	0.681	0.681	0.682	0.658	0.637
SEXMERGE	0.965	0.831	0.769	0.800	0.771
ETHNICME	0.965	0.831	0.769	0.800	0.771

	Covariance Coverage				
	W2DIFFIC	W2ENJOYA	W2FACEPR	W2DEPRES	W2LOWCON
W2DIFFIC	0.769				
W2ENJOYA	0.758	0.801			
W2FACEPR	0.756	0.784	0.798		
W2DEPRES	0.752	0.778	0.775	0.793	
W2LOWCON	0.756	0.781	0.780	0.781	0.798
W2HAPPY	0.740	0.765	0.761	0.757	0.763
W4SLEEPL	0.637	0.663	0.660	0.656	0.660
W4UNDERS	0.637	0.662	0.658	0.655	0.658
W4DIFFIC	0.635	0.660	0.657	0.654	0.657
W4ENJOYA	0.640	0.666	0.663	0.659	0.663
W4FACEPR	0.639	0.664	0.661	0.657	0.661
W4DEPRES	0.635	0.660	0.657	0.654	0.658
W4LOWCON	0.638	0.663	0.660	0.657	0.660
W4HAPPY	0.636	0.661	0.658	0.654	0.658
SEXMERGE	0.769	0.801	0.798	0.793	0.798
ETHNICME	0.769	0.801	0.798	0.793	0.798

	Covariance Coverage				
	W2HAPPY	W4SLEEPL	W4UNDERS	W4DIFFIC	W4ENJOYA
W2HAPPY	0.776				
W4SLEEPL	0.643	0.714			
W4UNDERS	0.642	0.706	0.712		
W4DIFFIC	0.641	0.705	0.704	0.711	
W4ENJOYA	0.647	0.711	0.709	0.709	0.718
W4FACEPR	0.645	0.710	0.708	0.707	0.713
W4DEPRES	0.641	0.705	0.704	0.703	0.709
W4LOWCON	0.644	0.708	0.706	0.706	0.712
W4HAPPY	0.642	0.705	0.703	0.703	0.709
SEXMERGE	0.776	0.714	0.712	0.711	0.718
ETHNICME	0.776	0.714	0.712	0.711	0.718

	Covariance Coverage				
	W4FACEPR	W4DEPRES	W4LOWCON	W4HAPPY	SEXMERGE
W4FACEPR	0.716				
W4DEPRES	0.707	0.711			
W4LOWCON	0.710	0.708	0.714		
W4HAPPY	0.707	0.703	0.706	0.711	
SEXMERGE	0.716	0.711	0.714	0.711	1.000
ETHNICME	0.716	0.711	0.714	0.711	1.000

	Covariance Coverage
	ETHNICME
ETHNICME	1.000

PROPORTION OF DATA PRESENT FOR U

	Covariance Coverage		
	W1CAREHO	W2CAREHO	W3CAREHO
W1CAREHO	0.965		
W2CAREHO	0.817	0.831	
W3CAREHO	0.757	0.756	0.769

PROPORTION OF DATA PRESENT FOR Y

	Covariance Coverage				
	W2SLEEPL	W2UNDERS	W2DIFFIC	W2ENJOYA	W2FACEPR
W2SLEEPL	0.800				
W2UNDERS	0.756	0.771			
W2DIFFIC	0.753	0.742	0.769		
W2ENJOYA	0.780	0.759	0.758	0.801	
W2FACEPR	0.777	0.755	0.756	0.784	0.798
W2DEPRES	0.774	0.754	0.752	0.778	0.775
W2LOWCON	0.778	0.756	0.756	0.781	0.780
W2HAPPY	0.759	0.741	0.740	0.765	0.761
W4SLEEPL	0.660	0.639	0.637	0.663	0.660
W4UNDERS	0.659	0.638	0.637	0.662	0.658
W4DIFFIC	0.657	0.637	0.635	0.660	0.657
W4ENJOYA	0.663	0.642	0.640	0.666	0.663
W4FACEPR	0.662	0.641	0.639	0.664	0.661
W4DEPRES	0.658	0.637	0.635	0.660	0.657
W4LOWCON	0.661	0.640	0.638	0.663	0.660
W4HAPPY	0.658	0.637	0.636	0.661	0.658
SEXMERGE	0.800	0.771	0.769	0.801	0.798
ETHNICME	0.800	0.771	0.769	0.801	0.798

