THE EXPERIENCE OF YOUNG CARERS IN THE CONTEXT OF A RANGE
OF PARENTAL CONDITIONS: PHYSICAL DISABILITY, MENTAL
HEALTH PROBLEMS AND SUBSTANCE MISUSE

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A thesis submitted in partial fulfilment of the requirements of The Robert Gordon
University for the degree of Doctor of Philosophy

December 2006

Abstract

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Doctor of Philosophy

The experience of young carers in the context of a range of parental conditions: physical disability, mental health problems and substance misuse

The current study set out to explore the affect and significance of differing parental conditions on the experiences commonly reported by young carers. Previous studies on young caring have reflected on the impacts of caring for parents with particular 'types' of conditions (normally physical disability or mental health problems) or a specific diagnosis. However, these have not contrasted or discriminated young carers' experiences according to different parental conditions. To address this gap in knowledge, the current study considered the experiences of young carers supporting parents with different 'types' of conditions, namely physical disability, mental health problems and substance misuse. The participants discussed the impact of caring on a range of areas such as their education, social life, health, spatial transitions, relationships and role reversals. Additionally, definitional issues were considered. This included young carers own understanding and subscription to the term 'young carer' and the significance of this to their identification.

In terms of methodology, the study was firmly grounded within the qualitative domain and influenced by a constructive-interpretive paradigm, specifically symbolic interactionism. Within this, the grounded theory approach was used insofar as it provided a method to conduct the study. A range of data-collection techniques were employed. Semi-structured interviewing was the principal method used, with additional data gathered through a self-esteem tool, observations and diaries. The sample consisted of 30 young carers.

The results showed firstly that the participants did not necessarily comprehend the term 'young carer' or apply it to their own caring roles at home. Arguably, this contributed to their 'hidden-ness' (i.e. invisibility) and as a result their needs were overlooked. The need for a new definition which embraces their understandings, together with appropriate awareness-raising programmes within schools and for key social care and health professionals was evidenced and called for. Secondly, whilst the participants shared common experiences regardless of the nature of the parental condition, other issues reported were specific to particular situations. Those most adversely affected were caring in the contexts of parental substance misuse or parental mental health problems. Such young carers were dually disadvantaged, as they experienced the most extreme difficulties, yet their caring roles and needs were least likely to be addressed.

The experiential differences reported by young carers in different caring contexts have important practice implications. Nevertheless, the extent to which the experiences reported could be wholly attributed to the caring role, rather than other structural and socio-economic factors was questionable.

Key words

'Young carer', 'impacts of young caring', 'physical disability', 'substance misuse', 'mental health problem', 'hidden-ness', 'parentification'

I hereby declare that this submission is my own work and that, to the best of my knowledge and belief, it contains no material previously published or written by another person except where due acknowledgment has been made in the text nor material which has been accepted for the award of any other degree or diploma of the university or other institute of higher learning.

Emma Christie

20th December 2006

Acknowledgements

I would like to express my sincere gratitude to all of those individuals who assisted me in completing this thesis.

I would especially like to thank my Ph.D. supervisor Dr. John Love for his time, enthusiasm, encouragement, sound advice, sincerity and his great efforts to explain things in a clear and simple manner. Not only did he make the Ph.D. process manageable, but also highly enjoyable. My gratitude must also be extended to Julian Bell, my second supervisor, for his thought-provoking comments and suggestions. Over the past three years, other staff members based within the Faculty of Health and Social Care at The Robert Gordon University have been particularly helpful in offering their time, advice and support particularly Professor Joyce Lishman and Professor Rosemary Chesson.

Fundamentally, this research would not have been possible without the participation of the young carers who agreed to take part and thus, a big thanks to all of them for sharing their precious time and providing an insight into their daily lives. Additionally, sincere gratitude must be extended to all of the agencies and professionals who assisted with the project, especially Fiona Gill, Andrea Hauxwell and Mary Drever.

On a personal note, I wish to thank all of my friends for their support and understanding, particularly to Aine for our 'supervision' sessions at Starbucks. Lastly, and most importantly, I wish to thank my parents, Bill and Rosemary, as well as Murdo, Jennifer, Nicola, Abbie, Cameron and Emily for their love, understanding, support, and for believing in me. To them, I dedicate this thesis.

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Introduction to the Prologue

It is both helpful and necessary to begin by offering a word about the researcher's professional background and the language utilised within the current study. As will be highlighted, the language used and the meanings attached to this were considered from and influenced by the researcher's social work standpoint.

The Background and Position of the Researcher

The researcher, a qualified social worker was employed within this capacity for a number of years prior to commencing this study. Her professional experience included working with adult and young carers in the context of a dedicated carers' centre. Prior to starting the study, the researcher resigned from the social work position[1], but continued to work in a voluntary capacity with young carers. Both her social work and volunteering roles broadly involved supporting carers' to address their needs in relation to a range of areas such as their health, education, employment, housing, welfare rights and respite. Exposure to and experience within this area provided an insight into the core issues affecting carers and ultimately underpinned the decision to conduct research within this area. This familiarity also proved useful in terms of recruiting young carers into the study and developing rapport with them. Nevertheless, this also necessitated the renegotiation of relationships already established with the young people. To achieve this and to proceed with the study in a sound ethical manner, it was necessary to address issues such as role confusion, ambiguity over the purpose of contact, as well as over-familiarity with the participants. These issues will be further discussed and reflected on at a later stage within the methodology chapter.

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[1] The researcher resigned from her social work post when she started a new position as a research assistant within the department in which she was studying.

The Reciprocity of Language

Concepts which informed and were informed by the Study

As a researcher with a background in social work, the terminology relating to 'disability' was recognised as being both highly emotive and contentious due to the connotations attached to language and labels. Whilst a professional background in social work and the associated value base shaped the researcher's understanding of such language, the terminology used within the study and presented in this thesis was largely determined by the participants on the basis of being the most familiar and meaningful language to them. This was particularly fitting within the constructive-interpretive approach that guided the study, as the aim was to access the young carers understanding of their own worlds. Accordingly, it was recognised that the language used was particularly important as this informed the participants understanding of their own situations. Whilst individually they perceived and attributed different meanings to their Worlds, commonalities were noted in terms of how the young carers collectively referred to their caring roles and their parent's illness, disability or condition. The language utilised by the researcher when communicating with the individual participants reflected that used by them. Also, the terminology presented in this thesis reflected that used by the majority of the participants. However, the *meanings* attributed to the terms required the interpretation of the researcher.

Additionally, whilst the language used and presented within the thesis embraced the conventions of other social work researchers (Frank, 1995; Becker, 2000; Dearden, 2000)[2], at some level it also represented a challenge to the researcher's commitment to anti-oppressive practice. This, as well as the terminology relating to young carer, disability, illness and substance misuse will now be discussed.

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[2] The observations around the language used were specific to contemporary conventions in the UK.

Definitions and Implications of the Term 'Young Carer'

Whilst the terminology 'young carer' was used almost instinctively - as informed by a background working with young carers - it was important to reflect on the acceptability and significance of the term before adopting this within the current study. One the one hand, it was recognised that the term was not universally approved because of its associations with a need to protect, supervise and look-after disabled people (Morris, 1993). On the other hand, it was assessed as being the most appropriate term to adopt on the basis of two reasons. Firstly, this was used by the majorty of the participants in the study; and secondly, it has been accepted and adopted by the Carers movement in the U.K. (Carers UK, 2002).

Nevertheless, the term was used by the researcher with a degree of caution. For instance, several of the participants had no previous professional contact with a dedicated young carers' service and on this basis, it was thought possible that they had never applied the term to themselves. It was thus recognised that a sudden and unexpected realisation of their status as young carers could have caused emotional distress and therefore the term was not directly referred to either in the information material supplied[3] or the interview schedule used with such young people, until it had been established that they subscribed to the term. Instead more implicit terms and phrases such as 'caring for' or 'supporting' were used.

As well as the usage of the actual term, the definition of 'young carer' has also been disputed. As a result there was no single universally accepted definition of the term which could be employed in the study. However, the study drew upon Becker's (2000) definition 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.

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[3] Whilst the Information Sheet (displayed in Appendix 1) contains references to 'young carer', it must be stated that these were only provided to those participants accessed through dedicated young carers' projects. Those identified through other agencies were provided with amended versions of these which did not contain such references.

They carry out, often on a regular basis, significant or substantial caring tasks and assume a level of responsibility which would usually be associated with an adult. The person receiving care is often a parent but can be a sibling, grandparent or other relative who is disabled, has some chronic illness, mental health problem or other condition connected with a need for care, support or supervision...some young carers experience impaired psychosocial development, including poor educational attendance and performance, and restricted peer networks, friendships and opportunities. These will have implications for their own adulthood (Becker, 2000, p378).

In accordance with this definition, it was understood and acknowledged that those aged 18 and over would be classed as 'young adult carers', rather than young carers. However, within the current study, all of the participants including those over the age of 18 were referred to as 'young carers'. This was based on the logic that they were all 'young people' and was also in line with other studies which failed to use different terms for those under and those over the age of 18 (Dearden and Becker, 2000). This decision was also due to reasons of brevity. For instance, of the thirty participants, 23 were under the age of 18 and seven were aged 18-25. However, the older group included one participant who had ceased caring and thus, was actually a former carer. Using each of the relevant terms 'young carer', 'young adult carer' and 'former young carer' was assessed as being somewhat prolix and would have possibly detracted from the main emphasis of the study, which was about young caring in different caring contexts, not age. As will be discussed, 'young adult carers' have been included under general definitions of 'adult carers'. However, to address their specific needs, the merit of formulating a separate definition can be queried.

Terminology Surrounding Disability, Illness and Substance Misuse

In recognition of the value laden-ness of language, careful consideration was given to the terminology used relating to disability, illness and substance misuse. Prior to discussing this however, it is important to highlight the overlaps between terminology and definitions. Firstly, some of the parents had multiple 'types' of

health problems - such as a physical and mental health problem – but were presented according to the main condition experienced, as defined by the participants. Secondly, substance misuse is included as a mental health problem under the Disability Discrimination Act, but the two were considered as distinct categories within the current study. This was because there were particular issues relating to each deemed worthy of separate exploration.

As already stated, the language adopted throughout the study reflected that used by the young carers themselves. Thus, the researcher attempted to ascertain at an early stage the terminology that was meaningful to the individual participants. This was achieved by a deliberate avoidance of terminology relating to disability and substance misuse by the researcher. For instance, in the initial information sheet provided to the participants (see Appendix 1 for a copy of this), the terms 'health problem' and later 'condition' were used rather than more specific descriptions such as disability, mental health problem, learning difficulties or substance misuse. Within the interviews, a preliminary open question was posed at the start - *"So tell me a bit about you and your mum/ dad"*. It was found that the participants usually referred to their parent's health or condition in their response to this question, which allowed them to express in their own words how they regarded and referred to this. Subsequently, commonalities were noted in the participants' usage of language and the vast majority referred to one or more of the following terms: **mental health problem, learning difficulties** and **physical disability**. Whilst the participants used various different terms to refer to their parent's drinking and drug use, **problem alcohol use** and **drug use** were adopted as these generally reflected contemporary conventions in the UK (Scottish Executive, 2003).

However, these terms have not been universally accepted. Terminology relating to disability and illness has been surrounded in controversy due to its potentially oppressive impact on disabled people. In terms of this, proponents of the social

model of disability[4] or the 'disability approach' have rejected the medical understanding of 'disability' as an individual bodily deficit or abnormality (London Borough of Barking and Dagenham, 2002). They have advocated that rather than being an individual problem, disability should be comprehended according to the socially constructed barriers and discrimination experienced by people with physical, mental or sensory impairments (Disabled Peoples' International, 1981). These barriers have been detailed to include attitudinal, political and structural processes, such as judgemental attitudes, inappropriate policies and legislation, negative stereotypes perpetuated by the media, as well as inaccessible buildings and information. Together, these have created a loss of opportunities for individuals to partake in ordinary community life (Disabled Peoples' International, 1981). In line with this, they have proposed that an individual's medical condition should not be referred to as a disability, but rather as an 'impairment' - the '...termporary or permanent loss or limitation of physical, mental or sensory function...caused by illness, trauma or age...' (Thomas and Pierson, 1998, p.181).