	Covariance Coverage				
	W2DEPRES	W2LOWCON	W2HAPPY	W4SLEEPL	W4UNDERS
W2DEPRES	0.793				
W2LOWCON	0.781	0.798			
W2HAPPY	0.757	0.763	0.776		
W4SLEEPL	0.656	0.660	0.643	0.714	
W4UNDERS	0.655	0.658	0.642	0.706	0.712
W4DIFFIC	0.654	0.657	0.641	0.705	0.704
W4ENJOYA	0.659	0.663	0.647	0.711	0.709
W4FACEPR	0.657	0.661	0.645	0.710	0.708
W4DEPRES	0.654	0.658	0.641	0.705	0.704
W4LOWCON	0.657	0.660	0.644	0.708	0.706
W4HAPPY	0.654	0.658	0.642	0.705	0.703
SEXMERGE	0.793	0.798	0.776	0.714	0.712
ETHNICME	0.793	0.798	0.776	0.714	0.712

	Covariance Coverage				
	W4DIFFIC	W4ENJOYA	W4FACEPR	W4DEPRES	W4LOWCON
W4DIFFIC	0.711				
W4ENJOYA	0.709	0.718			
W4FACEPR	0.707	0.713	0.716		
W4DEPRES	0.703	0.709	0.707	0.711	
W4LOWCON	0.706	0.712	0.710	0.708	0.714
W4HAPPY	0.703	0.709	0.707	0.703	0.706
SEXMERGE	0.711	0.718	0.716	0.711	0.714
ETHNICME	0.711	0.718	0.716	0.711	0.714

	Covariance Coverage		
	W4HAPPY	SEXMERGE	ETHNICME
W4HAPPY	0.711		
SEXMERGE	0.711	1.000	
ETHNICME	0.711	1.000	1.000

UNIVARIATE PROPORTIONS AND COUNTS FOR CATEGORICAL VARIABLES

W1CAREHO		
Category 1	0.992	15222.000
Category 2	0.008	121.000
W2CAREHO		
Category 1	0.991	13098.000
Category 2	0.009	114.000
W3CAREHO		
Category 1	0.990	12108.000
Category 2	0.010	126.000