Language Surrounding Physical Disability

However, in the current study the participants used the term 'disability' rather than impairment to refer to their parents' physical illness or medical condition – which posed a professional conflict for the researcher. Informed by her social work background, the definitional position proposed by the social model of disability underpinned the researcher's own understanding. Additionally, as stated, this was congruent with the values of those people to which the term applied, which in the current study, was the parents. However, the research was not about the parents' understandings, but rather focused on the understanding of the young people and therefore, to access and represent this as accurately as

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[4] The social model of disability was developed by the British disabled people's civil rights movement in response to the discrimination, segregation and exclusion experienced by disabled people in society (Union of Physically Impaired Against Segregation, 1976; Oliver, 1983).

possible, their language and the associated meanings were upheld. Nevertheless, a few of the participants did make some reference to disability according to the social, structural, attitudinal and political barriers encountered by their parents. This was described according to stigmatising treatment experienced and a lack of understanding of other people, as well as unsuitable housing, inaccessible buildings, a lack of access to appropriate forms of care and welfare benefits, all of which magnified or were at the root of such difficulties. Indeed, as will be later discussed, it was a combination of the parental illness, impairment or disability, as well as a range of socio-economic factors which firstly, instigated the young caring role and subsequently served to shape the experience of caring. Thus it was felt that this element should also be acknowledged within the definition as follows:

> **Physical Disability:** a disability deriving from an impairment that is physical rather than intellectual (Thomas and Pierson, 1995, p.271).

Language Surrounding Mental Health Problems and Learning Difficulties
The terminology surrounding mental health problems and learning difficulties was also considered from the perspective of the social model. Firstly, references to the 'mentally ill' and to 'mental health problems' have been deemed as both misleading and offensive to the people that they have been applied to (Clark and Marsh, 2002). In particular, it has been suggested that the term 'mental illness' has served to confuse disability with illness and disease processes (Barnes, 1991). However, the associated need for medical intervention, treatment and cure may be unsuitable or unattainable for disabled people:

> ...whilst medical intervention for treating illness and disease may be quite appropriate, from the perspective of the disabled people it is quite inappropriate for treating disability (Barnes, 1991, p.24).

Instead proponents of the disability movement have proposed usage of the term 'mental health difficulties' (Clark and Marsh, 2002) as being both an acceptable alternative and more readily identified with, by those to which it applies. Within the current study, this was potentially problematic as there was an evident

divergence between the terminology used and recognised by the young carers (which was 'mental health problem') and that preferred by those to which the term was applied, in this case the parents ('mental health difficulties'). Whilst this created a level of unease, the terminlology which corresponded to the young carers own understanding was adopted. This was viewed as fundamental in terms of accessing and presenting an accurate and full picture of their Worlds. Their understanding of the term related exclusively to the condition as a medical phenomenon. Thus, the definition which informed the study was as follows:

> **Mental health problem:** one or more of a range of difficulties relating to the 'mind'...including stress-related conditions, anxiety and depression as well as manic depression and schizophrenia and dementia (Cockerham, 1992, p. 225).

Secondly, of the various terms which have been used to refer to people with learning difficulties, again some have been deemed offensive, whilst others have been viewed as misleading. For instance, 'learning disabilities' has been commonly used within both health and social care settings (Scottish Executive, 2005), yet has been rejected by proponents of the disability movement because of links between this and individual deficiencies (Fairbairn, Rowley and Bowen, 1995) and notions of learning as unachievable for such individuals:

> ...if we talk about disabilities, it makes it sound as though we can't improve. Everybody with a learning difficulty can improve, even if it is only a little (People First, 1992).

Instead, the term learning difficulties has been forwarded as the most acceptable alternative. However, some authors have used the terms learning disability and learning difficulties interchangeably, as did the professionals who were contacted in the current study and therefore, initially both terms were used synonymously. This was later reviewed and standardised according to the terminology presented by the one young carer in this context who was involved in the study. As she referred to **learning difficulties**, this was the term used throughout the thesis. Again, the participants appeared to associate the term with individual intellectual

deficits. Thus, the following definition was adopted within the study and presented in this thesis:

> **Learning difficulties:** where intellectual functioning is more limited and is developing or has developed more slowly than is the case for most of the population (O'Brien, 1986, p. 202).

Language Surrounding Substance Misuse

Much controversy has also surrounded the language relating to substance misuse. As previously, this was an area where both social and medical comprehensions have been offered. Similarly, this area required much reflection in order to ensure that the language utilised best reflected the young carers understanding. Whilst the young people referred to various terms to describe their parents drinking and drug-taking, all construed this as a problem and as a source of difficulties for the parent, themselves and sometimes, their wider families, in terms of a range of health, financial and social difficulties.

As various terms were used by the participants, it was decided to adopt the language used in a recent policy document pivotal within this area – *'Getting Our Priorities Right'* (Scottish Executive, 2003). Thus, the terms **'problem alcohol use'** and **'drug use'** (Scottish Executive, 2003, p8) were applied as these generally reflected the essence of what the young people communicated.

Within the current study, young carers experiences of supporting parents with 'problem alcohol use' and 'drug use' were considered in a largely blanket sense due to a small sample size which rendered comparisons between each unachievable. Despite distinct differences between alcohol and drug use in terms of firstly, the legality and social acceptability of alcohol compared to other substances and secondly, the risks to health and employment (Tunnard, 2002b), it was considered appropriate to regard the two in a collective sense. This was underpinned by their key similarities in terms of the risks posed by each including discord in family functioning and relationship difficulties. Therefore, as a widely accepted convention, these were considered under the umbrella term **'substance**

misuse' (Tunnard, 2002a; Tunnard, 2002b; Scottish Executive, 2003). This collective term was used only in the presentation of the thesis, rather than in any direct contact with the young people. In the thesis where only one or the other is referred to, this will be indicated explicitly by usage of the terms 'problem alcohol use' and 'drug use', rather than substance misuse.

Various definitions of 'substance misuse' have been forwarded, each with a different emphasis and the majority originating from a medical understanding. For instance, definitions have largely highlighted the detrimental effects of substances on the body (Griffiths and Pearson, 1988; Health and Safety Executive, 1994; Department of Health, 1995; Eurocare, 1998; National Institute on Drug Abuse, 2005) and the resulting need for intervention from specialists (Harbin and Murphy, 2001). However, based on the accounts offered by the young people in the current study, such definitions had to acknowledge the health and social impacts for the individual and their family. Thus, this term was understood and applied as follows:

> **Substance misuse:** People who are dependent on illegal drugs or alcohol, whose use significantly impairs their health and social functioning. Their usage is usually characterised by addiction to the substance (Scottish Executive, 2003).

Whilst the young people's own usage of terminology shaped that adopted within the study as far as possible, knowledge was recognised as the product of an inter-subjective process between the young carers and the researcher. In terms of the influence of the researcher in relation to the terminology used, firstly, she devised the research questions which centred on the experiences of young caring according to different parental *illnesses*. On reflection, perhaps this was based on an early assumption that physical disability, mental health problems, learning difficulties and substance misuse could be broadly considered as illnesses (i.e. conditions that shared a subjective experience of pain, discomfort or lack of wellbeing that impacted not only on the individual concerned but also his/ her significant others). In retrospect however, this was misleading. Illness denotes

poor health and a need for treatment or cure, which was not relevant to many of the parents. For instance, people with a physical disability may be physically well and being 'cured' certainly does not apply to those with learning difficulties. Nevertheless, the increasing medialisation of aspects of living has brought all of these conditions within the confines of the medical profession sufficient to justify the researcher's initial use of the medical label. Moreover, the term 'illness' was used throughout the interview schedule, but during the interviews was actually replaced with the language used by the young carers (e.g. disability, illness, drug or drink problem). However, its appearance was perhaps again indicative of the researcher's early presumptions. On reflection, usage of this term represented an attempt to locate a suitable collective phrase which could embrace each of the caring contexts.

Secondly, whilst the researcher attempted to adopt the terminology used by the young carers, most were aware of her social work background which may have shaped their terminology. For instance, perhaps they used language that they had heard other social workers use or terms that they deemed to be 'politically correct'. Lastly, whilst the usage of the terms by the participants could be observed, the meanings attributed to these required interpretation. Thus, the researcher played the central role in relation to this.

In terms of the researcher's own interpretations, two issues became apparent during the writing of the thesis which necessitated the development of other terminology. As these came to light at a late stage, the terms devised had no bearing on the participants during data collection. Firstly, one of the key findings related to the similarities in the experiences of those caring for parents who misused substances or had a mental health problem, compared to those with a physical disability. This was underpinned by the invisibility of the parental conditions and the caring roles, because neither was physical or observable. Thus, where this issue was discussed within the thesis, for reasons of brevity, initially the term 'non-physical disability' was employed to refer to caring in these contexts. However, following a period of reflection, this term was rejected on the

basis of being misleading. Indeed the young carers understood mental health problems and substance misuse according to a medical understanding, rather than in terms of disability. Thus, this was replaced with the term **'non-physical condition'**. This was in line with the usage of the term **'condition'** which was the umbrella term adopted to refer to all or any of the following: physical disability, mental health problems and substance misuse. Secondly, when writing the thesis, it was necessary to make frequent references to the situations in which the young carers were living and caring, according to the nature of the parental condition. In order to address this, initially the phrases 'parental illness context', 'parental illness type' and 'parental disability context' were utilised interchangeably to encompass the various contexts. On reflection, however, these merely served to confuse disability with illness and thus, were abandoned in favour of the term **'caring context'**. The usage of these and other key terms are summarised in the glossary on the following page.

Glossary of Key Terms Applied in the Study

Caring for/ supporting: these terms were used interchangaby to refer to the caring and supportive roles and tasks undertaken by the young carers.

Caring context: the situation in which one was caring in terms of the nature of the parent's health condition.

Learning difficulties: where intellectual functioning is more limited and is developing or has developed more slowly than is the case for most of the population (O'Brien, 1986, p. 202).

Mental health problem: one or more of a range of difficulties relating to the 'mind'...including stress-related conditions, anxiety and depression as well as manic depression and schizophrenia and dementia (Cockerham, 1992, p. 225).

Non-physical condition: a parental health problem non-physical in nature, such as substance misuse and mental health problem.

Parent: a father or mother; one who begets or one who gives birth to or nurtures and raises a child (Word Web Online, 2003).

Condition: a collective term used to denote all or any of the following: physical disability, mental health problems and substance misuse.

Physical disability: a disability deriving from an impairment that is physical rather than intellectual (Thomas and Pierson, 1995, p.271).

Service user: this term was adopted rather than 'client' as it was recognised that client has negative connotations relating to a *'fatheristic idea of the welfare system'* (Fairbairn et al, 1995, p.2). In contrast, service user simply indicates that individuals use particular services.

Substance misuse: People who are dependent on illegal drugs or alcohol who use significantly impairs their health and social functioning. Their usage is usually characterised by addiction to the substance (Scottish Executive, 2003).

Young carers: children and young persons under 18 who provide, or intend to provide, care, assistance or support to another family member. They carry out, often on a regular basis, significant or substantial caring tasks and assume a level of responsibility which would usually be associated with an adult. The person receiving care is often a parent but can be a sibling, grandparent or other relative who is disabled, has some chronic illness, mental health problem or other condition connected with a need for care, support or supervision...some young carers experience impaired psychosocial development, including poor educational attendance and performance, and restricted peer networks, friendships and opportunities. These will have implications for their own adulthood (Becker, 2000, p378).