UNIVARIATE SAMPLE STATISTICS

UNIVARIATE HIGHER-ORDER MOMENT DESCRIPTIVE STATISTICS

Variable/ Sample Size	Mean/ Variance	Skewness/ Kurtosis	Minimum/ Maximum	% with Min/Max	20%/60%	Percentiles 40%/80%	Median
W2SLEEPLOS	1.773	0.954	1.000	47.54%	1.000	1.000	2.000
12718.000	0.786	0.048	4.000	5.74%	2.000	2.000	
W2UNDERSTR	1.965	0.663	1.000	37.96%	1.000	2.000	2.000
12262.000	0.890	-0.525	4.000	8.31%	2.000	3.000	
W2DIFFICUL	1.850	0.871	1.000	41.61%	1.000	1.000	2.000
12227.000	0.796	-0.007	4.000	6.79%	2.000	2.000	
W2ENJOYACT	1.898	0.721	1.000	23.68%	1.000	2.000	2.000
12742.000	0.417	1.690	4.000	2.79%	2.000	2.000	
W2FACEPROB	1.826	0.746	1.000	28.61%	1.000	2.000	2.000
12690.000	0.419	1.661	4.000	2.54%	2.000	2.000	
W2DEPRESSE	1.878	0.832	1.000	44.48%	1.000	1.000	2.000
12612.000	0.927	-0.362	4.000	8.71%	2.000	3.000	
W2LOWCONFI	1.704	1.137	1.000	54.07%	1.000	1.000	1.000
12693.000	0.829	0.308	4.000	6.53%	2.000	2.000	
W2HAPPY	1.868	0.781	1.000	27.70%	1.000	2.000	2.000
12341.000	0.470	1.352	4.000	3.26%	2.000	2.000	
W4SLEEPLOS	1.921	0.693	1.000	39.45%	1.000	2.000	2.000
11361.000	0.843	-0.442	4.000	6.93%	2.000	3.000	
W4UNDERSTR	2.136	0.383	1.000	29.74%	1.000	2.000	2.000
11319.000	0.899	-0.824	4.000	9.33%	2.000	3.000	
W4DIFFICUL	1.883	0.750	1.000	39.52%	1.000	2.000	2.000
11304.000	0.778	-0.221	4.000	5.94%	2.000	3.000	
W4ENJOYACT	1.954	0.617	1.000	23.85%	1.000	2.000	2.000
11420.000	0.492	0.753	4.000	3.18%	2.000	2.000	
W4FACEPROB	1.862	0.655	1.000	26.43%	1.000	2.000	2.000
11384.000	0.418	1.385	4.000	2.32%	2.000	2.000	
W4DEPRESSE	1.905	0.734	1.000	44.80%	1.000	1.000	2.000
11312.000	0.962	-0.616	4.000	8.54%	2.000	3.000	
W4LOWCONFI	1.690	1.120	1.000	55.56%	1.000	1.000	1.000
11362.000	0.822	0.214	4.000	5.85%	2.000	2.000	
W4HAPPY	1.902	0.619	1.000	25.82%	1.000	2.000	2.000
11311.000	0.460	0.915	4.000	2.58%	2.000	2.000	
SEXMERGE	0.508	-0.034	0.000	49.16%	0.000	0.000	1.000
15906.000	0.250	-1.999	1.000	50.84%	1.000	1.000	
ETHNICMERGE	0.656	-0.657	0.000	34.39%	0.000	1.000	1.000
15906.000	0.226	-1.568	1.000	65.61%	1.000	1.000	

THE MODEL ESTIMATION TERMINATED NORMALLY

MODEL FIT INFORMATION

Number of Free Parameters 50

Loglikelihood

H0 Value -204711.639
H0 Scaling Correction Factor 1.2530
for MLR

Information Criteria

Akaike (AIC) 409523.279
Bayesian (BIC) 409907.001
Sample-Size Adjusted BIC 409748.105
(n* = (n + 2) / 24)

MODEL RESULTS

	Estimate	S.E.	Est./S.E.	Two-Tailed P-Value
MH2 BY				
W2SLEEPLOS	1.000	0.000	999.000	999.000
W2UNDERSTR	1.092	0.012	90.397	0.000
W2DIFFICUL	1.026	0.013	78.375	0.000
W2ENJOYACT	0.567	0.011	53.058	0.000
W2FACEPROB	0.472	0.011	41.218	0.000
W2DEPRESSE	1.331	0.015	90.844	0.000
W2LOWCONFI	1.145	0.015	75.395	0.000
W2HAPPY	0.645	0.011	56.623	0.000
MH4 BY				
W4SLEEPLOS	1.000	0.000	999.000	999.000
W4UNDERSTR	1.092	0.012	90.397	0.000
W4DIFFICUL	1.026	0.013	78.375	0.000
W4ENJOYACT	0.567	0.011	53.058	0.000
W4FACEPROB	0.472	0.011	41.218	0.000
W4DEPRESSE	1.331	0.015	90.844	0.000
W4LOWCONFI	1.145	0.015	75.395	0.000
W4HAPPY	0.645	0.011	56.623	0.000
MH4 ON				
MH2	0.521	0.011	46.050	0.000
MH4 ON				
W1CAREHOUR	0.061	0.069	0.893	0.372
W2CAREHOUR	0.175	0.071	2.465	0.014
W3CAREHOUR	0.080	0.074	1.077	0.282
MH2 ON				
W1CAREHOUR	-0.017	0.065	-0.258	0.797
W2CAREHOUR	-0.054	0.063	-0.862	0.389
W2CAREHOSH ON				
W1CAREHOUR	3.313	0.281	11.788	0.000
SEXMERGE	-0.262	0.194	-1.351	0.177
ETHNICMERG	-0.770	0.195	-3.951	0.000
W3CAREHOSH ON				
W2CAREHOUR	3.429	0.288	11.916	0.000
SEXMERGE	-0.462	0.190	-2.435	0.015
ETHNICMERG	-0.707	0.189	-3.748	0.000
W1CAREHOSH ON				
SEXMERGE	-0.326	0.186	-1.756	0.079
ETHNICMERG	-0.863	0.183	-4.708	0.000

Intercepts				
W2SLEEPLOS	1.841	0.007	274.425	0.000
W2UNDERSTR	2.043	0.007	287.942	0.000
W2DIFFICUL	1.864	0.006	288.726	0.000
W2ENJOYACT	1.923	0.005	416.141	0.000
W2FACEPROB	1.842	0.004	413.124	0.000
W2DEPRESSE	1.888	0.007	263.357	0.000
W2LOWCONFI	1.698	0.007	254.841	0.000
W2HAPPY	1.886	0.005	394.917	0.000
W4SLEEPLOS	1.841	0.007	274.425	0.000
W4UNDERSTR	2.043	0.007	287.942	0.000
W4DIFFICUL	1.864	0.006	288.726	0.000
W4ENJOYACT	1.923	0.005	416.141	0.000
W4FACEPROB	1.842	0.004	413.124	0.000
W4DEPRESSE	1.888	0.007	263.357	0.000
W4LOWCONFI	1.698	0.007	254.841	0.000
W4HAPPY	1.886	0.005	394.917	0.000
Thresholds				
W1CAREHO\$1	4.190	0.147	28.430	0.000
W2CAREHO\$1	4.345	0.174	24.925	0.000
W3CAREHO\$1	4.113	0.159	25.946	0.000
Residual Variances				
W2SLEEPLOS	0.458	0.008	56.350	0.000
W2UNDERSTR	0.481	0.009	54.918	0.000
W2DIFFICUL	0.425	0.009	47.744	0.000
W2ENJOYACT	0.319	0.005	61.714	0.000
W2FACEPROB	0.343	0.005	67.481	0.000
W2DEPRESSE	0.324	0.007	43.255	0.000
W2LOWCONFI	0.366	0.008	48.139	0.000
W2HAPPY	0.333	0.005	60.812	0.000
W4SLEEPLOS	0.496	0.009	56.693	0.000
W4UNDERSTR	0.505	0.008	59.697	0.000
W4DIFFICUL	0.429	0.008	52.032	0.000
W4ENJOYACT	0.370	0.006	64.438	0.000
W4FACEPROB	0.342	0.005	66.876	0.000
W4DEPRESSE	0.348	0.007	46.422	0.000
W4LOWCONFI	0.388	0.008	51.576	0.000
W4HAPPY	0.316	0.005	61.717	0.000
MH2	0.344	0.008	42.337	0.000
MH4	0.251	0.007	38.294	0.000

LOGISTIC REGRESSION ODDS RATIO RESULTS

	Estimate	S.E.	(Est. - 1) / S.E.	Two-Tailed P-Value
W2CAREHOSH ON				
W1CAREHOUR	27.458	7.717	3.429	0.001
SEXMERGE	0.769	0.149	-1.545	0.122
ETHNICMERG	0.463	0.090	-5.951	0.000
W3CAREHOSH ON				
W2CAREHOUR	30.845	8.876	3.362	0.001
SEXMERGE	0.630	0.119	-3.095	0.002
ETHNICMERG	0.493	0.093	-5.450	0.000
W1CAREHOSH ON				
SEXMERGE	0.722	0.134	-2.076	0.038
ETHNICMERG	0.422	0.077	-7.473	0.000

QUALITY OF NUMERICAL RESULTS

Condition Number for the Information Matrix 0.110E-03
(ratio of smallest to largest eigenvalue)

DIAGRAM INFORMATION

Use View Diagram under the Diagram menu in the Mplus Editor to view the diagram.
If running Mplus from the Mplus Diagrammer, the diagram opens automatically.