Young people/ participants: used interchangeaby with 'young carer' to refer to those that took part in the current study.

Chapter 1 – Introduction to the Thesis

1.1 Introduction

The principal aim of the current study was to describe and understand the experiences reported by young carers according to the caring contexts in which they were placed. By way of explaining how this was carried out, the present chapter will begin by providing a rationale for the study, before outlining the research objectives and research questions that guided the enquiry. Finally an overview of each of the six chapters of the thesis will be provided.

1.2 Rationale for the Study

Research and policy interest in young caring has been a relatively recent development. Nevertheless, the notion of young caring has been around for many years, with accounts of children adopting caring roles apparent in popular literature dating back to the mid-1800s (Becker, Aldridge, Brittain, Clasen, Dietz, Gould, and Hantrais, 1995). Also, there was much clinical interest into the effects of parental illness and disability on children throughout the latter half of the last century. However, explicit concern by researchers and politicians alike has been evident only since the late 1980s. This was initially instigated by a British Broadcasting Corporation (BBC) documentary which detailed the lack of welfare support for disabled parents and the inappropriate caring roles assumed by children as a result (*Little Goldfish People*, 1985). One key development - which resulted from the widespread concern about the welfare and needs of such children – was the establishment of the Young Carers Research Group (YCRG) at Loughborough University in the early 1990s. Ultimately, this development heralded the onset of dedicated research interest within this field. Originating from a 'children's rights' philosophy, research from the YCRG has been

instrumental as it has facilitated the recognition and support of young carers at the levels of both policy and practice in the UK.

Despite a growing understanding of the extent of young caring and the experiences and needs of young carers, one fundamental issue which has not been resolved relates to the definitional understanding of 'young caring'. Indeed, at the time of writing this thesis, there was no universal agreement over what constituted a 'young carer', in terms of their age, relationship to the cared-for person, roles and tasks, the amount of time spent caring or the consequences of caring. Official definitions such as that offered by the Department of Health, have been ambiguous and have differed from those offered by researchers and academics originating from a young carers' approach, in how they conceptualise young caring. On the one hand, official definitions (which largely inform professional practice) comprehend young caring according to the caring responsibilities and the time spent on these. On the other hand, those from a 'young carers' perspective' emphasise the detrimental impacts of young caring. Elsewhere, to further complicate matters, advocates of the 'disability rights' strand of the 'social model' generally dismiss the concept of young caring. They argue that defining such young people according to their caring role undermined the rights of disabled parents (such as Keith and Morris, 1995). Nevertheless, the current study found that conceptual clarity was directly linked to the identification of young carers and their needs. Therefore, it is necessary to resolve rather than dismiss such ambiguities. Indeed, young caring has remained covert and the needs of young carers neglected, as a result of both narrow or dismissive definitions and the lack of a universally accepted and applied definition. Furthermore, young carers' own understanding of and identification with the term are arguably key factors in terms of the formal recognition and identification of young carers and their needs. Nevertheless, prior to the current study this had not been considered. Therefore, young carers' own understandings of the term as well as the consequences of definitional ambiguity were identified areas of interest worthy of investigation within the current study.

Moreover, the work of researchers in the young caring field (principally the YCRG) has highlighted the restrictions that caring in childhood can impose. This has been described mainly in terms of educational and social difficulties. However, very few studies have specifically considered the impacts in relation to adolescent development, even though adolescence has long since been associated with a range of distinct developmental tasks (Kegan, 1982). Where such research has been undertaken, it has been concluded that adolescent young carers can experience a range of difficulties in relation to their education, social life, employment, health and relationships (Frank, Tatum and Tucker, 1999; Dearden and Becker, 2000). In terms of relationships, questions have been raised about the nature of parental-child relationships and in particular, role reversals (Aldridge and Becker, 1994; Keith and Morris, 1996).

Nevertheless, the degree to which young caring can be considered as the primary cause of such issues and problems has been somewhat 'glossed over' in the young carers' literature. For instance, studies have commonly indicated a causal link between young caring and educational difficulties and poor employment prospects. However, living in a situation of poverty may also have a negative effect on one's life chances in relation to education, employment and health. Moreover, whilst the nature of the care recipient's condition may also underpin the experiences frequently reported, minimal attention has been given to this.

Previous studies have most commonly considered the experience of young caring in relation to parents with a physical disability. Whilst this perhaps reflects the demographics of young caring in contemporary western society, as a result, less is known about young caring in relation to other caring contexts. Notwithstanding this, several studies have considered parental mental health problems (Dearden and Becker, 2000; Aldridge and Becker, 2003), but other caring contexts such as parental substance misuse and learning difficulties have been completely overlooked.

Although caring in relation to various contexts has been considered within the young carers' literature, there has been no attempt to *discriminate* their experiences according to different caring contexts. Nevertheless, the findings of studies from other bodies of literature (such as social and medical literature) have suggested differences in children's experiences of living with parental illness and disability according to different diagnoses and prognoses (Rolland, 1987). This paucity of knowledge and understanding provided the necessary focus for the current study. As such, the impact of the caring context in relation to the experience of young carers was a fundamental area of interest.

1.3 Research Objectives and Research Questions

The identified areas of interest within the current study were translated into five key objectives and five research questions as indicated in Table 1.1 below.

Table 1. 1 - Identified Research Objectives and Research Questions

Research Objectives	Research Questions
1. To investigate what is understood and implied by the term 'young carer', particularly by young carers themselves.	1. What do young carers comprehend by the term 'young caring' and to what extent do these understandings concur with previously proposed definitions?
2. To investigate the significance of definitional ambiguity surrounding the term 'young carer'.	2. What is the significance of 'definitional ambiguity' in terms of the various understandings of young caring?
3. To identify the extent to which young caring affects certain key developmental tasks.	3. How and to what extent does undertaking a young caring role impact upon the developmental tasks that young people undertake in relation to education, social life, health, spatial transitions and relationships?
4. To explore the extent to which the experiences of young carers differ according to their caring context.	4. How and to what extent does the nature of the parental condition affect the experiences of being a young carer?
5. To examine the extent to which 'parentification' or 'parent-child role reversals' is firstly, evident within a young caring context and secondly, differs according to the type and nature of the parental condition.	5. Within a young caring context, to what extent are 'parentification' or parental-child role reversals evident and how does the nature of the parental condition impact upon the experience of parental-child role reversals?

1.4 Overview of the Subsequent Chapters

The rest of the thesis is structured as follows:

Chapter Two – 'Literature Review': the literature review contextualises the current study. The gaps in the literature will be highlighted in order to justify the area of investigation. The key messages contained within the review are as follows:

i.   Defining young carers according to their caring roles can facilitate their recognition and support. However, many young carers have been overlooked partly because of the lack of a universally accepted definition.

ii.   Previous studies have fallen into two broad types: those which have attempted to quantify the numbers of young carers and those which have described young carers' experiences.

iii.   Studies have suggested that young carers may experience a range of problems or issues across a range of domains, including their education, social life, health, relationships and spatial transitions.

iv.   The experience of young caring according to different caring contexts has been a largely neglected area.

Chapter Three - 'Methodology': within this chapter, the research design and methodologies used will be discussed and justified. In basic terms, the study was set within the qualitative domain and influenced by a constructive-interpretive paradigm, specifically, symbolic interactionism. Grounded theory methods were used insofar as they enabled data-collection and analysis. Informed by this approach, a range of data-collection tools were used with a total of 30 young carer participants across three caring contexts. Also as will be more fully explained within the methodology chapter, the study initially set out to investigate four caring contexts: parental physical disability; mental health problems; substance misuse and learning difficulties. However, it was not possible to explore the

effects of caring for parents with learning difficulties because of difficulties identifying potential participants.

Chapter Four – 'Findings': Within this chapter, the results of the study will be presented. The key findings are as follows:

    i.   The participants understood the term 'young carer' in different ways, which did not necessarily relate to their own caring roles at home. For instance, many related the term to being a member of a young carers group. This failure to recognise oneself as a carer essentially exacerbated their hidden-ness.

    ii.   The impacts of caring were discussed mainly in negative terms in relation to a range of domains such as education, social life, work, health and relationships. Some positive issues were noted however.

    iii.   Some of the experiences reported were common to the majority of the young carers across the different caring contexts. Other issues however, were specific to particular caring contexts. Generally, those young carers most adversely affected across the range of areas were caring for parents with a substance misuse or mental health problem.

    iv.   Family structures were significant as having a second parent at home offered some protection against these negative effects.

Chapter Five – 'Discussion': a critical assessment of the findings will be offered by locating them within the wider body of literature. The key messages contained within this chapter are as follows:

    i.   The invisibility of young caring may be viewed as the product of various inter-related factors including definitional ambiguity, professional ignorance and the 'silence' exhibited by young carers and/ or their families. This may be addressed through definitional clarification and appropriate awareness-raising within schools and with professionals.

    ii.   Caring should be conceptualised on the basis of both the amount of care undertaken and/ or the impacts experienced. A 'one size fits all'

approach is not helpful. The new definition presented within this chapter represents a starting point which requires further discussion and development.

iii.   The identification and support of young carers should not be the sole responsibility of a single agency (namely social work). Instead, this should be the collective responsibility of both health and social care agencies.

iv.   The experiential differences reported by young carers in different caring contexts have important practice implications. Thus, it is fundamental that professionals are aware of these issues so that they can better focus their intervention with young carers.

v.   The issues and problems experienced by young carers may be at least partly attributable to other structural and socio-economic factors.

Chapter Six – Conclusion – this chapter will reiterate the key findings and outline their relevance to the existing body of knowledge. In addition, the limitations of the present study and possible directions for future research will be highlighted. Lastly, various recommendations relating to the identification and support of young carers will be presented.

i.   Young carer awareness must be promoted in mainstream education, as well as in the training and development of a wide range of health and social care professionals.

ii.   Professionals should be trained to appropriately recognise and support young carers and their families.

iii.   The improved recognition and support of young carers and their diverse needs should be managed through co-ordinated, flexible and sensitive collaboration of health and social care professionals. This should be at the heart of future policy developments.

iv.   Future research conducted in the field should address the following areas: the extent to which structural and socio-economic factors influence the experiences of young carers; the experiences of young caring according to specific parental diagnoses and in relation to

parental learning difficulties; as well as the specific needs of young adult carers.

1.5 A Note about the Age Range of the Participants

It was not the intention, nor was it possible to systematically differentiate between the views of the older and younger carers involved in this study. Firstly, the study set out to explore the effects of differing caring contexts – not age – on the experience of young caring. Secondly, recruiting a sample of young carers proved problematic, particularly in relation to those aged 18 and over as they were rarely in contact with health and social care agencies or services on the merit of their own caring roles. Thus, the older young carers were included in the sample in order to gain an insight into how young caring affected them during both adolescence and beyond into young adulthood. Whilst it was not possible to fully discriminate between the younger and older participants, some key differences were evident. Specific issues discussed only by the older participants will be highlighted in the discussion chapter.

Chapter 2 – A Review of the Literature Relating to Young Caring

2.1 Introduction to the Literature Review

The late 1980s marked the inception of research interest in young carers within the United Kingdom. The body of subsequent work has been concerned with five key areas:

- arguments for and against the conceptualisation of children who assist with the practical and emotional care of family members as 'young carer';
- research on the experiences and needs of young carers;
- discussion of their legal entitlements;
- advocacy of particular policy and service responses to young caring; and
- descriptions of service developments mainly specific young carer projects[5] (Banks, Gallacher, Hill and Riddell, 2002, p.12).

Holistically, this body of research has served to increase knowledge around the scale of young caring as well as the circumstances and needs of such children. Also, it has provided working definitions of young caring and ultimately, shaped policy and practice within this area. In terms of the current study, the initial two issues (definitions and experiences of young carers) were of particular importance.