Diagram output
d:\standardmodelhigh.dgm

Appendix W

Phenomenology participant biographies

YP1: Sophie		
I1: March 2019	I2: July 2019	I3: October 2019
<p>Sophie was 13 years old and was caring for her mother who had diabetes and a hearing impairment. She had been helping her mother communicate since age four, but over time her responsibilities were increasingly related to her mother diabetes. In particular her mother's blood sugar levels would often spike or crash at night. Sophie was providing care every night, including monitoring her blood sugar levels and helping her eat or giving injections if needed.</p> <p>Sophie lived with her mother and younger sister. She was the main carer though her grandmother lived nearby in case of emergencies. Sophie had told a few friends, but her mother was reluctant for people to know. They had not informed services, though Sophie had been identified by a diabetic nurse who was increasingly informing and involving her in decisions.</p> <p>Sophie felt valued by her family and was proud to be a carer, though tiredness could affect her mood and her view of caring. She also felt that caring was not her choice as her mum was not able to manage her illness alone.</p> <p>The three interviews offered the chance to study the impacts of Sophie's mother being fitted with a new diabetic pump. At the time of the first interview Sophie was expecting to be trained in using the pump. At the second interview the pump had been fitted and Sophie had received the training, though there were equipment issues. At the third interview these problems had been resolved, and Sophie was becoming more confident in using the pump. In addition, the pump had decreased her mother's dependence, with Sophie providing less night-time care. This had positive benefits on tiredness and mood.</p>		

YP2: Angela		
I1: March 2019	I2: July 2019	I3: December 2019
<p>Angela's mother had Multiple Sclerosis and she had been a carer for approximately two years. Her responsibilities included domestic responsibilities and occasional physical support around the home. These tasks totalled a few hours each week and she felt that she managed these tasks alongside school and a social life. In addition, she was often providing companionship.</p> <p>Angela was part of a caring unit with her father and brother, though Angela was at times frustrated that they were taking on less responsibilities, resulting in her increasingly becoming the main carer. While she was also receiving support from other relatives, caring was managed within the family, and she was not known to services. She had talked to her friends about it but her neighbours did not know.</p> <p>Angela was proud of taking on the responsibilities and felt that the impacts were largely beneficial, including maturity, hardworking and listening skills. However, she did not value the young carer identity.</p>		

YP3: Kirsty		
I1: March 2019	I2: July 2019	I3: December 2019
<p>Kirsty was a former young carer. She had cared for her mother who had spina bifida, hydrocephalus and epilepsy, until her death a few years before the research began. Her responsibilities had included domestic responsibilities and companionship. Kirsty felt that she had had a good balance with her caring responsibilities fitting around the school day. She identified benefits of caring as including maturity, confidence and independence, but had also become isolated from friends.</p> <p>Kirsty's father also cared for her mother and his responsibilities including physical support that Kirsty could not give. At the time that Kirsty was a carer she was not known to services, though she had talked to individual primary school teachers that she trusted. Kirsty had felt appreciated by her mother and they had a very close relationship. Kirsty saw caring as a vocation and a normal part of her life.</p> <p>Following the death of her mother she was worried about losing her caring identity and the positive benefits that she had developed. In addition, Kirsty was struggling with the impacts of bereavement and an increasingly distant relationship with her father. The impacts of additional adversities were related but separate to those of the caring role.</p>		