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[5] Young carers' projects have been set up around the UK to cater for the needs of young carers. Typically, they are funded by voluntary agencies and provide a range of services such as counselling, homework support and leisure opportunities. They are mainly staffed by support workers commonly referred to as 'young carers' workers' with professional backgrounds in social work, community education or health.

Therefore, within this chapter, firstly, the strategies adopted and the parameters set to manage the search and review of the literature will be outlined. Secondly, definitional and conceptual issues and ambiguities will be discussed. Thirdly, the existing body of research on young carers will be considered and a historical account provided in order to contextualise the current study. Fourthly, the key areas of impact commonly experienced by young carers will be critically reviewed and lastly, the notion of 'hidden-ness' will be examined. Throughout this review, particular attention will be paid to the contribution of contemporary young carers research and in addition, reference will be made to clinical and social studies conducted from the 1950s to the present day. The inclusion of these other bodies of literature has facilitated a more comprehensive understanding of the young carers debate. Moreover, whilst this review concentrates primarily on young carers research conducted in the UK, studies undertaken in other geographical locations have been included where they have offered a particular contribution. For instance, the social and clinical studies were conducted mainly in the UK and the US.

A range of computer databases (including ASLIB, ASSIANet, CINAHL, Social Science Citations Index and ZETOC) were utilised in the literature search. A number of key terms (such as 'Young Carer' 'Impairment' and 'Disability') were used to conduct the search. Thereafter, these enabled access to a wide range of peer reviewed papers (see Appendix 2 for a copy of the matrix utilised to facilitate the literature search) and in turn, the work referenced within these original sources was accessed. Additionally, various websites were utilised, which included dedicated young carers sites and others which related to children or health (such as: www.youngcarer.com; www.show.scot.nhs.uk; www.lboro.ac.uk/departments/ss/centres/YCRG; www.barnardos.org.uk). These served to highlight policy and practice issues.

2.2 Definitional Issues

Definitional Understanding of Young Caring

In terms of a contemporary understanding, the definition of 'young carer' stated in the *'Blackwell Encyclopaedia of Social Work'* has been frequently referred to:

> Young carers are children and young persons under 18 who provide, or intend to provide, care, assistance or support to another family member. They carry out, often on a regular basis, significant or substantial caring tasks and assume a level of responsibility which would usually be associated with an adult. The person receiving care is often a parent but can be a sibling, grandparent or other relative who is disabled, has some chronic illness, mental health problem or other condition connected with a need for care, support or supervision...some young carers experience impaired psychosocial development, including poor educational attendance and performance, and restricted peer networks, friendships and opportunities. These will have implications for their own adulthood (Becker, 2000, p378). (Becker, 2000, p.378).

Nevertheless, this definition has not been universally accepted (Aldridge and Becker, 2003). Indeed definitional understanding has been a contentious issue due to a fundamental lack of agreement over what constitutes a 'young carer'. This relates to the age of young carers, their relationship to the cared-for person, the tasks undertaken, the time spent caring and the consequences of caring. The notion of 'young carer' has been further complicated by their dual and somewhat incompatible status as both children and carers. Thus, much controversy has surrounded the issue, firstly, in terms of whether children should ever be defined as 'young carers' and secondly, where the label has been accepted, how and to whom this should be applied.

It could be argued that defining young carers has been integral to quantifying the scale of the 'problem', identifying young people with caring responsibilities and their resultant needs and delimiting agency responsibility in addressing such

needs. Nevertheless, this assertion has attracted much debate. On the one hand, advocates of the young carers approach contend that the definition and the identification of young carers as a distinct 'welfare category' increases the recognition and acknowledgement of their distinct needs as both children and as carers. Indeed, whilst preliminary research utilised definitions of 'carer' as applied in relation to adults (O'Neill, 1988; Bilsborrow, 1992), this has since been contested due to a growing awareness of the distinct needs and concerns of young carers. Thus, the importance of acknowledging these distinct needs in definitions has been paramount (Aldridge and Becker, 1993a; Jenkins and Wingate, 1994).

On the other hand, the disability rights approach has dismissed the concept of 'young carer' on the basis that it undermines the needs and rights of disabled people. As a result of the dedicated interest in young caring, attention has been deflected away from the needs of disabled parents and in particular, the responsibilities owed to them by statutory services to support them in their parenting role (Morris, 1995; Olsen, 1996; Morris, 1997). Advocates of this approach contend that in the context of adequate service provision, children would not be required to provide care (Banks et al, 2002b). Whilst this argument has been fully acknowledged by the young carers approach, they have viewed this as somewhat idealistic, as formal provision has always been - and continues to be - inadequate in meeting the ever-changing needs of disabled parents. Therefore, young caring must be recognised as an issue in its own right (Becker, Aldridge and Dearden, 1998; Becker and Aldridge, 2003). As highlighted in the literature, arguments regarding the rectitude and implications of defining children as young carers have been most relevant to situations involving children caring for parents with a physical disability:

The debate concerning the definition of 'young carers' and the rights of disabled people often seems to relate mainly to children of parents with physical disabilities...what is clear however, is that many children are living in different situations...Keith and Morris (1995) do not make it clear whether they include mental health problem, or drug and alcohol addiction, in their use of the term 'illness'. In such cases, the ability for the parent to take active responsibility for their own care or for the care of their children is questionable (Thomas, Stainton, Jackson, Cheung, Doubtfire and Webb, 2003, p.42).

Even though the need to define has been accepted by both the young carers approach and policy makers alike, this has not led to the development and acceptance of a universally accepted definition. For instance, the definition proposed by policy-makers was originally driven by financial motives, whilst the definition offered by the young carers approach evolved in response to research findings - reflected in terms of the different conceptual emphases within each of the definitions. In terms of the practical impacts, this disparity between the perspectives has created a situation of definitional ambiguity with problematic implications such as a lack of recognition and identification of young carers. Nevertheless, definitional consensus could create further problems in terms of delimiting the responsibilities of different agencies (social work, education, health and/ or voluntary agencies) in providing support for young carers.

As has been suggested, difficulties in defining young carers may be '...complicated by issues of cause, impact, type and level of caring' (Rose and Kennedy, 1995, p.1). In terms of 'cause', the definitions proposed by the young carers approach refer to the presence and nature of the care receiver's condition. Whilst the concept of young carer initially referred to children caring for parents with a physical disability, this has since been extended to include other situational and caring contexts:

> ...in keeping with the widening concept of disability in legislation, young caring has been extended to encompass circumstances where parents have a

range of issues – physical impairment, chronic or terminal illness, mental health problem and dependency on drugs or alcohol. It has also been recognised that children may take on a care role in respect to other family members (Banks, Cogan, Deeley, Hill, Riddell, and Tisdall, 2002, p.231).

Emphasis on Impact 'versus' Level of Caring

In terms of contemporary understanding, the principal divergence between official definitions and those proposed by the young carers approach relate to the basis on which young caring should be conceptualised. On the one hand, official definitions quantify young caring in terms of the amount and level of caring work undertaken. On the other hand, proponents of the young carers approach suggest that the fundamental defining feature should revolve around the restrictions imposed by caring, to the health and development of young people. Thus, key terminology within official definitions include terms such as *'significant'*, *'substantial'* and *'regular'*. For example the Department of Health define a young carer as:

> Children and young people (under 18) who provide or intend to provide a substantial amount of care on a regular basis (Department of Health, 1996, p.2).

In contrast, advocates of the young carers approach highlight the resultant detrimental impacts of young caring:

> anyone under the age of 18 whose life is in some way restricted because of the need to take responsibility for the care of a person who is ill, has a disability, is experiencing mental distress or is affected by substance misuse (Carers National Association, 1998, p.1).

Arguably, the definitions forwarded by the young carers approach are more inclusive than the official definitions. Nevertheless, potential difficulties exist in relation to both the 'broader' and 'narrower' definitions:

> A broad definition may distract attention from the severe difficulties faced by those children undertaking a very significant caring role. A narrow

definition on the other hand, focuses attention on those with the greatest need but risks excluding others who are genuinely in need of help (Rose and Kennedy, 1995, p.2).

Perhaps there are two fundamental difficulties in terms of official definitions. The first concerns the usage of ambiguous terminology. As key terms such as 'regular' and 'substantial' are themselves not clearly defined, it is at the discretion of local authorities to determine which young carers fit the criteria to have their needs assessed and addressed (Banks et al, 2002b). This difficulty was acknowledged by one researcher who conducted governmental commissioned research into the extent of young caring:

> ...the problem in estimating numbers is the application of the definition of a 'young carer'...what are 'significant caring tasks' or an 'appropriate role' for a young person... (Walker, 1996, p.3).

The second elementary difficulty of the official definitions surrounds their 'failure to address needs of other children on the edges of care' (Heron, 1998, p.48), particularly in relation to those undertaking invisible or unquantifiable care such as emotional support:

> Such terminology can be criticised on the basis of its ambiguity and insular focus, which neglects those undertaking very often unquantifiable or largely hidden roles, such as young carers providing emotional support...a child who worries a great deal about their parent's illness or addiction may be regarded as a young carer on the grounds of undertaking emotional labour, even if they are not undertaking additional caring tasks... (Banks et al, 2002b, p.15).

The neglect of such young carers was highlighted within a critique of a quantitative study carried out by Walker (1996) on behalf of the Department of Health. This study unearthed difficulties when it attempted to measure the extent of young caring by utilising the official definition presented within the 1995 Carers Act:

> It [the study] fails to encompass all children and young people who may not provide substantial or regular care, but who are adversely affected (Dearden and Becker, 1998, p.8).

Moreover, policy-makers argue that a quantifiable element is necessary in order to differentiate the normative tasks undertaken by children in all families, compared to the additional responsibilities undertaken by children deemed to be young carers. However, perhaps this assertion is underpinned by financial motives.

Nevertheless, potential conceptual difficulties also stem from impacts-based definitions due to the unquantifiable and subjective nature of impacts and restrictions. Firstly, a definition framed around this understanding arguably creates a situation where all children in all families could potentially be regarded as young carers:

> ...there is imprecision about which children fall within and outwith the category of young carer, with the possibility that every child in a family with a disabled member is assumed to fall within the young carer role... (Strathclyde Centre for Disability Research (SCDR) and the Centre for the Child and Society (CCS), 1999, p.50)

Secondly, due to the unquantifiable and subjective nature of restrictions or impacts, perhaps those young carers that experience similar restrictions (such as enforced school absenteeism) interpret these differently according to a range of factors such as their familial relationships, length of and feelings toward their caring role and their own personal aspirations. Thus, whilst some may well recognise these impacts and consequently, identify their caring roles on this basis, this may not be applicable to all young carers.

Moreover, it must be questioned whether young carers acknowledge or indeed recognise such detrimental impacts at all and thus, whether they comprehend their caring roles on the basis of any negative impacts experienced. Perhaps young carers accustomed to the restrictions or impacts that their caring role imposes may

overlook these. Also, where these are recognised, young carers may fail to disclose the detrimental impacts to those outside the family for fear of negative repercussions, such as being removed from their family. This issue was highlighted within a preliminary study which utilised an impacts-based definition to identify young people as research participants: 'anyone whose life is restricted by the continuing need to care for a family member...' (O'Neill, 1988, p.6). Within this study it was found that many young carers did not recognise their role on the basis of the impacts alone and thus, further explanation was required. Therefore, it was further stated:

> ...anyone who says that they undertake any of the caring tasks which are associated with looking-after someone who is frail, ill or has a disability (O'Neill, 1988, p.7).

Synthesis of the Two Main Definitions

In sum, the main divergence in emphasis between the definitions relates to whether young caring should be conceptualised primarily according to quantity or consequence of caring. Nevertheless, these definitions are now not as disparate as they used to be. Indeed, deliberation and development of knowledge instigated the reworking and expansion of ensuing definitions. This has resulted in a greater level of agreement between the apparently contradictory definitions, as has been acknowledged by advocates of the young carers approach:

> Despite the lack of a universally accepted definition, there is now considerable agreement regarding the characteristics of 'young carers', namely their involvement in exaggerated levels of caring which have a restrictive or negative impact on their experience of childhood (Aldridge and Becker, 1999, p.307).

Indeed in relation to both policy-makers and advocates of the young carers approach, there has been a consensus on the need to highlight both a quantifiable and consequential element to ensure a comprehensive definition. In terms of the amount of caring undertaken, initial definitions made a clear distinction between those undertaking 'primary' and 'secondary' caring roles (O'Neill, 1988,

Meredith 1991a; Meredith, 1991b; Aldridge and Becker, 1993a). However, the utility of this distinction was later discounted in favour of promoting a more inclusive approach based on the restrictions experienced:

> ...we recognise that while care giving may not always be substantial and regular among children, the contributions they make...may nonetheless be highly significant and important to families themselves (Aldridge and Becker, 2003, p.xiii).

Nevertheless, other research influenced by a young carers approach continues to emphasise this distinction between 'primary' and 'secondary' caring (Princess Royal Trust for Carers (PRTC), 1999; Watson, 1999; Banks, Cogan, Deeley, Hill, Riddell, and Tisdall, 2001; Banks et al, 2002a; Thomas et al, 2003). As Newton and Becker point out:

> As primary carers they spend a substantial part of their time in day to day care or are involved in personal and intimate care of another person... (1999, p.1).

Also, the young carers approach has often utilised equivalent terminology to convey a quantifiable element, such as 'sole carer', 'supportive carer' and 'sibling carer' (Frank, 1995).

Similarly, despite disregarding the usefulness of conceptualising young caring according to the level of care undertaken, the young carers approach continues to make explicit reference to this:

> They carry out, often on a regular basis, significant or substantial caring tasks... (Becker, 2000, p.378).

Furthermore, in relation to official definitions, it has been acknowledged that whilst some young carers may provide insubstantial or irregular care, they may nonetheless still experience detrimental impacts and restrictions:

> ...in the worst cases young people can be harmed by the responsibilities and expectations placed upon them (Department of Health, 1999, p.73).

However, perhaps the greatest consensus evident between the two approaches concerns the criteria indicating the lack of qualification as a young carer. For instance, the young carers approach has stated:

'children who 'baby-sit' siblings in families where parents are voluntarily absenting their parenting responsibilities (to go to work etc) and teenage mothers are not deemed to be Young Carers' (Frank, 2003, p.8).

This point is also reflected within official definitions (Walker, 1996; Scottish Executive, 2001).

Thus, whilst there is now some level of definitional consensus, this has not yet translated into a universally accepted working definition of the term 'young carer'. The principal implications of such definitional ambiguity relate to difficulties in quantifying the scale of the 'problem' as well as inconsistencies in the identification of young carers and the exemption of professionals and agencies from accepting responsibility for addressing the needs of young carers. In terms of this, it can be argued that:

The ways in which agencies identify young carers is affected by the complexities of definition (Banks et al, 2002b, p.13).

And further that:

Operational definitions require consensus or service becomes unfocused, loosely connected to need and more open to unintended consequences (Edwards and Smith, 1995, p.36).

Ultimately, this affects service provision at a 'grassroots' level in respect to young carers:

Certainly, many young carers are commonly defined by professionals with reference to the amount of care that children do – the notion of substantial and regular care (Aldridge and Becker, 2003, p.xiii).

Perhaps the most explicit manifestation of these inconsistencies in the identification of young carers is the discrepancy in the number of young carers identified within different studies. This has resulted from the usage of differing

definitions. Indeed, it can be asserted that: 'The hidden world of young carers may be partly a product of definition' (Banks et al, 2002b, p.1).

In conclusion, those considering the issue from an academic perspective suggest that a definition of young caring requires to be holistic and thus, should include three elements: the amount of caring; the significance of the care to the young person and family and the impact of care work (Banks et al, 2002b). Thus, arguably a consolidation of the established definitions, influenced by young carers' self-comprehensions of the term, may offer the most holistic, comprehensive definition.

Problems of Labelling Young Carers

A fundamental element in terms of definitional controversy relates to the value of 'labelling' children. In addition to the appropriateness of assigning labels, a second issue of concern relate to the implications of utilising a blanket label to describe a range of diverse situations.

On the one hand, proponents of the young carers approach argue that young carers need to be identified as an autonomous group in order for their role and distinct needs both as children and carers to be recognised and addressed (Rose and Kennedy, 1995; Edwards and Smith, 1995; Shah and Hatton, 1999; Becker, 2000). However, perhaps assigning the label 'young carer' is useful only where services are available to meet the distinct needs of such children and young people. On the other hand, whilst 'a label can give a sense of identity and recognition' (Campbell, 1995, p.2), there is a risk of this taking over one's whole identity (Rose and Kennedy, 1995; Edwards and Smith, 1995) or of 'trademarking' children into a caring role (Shah and Hatton, 1999, p.20), akin to something like a 'master status' (Hughes, 1945, pp.353-359).

Also, it can be argued that assigning the label 'young carer' may deter families from seeking appropriate external support, due to the fear of potential implications stemming from judgements about the inappropriate role occupied by the child

(Rose and Kennedy, 1995; Social Services Inspectorate (SSI), 1996; Aldridge and Becker, 2003). Advocates of the disability rights approach dispute the term 'young carer', as it denotes inverted responsibility and dependency within familial relationships:

> ...'young carer' infers that the child is taking responsibility for an adult and that thus, roles are reversed (Morris, 1995, p.4).

By implication, this neglects the interdependent nature of relationships within the family (SCDR and CCS, 1999).

A further pertinent issue concerns individual young carers' lack of acceptance of and subscription to the label (Fiedler, 1996; SCDR and CCS, 1999). For instance, Keith and Morris (1995, p.38) argue that the term was conceived by adults rather than young carers themselves:

> ...they have defined and named a role ['young carers'] which, until the children came into contact with researchers and professionals, was not how they described themselves.

And further that:

> ...they seem to have imposed their own definitions and perceptions on the subjects of their research... (Morris, 1995, p.5).

Also, it has been suggested that even where young carers associate themselves with dedicated young carers' services, this does not necessarily equate to an acceptance of the label:

> The willingness of children to attend young carer projects indicates that they do accept they have needs to be met, which may be recreational, social or emotional. On the other hand, evidence indicates that most do not like the term or identity of 'young carer (Banks et al, 2002b, p 9).

Moreover, it has been argued by some critics that all labels are problematic because of the broad differences in the young carers' situations:

> The support needs of a parent with mental health problems will be different to those of a lone parent with mobility problems or multiple sclerosis...there

is a tendency for the category young carer to be insensitive to this diversity (Parker and Olsen, 1995, p.70).

In response to these key criticisms of the term 'young carer', a range of alternative labels have been proposed. Nevertheless, these can still be regarded as labels and thus, the general criticisms around labelling apply regardless of the actual terminology used. In one study which considered caring-related school absenteeism, the term 'children with home responsibilities' was adopted, rather than 'young carer'. The justification for this was as follows:

> While much of this category of home responsibility related absence is associated with the illness of a family member, other responsibilities are also significant...such as simply 'being in' to answer the door to an official (Fox, 1995, p.222).

It has also been proposed that the term 'young carer' may be ambiguous and a more specific term such as 'children affected by illness, disability or substance misuse' would be more informative (Edwards, 1997, p.3). However, as others have suggested, this term may be somewhat maladroit (SCDR and CCS, 1999). As well as clumsy, this term may be contested by children and parents who do not wish to acknowledge the impact of the parental condition on the child, or indeed associate themselves with more stigmatised conditions. As proposed by advocates of both the disability rights and young carers approaches, not all children in all families where a member has some form of illness or disability will become a young carer. Thus, this label fails to acknowledge the special issues faced by those children with a caring role, compared to those living in families with some form of illness of disability, but who are not required to care.

Alternatively, it has been proposed that the term 'families and disability' may be more helpful than 'young carer' (Rose and Kennedy, 1995) as this intimates the multi-faceted effect that disability has on the family. However as the caring relationships within the family are not explicated within this phrase, the contribution of young carers may be overlooked. In recognition of these

problems, some academics have instead attempted to categorise the caring role, for instance in terms of physical labour; emotional labour; organisational and managerial behaviour (Nolan, Grant and Keady, 1996).

2.3 Historical Account of Young Carers Research in the UK

The Inception of Research Interest in Young Caring

Research on young caring has, so far, fallen into two broad methodological approaches: qualitative and quantitative. Within the contemporary body of literature on young carers, numerous qualitative studies have been conducted. These have largely served to uncover the needs and experiences of young carers. In addition, several quantitative studies have attempted to uncover the scale of the issue. Both 'types' of study will now be discussed.

The two earliest quantitative studies into young caring in the 1980s, 'The Tameside Study' (O'Neill, 1988) and 'The Sandwell Study' (Page, 1988) shared common aims and weaknesses. With respect to their aims, they sought to estimate the extent of caring amongst children within specific geographical areas. In addition, they shared common problems relating to their limited scope, reliance on statistically-based approaches and production of findings which lacked analytical rigour (Meredith, 1990, 1991a, 1991b, 1991c, 1992; Aldridge and Becker, 1993a). Although not the main focus, both of these studies also attempted to offer some level of insight into the needs and experiences of young carers, although again the data-collection methods adopted - and as a result the subsequent findings - were arguably erroneous. In terms of the findings of the studies, minimal numbers of young carers were identified and thus, ultimately the extent of the issue was grossly underestimated.

As was common practice in early research (Roy, 1990; Fox, 1995; Marsden and Lund, 1995) and largely due to the inaccessibility of children as research participants, 'The Sandwell Study' (Page, 1988) relied on 'proxy' accounts. In this case, the views of teachers, rather than the direct views of the young carers'

themselves were sought. However, later research has consistently found that teachers may be unaware of either the caring status of their pupils or the impacts of young caring and as a result, the findings of this study were perhaps somewhat dubious. Whilst *'The Tameside Study'* (O'Neill, 1988) to an extent addressed this particular methodological difficulty through consulting with young carers, this was achieved through a survey approach which was again later criticised as being inadequate in terms of the aim and purpose of the study (Becker, Aldridge and Dearden, 1998). Arguably, the use of leading and ambiguous questions created a systematic bias in terms of the responses. For instance, one particular question posed was *'Are you a carer?'* This made reference to a term which neither children nor adults were likely to identify with either because of fear or being unfamiliar with the language (Segal and Simpkins, 1993). This may have resulted in gross under-reporting of young carers and their experiences. Thus, rather than being of intrinsic value, arguably the key utility of these primary studies related to their role in highlighting the issue of young caring and initiating further research into a grossly undeveloped area.

Development of Systematic Research

Qualitative Studies

Whilst early studies provided a provocative starting point, the value of both these and later quantitative studies in estimating numbers of young carers is questionable. Instead, these perhaps were most valuable in highlighting the acute need for qualitative research to systematically investigate and develop an understanding around the needs and experiences of young carers, through direct consultation (Grimshaw, 1991). As such there was a need to define the concept of 'young caring' before measuring its scale. Arguably, the emergence of systematic research was heralded by the establishment of a dedicated Young Carers Research Group (YCRG) at Loughborough University in 1992, followed by a range of studies undertaken by both the YCRG, as well as other researchers guided by a children's rights approach (Bilsborrow, 1992; Aldridge and Becker, 1993a; Dearden and Becker, 1995; Frank, 1995; Newton and Becker, 1996; Thomas et al, 2003).