YP4: Martin		
I1: July 2019	I2: October 2019	I3: January 2020
<p>Martin had been a carer for approximately nine months, following his mother developing a blood disorder that resulted in aplastic anaemia. She had extreme fatigue as a result of the illness but also tiring fortnightly medical treatments. Martin was spending up to two-three hours each day carrying out domestic responsibilities, keeping her company and physically support her around the home.</p> <p>Martin lived alone with his mother and was her main carer. They had a very close relationship but Martin was still transitioning to his caring role. At time he was becoming frustrated with the large number of small tasks, and with his mother trying to do too much.</p> <p>Martin did not want to tell lots of people but his grandmother, a particular friend and some neighbours knew that he was a young carer, plus his mother's partner would stay for part of each week and provide care. With the exception of his mother's doctor he was not known to services, and was not accessing formal support. Instead he was receiving support from many informal sources that fluctuated over time.</p> <p>Martin felt he had little choice to be a carer but felt that caring was important. He preferred to help rather than watch his mother struggle.</p> <p>The three interviews followed Martin as he became increasingly accustomed to the role and navigated different support sources. The strong relationship with his mother was particularly important in resolving issues and reducing his frustrations.</p>		

YP5: Lyra		
I1: August 2019	-	-
<p>Lyra's mother had been diagnosed with bipolar disorder and sectioned in a mental hospital following the death of their father. After being released Lyra's caring responsibilities had included domestic tasks including cooking, cleaning and laundry, and she supported her mother through periods of depression. At the time of the first interview her mother was away, having been sectioned for a second time.</p> <p>Lyra's relationship with her mother was complicated by the fact that her bipolar disorder, as well as her medication, affected her emotions. Lyra was the middle sibling of three sisters, and her siblings were also participants (YP6 Lucy; and YP10 Thea) with them forming a tight caring unit. At these times wider family support was important, with them living with their aunts when their mother was away.</p> <p>Lyra was being supported by her local social services' young carers project, and her school were aware but not providing support.</p> <p>Lyra valued being a young carer, but she felt she had little choice as her mother could not manage alone.</p>		

YP6: Lucy		
I1: August 2019	-	-
<p>Lucy's mother had been diagnosed with bipolar disorder and sectioned in a mental hospital following the death of their father. Lucy did not become a young carer immediately due to her younger age, but she had been a carer for two years. Her caring tasks fluctuated depending on her mother's illness and included domestic responsibilities and looking after her mother when she was physically sick. At the time of the first interview her mother was being sectioned for a second time.</p> <p>Lucy was the youngest of three sisters, and her siblings were also participants (YP5 Lyra; and YP10 Thea). The sisters were a tight caring unit, and they also received support from wider family, particularly in housing them when their mother was away.</p> <p>Lucy was being supported through her local social services' young carers project. Her primary school had been aware but she was transitioning to secondary school at the time of her interview. Some friends and neighbours knew, and she found it useful to talk to them about her caring.</p>		

YP7: Harry		
I1: October 2019	I2: January 2020	I3: August (online)
<p>Harry was a carer for Sean, his younger brother who had autism. He had been a carer for approximately nine years, initially helping his brother settle at night. His responsibilities had grown over time to include helping him get up, physical support and helping him to and from school. These responsibilities were substantial but also stable at the time of the research. While Harry was often tired, the impacts of his caring were largely positive, including feeling useful, satisfaction from making a difference to his brother's life, confidence and maturity.</p> <p>Harry's parents were also part of the caring unit, and their responsibilities including toileting and feeding. Harry and his parents had a family routine, with Harry the main carer for his brother before and after school during the week. His parents then provided more care at the weekend, enabling Harry to do his homework and see friends. He had a very strong relationship with his parents and Sean.</p> <p>Harry was very open with his friends and neighbours, and his school knew though they were not providing support. He was accessing his local social services young carer project which he felt increased his confidence in his caring skills, and strongly felt part of a young carer community.</p> <p>Harry felt it had been his choice to become a young carer, though he viewed it as becoming increasingly necessary.</p> <p>Harry's third interview was conducted online due to the coronavirus pandemic. His family's situation had changed with neither Harry or his brothers in school and his dad being furloughed. However, there was little change in Harry's caring responsibilities.</p>		

YP8: Patrick		
I1: November 2019	I2: March 2020	I3: May 2020
<p>Patrick's sister Sara had cerebral palsy, poor eyesight and learning difficulties. He had been her carer since a young age and his responsibilities included physical support around the home, helping her get up in the morning and being on hand if anything was needed. He was also monitoring Sara every night after she went to bed. Patrick found it difficult to balance caring with homework and he had little time for social activities. He identified impacts including tiredness, sadness and frustration about his situation.</p> <p>Patrick was part of a caring unit with his parents. He was the main carer during the week, and they took on more responsibilities at the weekend, giving him free time. The family were keen to keep the caring in the immediate family and did not seek support from other relatives, neighbours or services. Patrick's friends knew that he was a young carer but he was extremely private and didn't talk to them about it. Patrick also did not talk to his parents about his caring.</p> <p>Patrick and Sara had a difficult relationship. Patrick attributed this as partly due to her frustration with her disabilities, but he felt that Sara could be angry and aggressive towards him. This affected his view of caring and he felt that he had little choice to be a young carer. He disliked the 'young carer' term and highlighted feelings of difference that exacerbated the impacts of caring itself. Overall, he had a very negative caring identity.</p> <p>Patrick's third interview was conducted online due to the pandemic. His family's situation had changed with Sara shielding and Patrick and his mother at home. This created a positive change in Patrick's balance of caring, school and free time, but his relationship with Sara deteriorated further. The longitudinal focus of the study enabled consideration of the impact of these changes.</p>		

YP9: Richard		
I1: December 2019	I2: February 2020	-
<p>Richard was caring for his mother who had mental health issues as a result of past substance misuse. He had been a young carer since the age of five and had cared for her while she overcame addictions to heroin, alcohol, and most recently cannabis. This included providing emotional support and domestic responsibilities for over five hours a day, though this had decreased to approximately two hours a day as her condition improved. Richard identified benefits including caring skills, confidence and maturity.</p> <p>Richard was her sole carer with no other family in the local area, though at the time of his second interview his mum had a new partner with this reducing Patrick's responsibilities further. They did not have good relationships with their neighbours and, while his friends knew though he rarely talked to them about it.</p> <p>He was known as a young carer in school and by his mother's mental health team. However, his family were very private and they did not want services to know the details of his caring. As a result, he was not accessing formal support, though had started attending an independent young carers project.</p> <p>Richard felt that he had had little choice to be a young carer in the past, though this had changed as his mother's health improved.</p> <p>In addition to caring, other adverse events in Richard's life included familial substance misuse and unhealthy relationships. He had also been diagnosed with autism.</p>		

YP10: Thea		
I1: December 2019	I2: February 2020	-
<p>Thea's mother had been diagnosed with bipolar disorder and sectioned in a mental hospital in 2015 following the death of her husband. Having been released she was sectioned again in 2019 due to her stopping taking her medication. At the time of Thea's first meeting, she had been recently released for the second time, and Thea was providing emotional support and companionship, as well as physical support and domestic responsibilities. She was caring for 6-7 hours a day when her mother was newly released with this decreasing over time. She struggled with the balance and at times had at times de-prioritised school and socialising to concentrate on caring.</p> <p>Thea was the oldest sibling of three sisters, and her siblings were also participants (YP5 Lyra; and YP6 Lucy) with them forming a tight caring unit. In addition, Thea was providing emotional support for her sisters when their mother was in hospital. Wider family support was also important, particularly in housing them when their mother was away.</p> <p>Thea was very positive about her local social services' young carers project and the individual support that was offered. In contrast, her school was aware but Thea was critical that they had young carer provision in place that was not actively running. Thea was very protective and preferred to seek the support of a particular teachers and friends.</p> <p>Thea liked caring but she felt that she had no choice to be a carer as she felt that her sisters would not manage without her, possibly resulting in her mother being permanently institutionalised.</p> <p>In addition to the impacts of caring, other additional adversities included the death of her father, as well as feelings of abandonment after her mother was sectioned.</p>		