Of these, the YCRG have been responsible for the majority of the studies conducted in the area and arguably, they have initiated an innovative and comprehensive approach to research activity. For instance, in their initial study *'Children Who Care'* (Aldridge and Becker, 1993a), an interpretative approach to analysis was utilised. This countered some of the criticisms from a further study conducted around the same time, *'You Grow Up Fast as Well'* (Bilsborrow, 1992), which was highly descriptive, yet lacked interpretation. The follow-on study *'My Child, My Carer'* (Aldridge and Becker, 1994), offered a further original element. In terms of this, the parents cared for by the children involved in the original study were questioned in order to triangulate the initial findings. Such an approach was exceptional at the time, although several later studies have utilised a similar approach with young carers and their parents (Tucker and Liddiard, 1998; Centre for the Child and Society (CCS) and Strathclyde Centre for Disability Research (SCDR), 1999; Harrison and O'Rooke, 2003; Aldridge and Becker, 2003).

Studies that were conducted in the early to mid-1990s consistently revealed a picture of multiple disadvantage experienced by young carers in relation to various key domains such as their education, health and social life. Fuelled by these findings, research interest moved on to focus on particular aspects of disadvantage, for instance education (Marsden and Lund, 1995; Fox, 1995), mental health concerns (Broadbent, 1999; Cree, 2003), bullying (PRTC, 1999; Currie, 2004) and the needs of young adult carers (Harrison and O'Rooke, 2003). As the immediate and short-term impacts of young caring had been established, studies in the late 1990s turned their attention to the long-term effects of caring in childhood. Two studies *'On Small Shoulders'* (Frank et al, 1999) and *'Growing Up Caring'* (Dearden and Becker, 2000) were groundbreaking in this sense.

Whilst both studies were principally concerned with the impact of young caring on future development and opportunities, they used different methods to access the required data. *'On Small Shoulders'* gained both qualitative and quantitative

information through a postal questionnaire method completed by 41 individuals and semi-structured interviews with 25 former young carers aged between 22 and 55 in England and Northern Ireland. In contrast, *'Growing up Caring'* used a sample of 60 current and former young carers aged 16-25 from across England.

Despite such disparities, the findings of both studies were remarkably similar, which arguably increased their validity. In broad terms, the findings identified a range of impacts experienced by young carers in relation to their education, training, employment, and moves away from their parent. Nevertheless, two issues regarding the methods adopted in *'On Small Shoulders'* should be mentioned. Firstly, the postal questionnaire achieved a low response rate, a problem discussed elsewhere in relation to postal questionnaires with young carers elsewhere (Hendessi, 1996). Secondly, the sample consisted of a 'retrospective' population, which could have affected the accuracy of the findings, due to poor memory recall of past events or *'ex post facto'* rationalisation.

Cumulatively, the range of qualitative studies conducted in the 1990s have offered an insight into the needs, circumstances and experiences of young carers and ultimately, have informed policy and practice in the area, including the formation of specialist young carers' services throughout the country. This research also revealed that young carers experience a range of detrimental impacts in relation to their education, social life, health, career and fulfilment as adults, as well as their own spatial transitions and relationships. The needs resulting from such issues have been summarised to include: sensitive, appropriate and flexible support; practical help; emotional support; and relevant information (Frank, 2002). These impacts will be critically discussed below with reference to the findings of key studies.

In addition, these studies addressed some of the heavily criticised philosophical and methodological issues pertaining to the earliest studies. Nevertheless, due to difficulties in recruiting young carers, the early studies were small-scale in design by necessity. Also, the majority were conducted in specific localities and most

relied on professionals and young carers' services to recruit young people as participants (Frank, 1995; Newton and Becker, 1996). Whilst some studies identified a sample of young carers through generic services such as schools (PRTC, 1999), this was fraught with difficulties due to confidentiality and privacy concerns (Banks et al, 2002b). These factors have attracted criticism, particularly from the disability rights approach:

> ...studies are small-scale and their samples are usually opportunistic and poorly designed (Morris, 1995, p.39).

Moreover, the principal data-collection method used in these qualitative studies was semi-structured interviews - although some adopted mixed methods, typically a survey method and interviews (Cree, 2003). The presentation of individuals as 'case studies', has also been common practice (Dearden and Becker, 1995; 1998 and 2000). The appropriateness of this however, may be questioned where the only data or evidence has been gathered through semi-structured interviews, rather than the multiple methods prescribed by this approach.

Further criticism from the disability rights approach has been directed at both early and later research, because of a failure to compare the experiences of young carers with other non-caring children. They have asserted that such research would serve to expose the other socio-economic factors responsible for the long-term disadvantage and negative impacts commonly reported by young carers (Keith and Morris, 1996; Olsen, 1996; Olsen and Parker, 1997). Two studies – *'Children Affected by Disability'* and *'The Easterhouse Study'*, both conducted by researchers from the 'Strathclyde Centre for Disability Research' (SCDR) and 'Centre for the Child and Society' (CCS) (CCS and SCDR, 1999; SCDR and CCS, 1999) have addressed some of these methodological and philosophical concerns. The initial study, undertaken within a local authority area in central Scotland, considered the situation of children affected by disability in the family, whilst the latter, carried-out within a particular locality was concerned specifically with young carers.

The aims of *'Children Affected by Disability'* were ambitious and multiple: to estimate the prevalence of children under 16 living in a household with a disabled member; to discover the needs and experiences of children due to having a disabled family member and to assess the availability of service provision. The main methods utilised were interviews with service providers, a postal survey of parents and interviews with affected children. This use of multiple methods facilitated the triangulation of findings. These findings revealed that firstly, approximately three percent of the young people were in households which contained at least one disabled member (mainly siblings). Secondly, it was suggested that there were both positive and negative aspects of living in such a family context, many of which were remarkably similar to those highlighted in relation to young carers. For instance, the negative impacts included educational and social difficulties, whilst the positive effects described involved closer family relationships, greater empathy, as well as an increased understanding of illness and disability (CCS and SCDR, 1999).

'The Easterhouse Study' shared aims similar to those presented in the first study, although this was undertaken in respect to young carers within a very specific geographical context – Easterhouse in Glasgow – rather than across an entire local authority area (SCDR and CCS, 1999). Thus, the aims were: to estimate the numbers of young carers living in various areas in Scotland with particularly high levels of poverty and disadvantage; to identify the needs and experiences of those young carers and to evaluate the extent to which local services had met their identified needs. To address these aims a range of both qualitative and quantitative methods were utilised, which again facilitated the triangulation of data. These included a large-scale school survey involving 509 pupils aged 11-17 years, a door-to-door survey with 20 parents and a focus group consisting of both young carers and non-young carers. Moreover, discussions with service providers investigated how professionals construed the 'problem'. (SCDR and CCS, 1999). Arguably, the focus groups addressed a further criticism of research undertaken by the young carers approach. As stated, no such studies had previously set out to compare the roles of young carers with non-young carers. However, through this

method, this study highlighted the extent to which young carers' responsibilities were qualitatively and quantitatively different from non-carers. The findings of the second study indicated that approximately six percent of those who had completed questionnaires were undertaking a caring role, a high proportion, which perhaps reflected the high level of poverty and deprivation in the area. Moreover, a range of positive and negative impacts, almost identical to those identified in the initial study, were highlighted.

A further neglected issue relates to the nature of the care receiver's condition. The majority of the early studies conducted have involved children caring for parents with physical disabilities. This was perhaps due to the inaccessibility of children caring in other contexts, such as parents with mental health problems:

> Children in families where mental ill health was an issue tended to be more hidden and less easy to identify. This is because of stigma attached to mental ill health, and the consequent reluctance by the family to identify themselves (Dearden and Becker, 1999, p.274).

Moreover, in terms of physical disability, research has related to a range of conditions, rather than specific diagnoses, although some studies have considered particular issues in relation to HIV (Alexander, 1995; Cree, Kay, Tisdall, and Wallace, 2006) and Multiple Sclerosis (Segal and Simkins, 1993).

Later studies have largely involved participants in a range of caring contexts, although there has been no discussion or interpretation of the impact of this on young carers' experiences. Furthermore, the majority of later studies have related to young carers supporting a parent, although some studies have involved participants caring for a range of family members, including parents, grandparents and siblings. However, the findings were not discussed, differentiated, or interpreted according to this. The vast majority have also largely related to white young carers with minimal discussion around the needs of young carers from other cultural backgrounds.

Nevertheless, one study considered the impacts of having a disabled sibling on other children in the family. This made some reference to young caring and highlighted findings similar to those of other studies, particularly in terms of the impacts on education and social life (Atkinson and Crawforth, 1995). A further study (Shah and Hatton, 1999) looked at young carers from South Asian communities. Again, this highlighted findings that were remarkably similar to those evident in the wider body of research. Later studies have indicated that such experiences are common to young carers from diverse areas in the UK (Frank, 1995) as well as other European countries and Australia (Aldridge and Becker, 1993a; Becker, 1995; Dearden and Becker, 1995; Noble-Carr, 2001).

Studies specifically concerned with young carers in the context of parental mental health have been exceptional. Two early, small-scale studies considered growing up with mental health problems in the family (Elliott, 1992; Landells and Pritlove, 1992). A further study which was set in a specific geographical location in Scotland – West Dumbartonshire – considered young carers of parents with a mental health problem. This utilised both qualitative and quantitative methods in order to quantify the number of children in this particular context and identify their needs (NCH, 1995).

Innovative as these studies were, each had methodological difficulties. The first was potentially weakened by its retrospective sample of nine former young carers aged 22-41 (Elliott, 1992). The others relied on data gathered from professionals in contact with children caring for parents, rather than the young carers themselves (Landells and Pritlove, 1992; NCH, 1995). The most recent study *'Children Caring for Parents with Mental Illness'* (Aldridge and Becker, 2003), conducted a decade after the initial study, arguably offers a much more comprehensive and holistic description and interpretation of the needs and experiences of young carers in this context. In-depth semi-structured interviews were carried-out with a total of 40 parents with severe and enduring mental illnesses, their young carers and relevant professionals. The study was concerned with developing an understanding of the experiences of such young carers. Of

particular significance, the findings suggested that the actual roles and responsibilities of the young carer participants were very much dictated by the specific needs of the parent according to the nature of their particular condition.

Quantitative Studies

By the mid 1990s, qualitative research had increased an awareness of young caring and the visibility of young carers to such an extent, it became possible to legitimise and conduct large-scale, quantitative studies. In relation to this development, two broad types of study were evident. The first type, surveys, have systematically described the experiences of young carers and added rigour to the findings of smaller-scale qualitative studies, branded anecdotal by some disability rights critics (Olsen, 1996). The second type has attempted to quantify the actual numbers of young carers. In relation to the former type, a series of three national surveys were conducted by the YCRG (Dearden and Becker, 1995; 1998; 2004). These involved 641, 2,303 and 6,178 young carers respectively and all utilised a qualitative and quantitative multi-method approach. This encompassed a large-scale survey method and follow-up interviews with a select number of young carers to triangulate the data. However, as all of the participants were recruited through young carers' projects, the findings were perhaps only representative of those supported by such services. Thus, the findings were perhaps not reflective of the large 'hidden' and unsupported population. Nevertheless, these surveys have contextualised young caring on a national scale and offered information on the characteristics of young carers in relation to age, gender, ethnicity, the nature of caring relationships, care needs within the family and the caring tasks undertaken. According to the most recent survey, tasks undertaken by young carers can include domestic assistance, nursing and personal care, emotional support, and child care for siblings. The majority of young carers are responsible for some domestic tasks and emotional care.

In terms of the validity of these and previous studies, findings from the national surveys have consistently reflected those of previous small-scale studies, particularly in relation to the characteristics of young carers. The socio-

demographic picture of young carers in the UK has revealed a largely white, female population, living in lone parent families and caring for mothers with a physical disability. In terms of caring contexts, findings have revealed that half of all young carers support a family member with a physical disability; 29%, a mental health problem, 17%, learning difficulties; and three percent, sensory impairments (Dearden and Becker, 2004). Again, such findings mirror those within other studies based on particular localities or where the main caring context has been physical disability (SCDR and CCS, 1999; PRTC, 1999; Cree, 2003). This has also added strength to the argument that the adoption of caring roles by children is underpinned by various socio-economic factors. In addition to the nature of the caring context, other precipitating factors could include:

> ...family structures, gender and co-residence, status and power, and the availability and nature of external support to the ill/ disabled parent and young carer... (Becker et al, 1998, p.xiii).

With regard to status and power differentials, children may be socialised into caring roles from an early age with a gradual increase in their responsibilities, or elected by another adult family member who perhaps refused to take on the role themselves (Aldridge and Becker, 1997).

Other studies have attempted to ascertain the extent of young caring across the UK (Parker, 1992; Parker, 1994, Mahon and Higgins, 1995; Walker 1996) although arguably, these have not successfully achieved their aim. Whilst the numbers of children living in families with some form of illness or disability has been estimated with some accuracy at approximately three million or 23% of all children in the UK (Eurostat, 1997), it has been argued that not all of these children will be required to care. For instance, many will live in contexts where other types of formal or informal support are available. Thus, estimating the number of young carers with any degree of accuracy is clearly a highly complex task. Generally, attempts to do so have produced great variations in numbers, partly due to the invisibility of young carers, yet also because of a range of other methodological factors. Firstly, different definitions of caring have been utilised within different studies (Watson, 1999) and secondly, attempts have been made to

generate national estimates based on small or specific localities, such as Glasgow (Edwards, 1997). Unsurprisingly, the proposed figures have been exposed as gross underestimates. Attempts to quantify the extent of the issue have proposed numbers of young carers on a national scale, ranging from 10,000 (Page, 1988, Fallon, 1990; O'Neill and Platt, 1992; Siddall, 1994); 15,000 to 40,000 (Dearden and Becker, 1995; Mahon and Higgins, 1995); 19,000 and 51,000 (Walker, 1996); 10,000 primary carers and up to 30,000 secondary young carers (Cohen, 1995; Francis, 1995) and 175,000 young carers in the last census (Census, 2001) - of which there were an estimated 16,701 under the age of 18 in Scotland (Scottish Executive, 2001; Sadler, 2003).

Nevertheless, the latest census figure (Census, 2001) is perhaps somewhat questionable. Whilst generally reflective of the numbers identified in other studies (Cawson, Wattam, Brooker and Kelly, 2000; Cawson, 2002), this figure of 175,000 young carers was based on information provided by adults about their children's caring responsibilities. Caring responsibilities therefore, may have been overlooked or denied by the parents (Fiedler, 1996). Also this does not take account of children caring in the context of parental substance misuse. Thus, the estimated figure of 175,000 is likely to be a gross underestimate. Also, the utility of such studies has been queried, as they have provided little or no information about the needs of young carers:

> ...headcounts of carers give little indication of the amount of caring that is involved, or the nature of the caring experience (Cree, 2003, p.303).

Insights into the Effects of Familial Disability from the Clinical and Social Literature

In addition to research conducted by proponents of the young carers approach, the contribution of earlier clinical and social research has also been significant. In particular, this examined the 'triggers' leading to the adoption of particular roles in childhood in relation to families with disability and illness (Aldridge and Becker, 1999). Clinical research undertaken between the 1950s and 1980s was largely concerned with the negative effects of parental illness and disability on the

family and in particular, on children. This was underpinned by notions that parental illness and disability meant ineffective parenting, which in turn, necessitated the adoption of particular roles by children. In relation to 'young caring', children's caring roles were largely recognised in implicit terms only, for instance, as children undertaking parental-type roles.

Whilst such research was guided by the doctrines of the 'medical model of disability', rather than the 'social model' which has governed later young carers research, some parallels between these bodies of literature can be drawn. For instance, findings concerning the impacts of illness and disability on children in the family are comparable to those discussed within the young carers' literature. In relation to the clinical body of literature, such impacts were summarised categorically in terms of 'acquisitional', 'social', 'emotional' and 'behavioural' (Becker et al, 1998, p.2). With respect to 'acquisitional' impacts, the risks of transmission of the parental condition - particularly in relation to mental health problems – were detailed (Anthony, 1970; Gottesman and Shields, 1972; Hatfield, 1978; Mednick and Mura, 1982). 'Social' impacts were described in terms of the 'social stigma' or 'courtesy stigma' experienced as a result of their association to a person with an illness or disability (Romano, 1976; Sargent, 1985; Frankenburg and Perry, 1985). Moreover, 'emotional' impacts were described in terms of a '...vulnerability to emotional disturbance...' (Sturges, 1977, p.89) and heightened anxiety about the parent's health (Power, 1977). Lastly in terms of 'behavioural' impacts, there were various accounts of children who had adopted 'idiosyncratic roles' to cope with the demands of the parental condition. Parallels are evident between these roles and those which have since been described in the young carers' literature, particularly in terms of the recluse, the escapee, the good child and the bad child and most significantly, the caretaker (Arnaud, 1959; Olsen, 1970; Heslinga, Schellen, and Verkuyl, 1974; Romano, 1976; Sturges, 1977; Frankenburg and Perry, 1985; O'Neill, 1985).

In later clinical and social studies, where the adoption of caring roles amongst children was actually acknowledged (Olsen, 1970; Hillbourne, 1973; Heslinga et

al, 1974). However, these were largely considered in terms of false maturity (Arnaud, 1959), precocious competence (O'Neill, 1985), caretaking (Sturges, 1978), or role reversals between parents and their children (Romano, 1976). Moreover, the wide-ranging impacts of caring in childhood were described in almost identical terms to those outlined in later young carers' literature. For instance, specific impacts referred to included a loss of freedom in childhood (Frankenburg and Perry, 1985), poor school attendance and a lack of adult fulfilment (O'Neill, 1985), as well as guilt (Sturges, 1978). As highlighted in one study, the similarities between the findings of these studies raises queries about the root cause of the impacts experienced:

> What we and other researchers have found is a wide range of individual needs...that relate as much to the impact of having someone in the family...who is ill or disabled as to the impact of actual 'caring' responsibilities (Thomas et al, 2003, p.43).

A further directional shift in terms of the clinical research was evident from the mid-1980s, at which point there was some recognition of the social and economic factors that shape the experiences of children and families (Aldridge and Becker, 1999). Of particular relevance were studies which highlighted these experiences in relation to specific parental conditions such as Multiple Sclerosis (Segal, 1991), Parkinson's Disease (Grimshaw, 1991), Huntington's Chorea (Harper, 1986) and schizophrenia (Webster, 1990). Nevertheless, despite the actual diagnoses, commonalities in the experiences of children were evident:

> All the research highlights common issues for children – social isolation, stigma and children being robbed of their youth (Elliott, 1992, p.5).

2.4 Impacts of Young Caring

Advocates of both the young carers and disability rights approaches have argued that caring during childhood should be viewed as normative and demonstrative of interdependence within families:

Some degree of caring in childhood is healthy and should be encouraged (Aldridge and Becker, 1999, p.304).

However, the young carers approach assert that young caring should be separated from normative caring undertaken within families on the basis of its exaggerated and potentially detrimental nature across a range of key areas such as their 'education and future opportunities; influencing personal health and wellbeing; social exclusion/ isolation...' (Frank et al, 1999, p.6).

However, as is now generally agreed across the various perspectives, these restrictions result not solely from the presence of disability or illness within the family or young caring itself, but instead are due to a complex range of inter-related socio-economic factors which accompany illness or disability' (Morris, 1995). As Dearden points out:

> ...The absence of family-focused positive and supportive interventions by professionals combined with inadequate income, have negative effects for young people and their parents. Parental illness or disability is usually an indirect influence. The more direct influences are the lack of appropriate, affordable social care services, educational difficulties, poverty, social exclusion and stress (Dearden, 2000, p.630).

Thus, the effects of poverty and low income - as either being caused by or leading to parental illness and disability – are significant in determining the experiences of young carers. Moreover, it is now acknowledged that the impacts experienced by young carers, may be common to other children living in conditions of socio-economic disadvantage or poverty. This further complicates the viability of the relationships between caring and its supposed impacts:

> In general children who live in poverty have worse health, worse educational opportunities and worse access to services than wealthier children (United Nation's Children's Fund (UNICEF), 2000, p.22).

The difficulties experienced by young carers may be best seen as inter-related. For the purposes of clarity within this section, however, the main impacts - in

terms of education, social life, health, career, employment opportunities, spatial transitions and relationships - will each be considered in turn.

<u>Educational Impacts Experienced by Young Carers</u>

Poor educational performance and attendance problems have been reported as the most significant impact experienced by young carers, perhaps due to the direct correlation between educational disadvantage and future life chances (SCDR and CCS, 1999; Frank et al, 1999; Dearden and Becker, 2000; Aldridge, 2003).

Preliminary studies reported few detrimental impacts in relation to young carers' education (O'Neill, 1988; Bilsborrow, 1992), which perhaps partly reflected the methodological approaches utilised within these, such as a reliance on proxy accounts. Due to the invisibility of young carers at the time, the professionals involved were unlikely to be aware of their existence, let alone their problems. Later studies using different forms of data-collection highlighted a range of educational difficulties experienced by young carers (Aldridge and Becker, 1993a; Frank, 1995; Mahon and Higgins, 1995). These have since been substantiated (to varying degrees) by the findings of both small-scale studies specifically concerned with educational impacts experienced by young carers (Marsden and Lund, 1995), as well as national surveys (Dearden and Becker 1995; 1998; 2004).

These have included one or a combination of difficulties in relation to **attendance problems** (Aldridge and Becker, 1993a; Fox, 1995; Marsden and Lund, 1995; Dearden and Becker, 1995; Dearden and Becker, 1998; Frank et al, 1999; Watson, 1999; Crabtree and Warner, 1999; Dearden and Becker, 2000; Aldridge and Becker, 2002; Aldridge and Becker, 2003), **punctuality** (Dearden and Becker, 1995; Marsden and Lund, 1995; Dearden and Becker, 1998), the **lack of time and opportunity to undertake homework tasks** (Dearden and Becker, 1995; Marsden and Lund, 1995; NCH, 1995; Dearden and Becker, 1998; Watson, 1999; SCDR and CCS, 1999; Thomas et al, 2003) **difficulties managing workload** (Dearden and Becker, 1995; Dearden and Becker, 1998; Frank et al, 1999), **tiredness affecting the quality of schoolwork** produced (Frank et al, 1999; Eley,

2004) as well as **experiences of collusion or a lack of understanding of teachers** (Dearden and Becker, 1995; 1998; 2000). In relation to the latter point, it has been found that teachers may ignore educational difficulties, either because of concerns about upsetting the child, or due to uncertainty about if and how to intervene. Ultimately, 'colluding' with the child has been found to be an unhelpful practice as it can prevent the identification or acknowledgement of the caring role. This may also serve to exacerbate educational difficulties, which may lead to future problems such as poor educational attainment (Dearden and Becker, 2000). In turn, poor attainment has been linked with compromised employment choices and a lack of opportunities in terms of further education and future life chances (Frank et al, 1999; Dearden and Becker, 2000).

Nevertheless, it must be acknowledged that young carers' experiences at school have not been described wholly in negative terms. For instance, school has been commonly reported as a form of escape, refuge or respite from home and one's caring responsibilities (Dearden and Becker, 1995; Frank, 1995; Gates and Lackey, 1998; Watson, 1999; Cree, 2003). Where further detail has been provided, school has been described as an opportunity for young carers to forget about the 'stresses', 'pressures' and 'worries' of their home situation (Frank, 1995, p.50; Dearden and Becker, 1995, p.26; Gates and Lackey, 1998, p.13). Indeed, it has been suggested that school occupies an integral position in terms of offering young carers social support: '…school may be the one place that can offer these children 'normality' and 'an opportunity to gain support' (Frank, 2003, p.8). Moreover, in a further study it was commonly reported by the young carer participants that their caring responsibilities had a positive impact on their education, in terms of making them more efficient in time management (SCDR and CCS, 1999).

Of the problematic issues outlined, absenteeism and particularly the extent and causes of this, has received the most attention within the literature. There have been discrepancies, however, in terms of the incidence of absenteeism amongst young carers, as reported in different studies. This perhaps reflects the various

methodological inconsistencies across the studies. For instance, the results of national surveys have noted an overall decrease in the incidence of such difficulties. The findings of small-scale qualitative studies however, have been more ambiguous. On the one hand, in national terms, young carers' self-reported absences and educational difficulties, have decreased from approximately 33% in 1995 to 28% in 1997, to 22% in 2003 (Dearden and Becker, 2004). On the other hand, the findings of some small-scale studies have suggested that the majority of young carers or a high proportion experience some form of educational disadvantage (Dearden and Becker, 1995). For instance, one study asserted that over 70% of the former young carer participants indicated that their education had been affected by their young caring role in childhood (Frank et al, 1999). Another found that of the participants aged 16-18 years, 20 of the 36 had missed at least some of their schooling due to their caring responsibilities (Dearden and Becker, 2000).

Various other studies have indicated educational difficulties amongst relatively low numbers of young carers. For instance, one study found that only 22% of the 91 pupils surveyed, reported that caring had an effect on their education – six stated that they sometimes missed school, nine had difficulties completing homework tasks and ten reported problems with punctuality (SCDR and CCS, 1999). Similarly, a further study found no evidence to suggest that young carers' school work suffered (Tucker and Liddiard, 1998). Perhaps these differences stemmed from the inconsistencies across studies in terms of the types and levels of caring responsibilities amongst the participants. This has led to queries regarding the actual extent and nature of educational difficulties, particularly from advocates of the disability rights approach. For instance, it has been asserted that only 'a relatively small core of heavily involved children may be in danger of missing out educationally' (Parker and Olsen, 1995, p.71).

Furthermore, the reasons behind absenteeism in relation to young carers have been variously described, yet in broad terms linked to a requirement to stay at home to look-after the cared-for person (Dearden and Becker, 1995). Such

behaviour may be initiated by either the parent or the child - to allay the young carer's concerns and worries about their parent's welfare in their absence, or to address the parent's fear of being left alone (Aldridge and Becker, 1993a; Dearden and Becker, 1995; Fox, 1995; Aldridge, 2003).

Nevertheless, one study called into question the suggestion that parents play a key role in terms of encouraging their children's absences. This was based on findings which suggested that the parents in the study attached a high value to their children's education and were unhappy about them taking time off school to care (Aldridge and Becker, 1994). However, these findings should be observed with caution. Parents may be unwilling to admit to such absences, due to their legal responsibilities as parents:

> What it is to be a good parent is in part a publicly determined and legal matter... a good parent ensures their child attends school, and what is more is required by law to do so... (Roche and Tucker, 2003, p.441).

Moreover, other studies have described various forms and causes of 'exclusion' as experienced by young carers, such as 'enforced exclusion' engineered by others, including parents. This system which has the effect of excluding young people from various domains including education (through enforced absences from school) may be underpinned by fear, intimidation and coercion (Frank et al, 1999). A further study identified caring responsibilities as the reason for absences, given by 43% of parents of non-illness related poor attendees (Galloway, 1980).

However, in addition to the caring role, a range of other contributory factors have been offered to explain absenteeism:

> Where children are missing school as a result of their caring roles, or are persistently late due to, for example waiting for homecare services to arrive, it is easy to see cause and effect. However, regarding other examples of educational disadvantage we cannot be certain that caring itself is responsible...variables that may have an impact on young carers' educational

disadvantage in addition to caring, [include factors] such as IQ, distance from school, poverty and social exclusion, personal interest, parental interest and stimulation (Dearden and Becker, 2001, p.6).

Nevertheless, the effect of the care receiver's condition on the young carer's school attendance, has received minimal attention. The findings of the most recent national survey indicated that whilst the prevalence of absences amongst young carers has decreased proportionally, those caring in the context of parental substance misuse appeared to experience more difficulties than previously noted. For instance, four in ten are absent from school on a regular basis or have other educational problems (Dearden and Becker, 2004). In contrast, it can be deduced from the findings of one qualitative study that young carers are liable to miss school regardless of the nature of their parent's condition (Dearden and Becker, 2000). It has also been argued that whilst all children may undertake tasks within the home, young carers differ not only in terms of the amount of tasks undertaken and the impact of these, but also in terms of the timing of tasks: 'young carers may have no choice as to when they undertake such tasks...' (Dearden and Becker, 2000, p.3).

Extending this argument in relation to the impact of the caring context, some young carers may need to stay at home to undertake specific types of tasks - which by their very nature require to be completed at specific times - such as meal preparation, personal care and the administration of medication. In comparison, this may not be necessary for others who provide less specific types of care, such as emotional support. On the one hand, 'emotional labour' may occupy the child both within and outside the home, for instance, in terms of being worried or concerned about the parent whilst at school. On the other hand, 'emotional support' may not necessarily need to be undertaken at specific times, or require the child to stay off school.

In addition to the young carers literature, similar educational difficulties have been acknowledged within the clinical and social literature. These have been

discussed in relation to children living with some form of parental illness or disability, particularly problem alcohol use (Laybourn, Brown and Hill, 1996) and drug use (Sowder and Burt, 1980; Kolar, Brown, Haertzen, and Michaelson, 1994; Hogan and Higgins, 2001; Advisory Council on the Misuse of Drugs (ACMD), 2003).

Social Impacts Experienced by Young Carers

In terms of optimal adolescent development and identity-formation, the importance of peer group interactions and friendships has been highlighted within the developmental literature (Clark-Lempers, Lempers and Ho, 1991; Laursen, 1993; Akers, Jones, and Coyl, 1998). As discussed in the young carers literature, young people may face a range of disadvantage and detrimental impacts in terms of their social functioning and friendships (Page, 1988; Meredith, 1992; Aldridge and Becker, 1993a; Jenkins and Wingate, 1994; Frank, 1995; Newton and Becker, 1996; Walker, 1996; Tucker and Liddiard, 1998; Tatum and Tucker, 1998; Shah and Hatton, 1999; Aldridge and Becker, 1999; Dearden and Becker, 2000; Lackey and Gates, 2001; Harrison and O'Rooke, 2003).

Whilst the specific issues of concern are described as 'impacts' within the literature, arguably these can be understood in terms of 'primary' impacts and 'secondary' consequences. Primary impacts include factors such as a **lack of involvement in extra-curricular or leisure activities** (Page, 1988; Banks et al, 2001) perhaps due to imposed or **self-imposed 'caring curfews'** (Aldridge and Becker, 1993a, p.48; Frank, 1995, p.49); **a reluctance or inability to invite friends home** (Bilsborrow,1992; Aldridge and Becker, 1993a; Frank, 1995; Gates and Lackey, 1998; SCDR and CCS, 1999); **a lack of time to socialise** (Page, 1988; Dearden and Becker, 1998) or an **inability to partake in social activities** (Banks et al, 2001; Thomas et al, 2003). These problems have been attributed to issues such as tiredness and stress (Meredith, 1991b); a lack of understanding or perceived stigma of one's familial situation amongst friends and peers as well as bullying (NCH, 1995; Crabtree and Warner, 1999; SCDR and CCS, 1999; Watson, 1999; Banks et al, 2001; Cree, 2003) or a reluctance to confide in others

(Frank, 1995; Dearden and Becker, 1998; Banks, et al 2002a). Arguably, the cumulative result of these primary impacts can be viewed as secondary consequences, such as difficulties establishing or sustaining friendships and isolation from peers (Bilsborrow, 1992; Aldridge and Becker, 1993a; Frank, 1995; Marsden and Lund, 1995; Gates and Lackey, 1998; Dearden and Becker, 1998; Broadbent, 1999; Dearden and Becker, 2000; Banks et al, 2001; Lackey and Gates, 2001; Cree, 2003; Currie, 2004).

Similar concerns have been highlighted within the body of social literature, particularly in terms of a reluctance to invite friends to the family home in the context of parental 'problem alcohol use' (Velleman, and Templeton, 2003) and general friendship difficulties in relation to both parents with learning difficulties (Booth and Booth, 1998) and drug use (Dore, Kauffman, Nelson-Zlupko, and Granfort, 1996; Barnard, 2003). Indeed the similarity of the impacts described within the various bodies of literature may suggest that social disadvantage can result from having a parent or sibling with some form of illness or disability, rather than young caring. Certainly a range of factors may contribute to the proposed social difficulties have been acknowledged, including '...a need to remain in close proximity to the parent...the attitude of care receiver; emotional pressures...such as guilt and loyalty (Aldridge and Becker, 1993a, p.45).

However, perhaps caution should be observed when drawing inferences about the universality of experience in terms of social impacts. As evidence has suggests, some young carers do endure a range of severe social restrictions, others however, do not. For instance one study highlighted the social impacts faced by young carers in a somewhat universal sense. However, this was a generalisation based on limited information:

> In one [out of 25 former young carers' interviewed] instance the child's social development was severely restricted by caring responsibilities (Frank et al, 1999, p.49).

Moreover, an initial study revealed that only around one-third of the 564 participants identified that their social lives had been detrimentally affected (Page, 1988). In a further study, whilst none of the participants felt that their relationships with friends had been enhanced by the presence of illness or disability, only one in four felt that their ability to invite friends home had been curtailed (SCDR and CCS, 1999). Lastly, another study found that 36% of the participants worried about being bullied and 35% worried about being abandoned by friends (Cree, 2003). Indeed, it must be questioned whether these figures are higher than those relating to children in general or other groups of disadvantaged children in particular.

Two particular factors relating to this merit closer consideration. These are the implicit systems relating to firstly, disclosure of the caring status and role and secondly, prioritisation within the family. Firstly, a lack of understanding of the young carer's family situation, as well as the young carers' failure to disclose their home situations, may be underpinned by both the notion of stigma and an acute adolescent need to 'fit in'. Although stigma will be examined later, at this point it is important to highlight that stigma has been linked to bullying, a problematic issue which can affect children's social lives and education (SCDR and CCS, 1999; Watson, 1999; Banks et al, 2001):

> ...a higher proportion of young people with caring responsibilities than non-carers were sometimes afraid to go to school because of bullying... (SCDR and CCS, 1999, p.39).

Moreover, the actual level of bullying reported amongst young carers has been consistently high. For instance, in two studies, it was concluded that 89% (Currie, 2004) and 71% (PRTC, 1999) of the young carers surveyed had been bullied. Also, difficulties surrounding bullying have been acknowledged by the parents of young carers (SCDR and CCS, 1999). The nature of the parental condition may be significant in terms of the root cause of bullying, as described in the social literature. For instance, it has been highlighted that the children of parents with learning difficulties or substance misuse problems may be bullied due to their

'shabby' or unkempt appearance (Elliott and Watson, 1998 as cited in Tunnard, 2002a; Mahoney and MacKechnie, 2001; Booth and Booth, 1998). In this context, bullying may also result from the value placed on the parental condition, e.g. *'Your mum's a junkie/ alkie'*, demonstrative of the notion of 'courtesy stigma' (Goffman, 1963) or stigma deriving from an association with the parent.

Secondly, it may be argued that implicit systems exist in the family which prioritise the needs of the parent over the young carer's needs. Arguably, this issue has been acknowledged yet not fully addressed within the literature. For instance, this finding was clearly evident in a summary of two preliminary studies which considered both the young carers and parents perspectives:

> What is interesting in considering the needs as expressed by children in the initial study and those expressed by the adult care receivers here, is that the children openly talked of their parents' needs, but the parents talked of their own needs and not those of their children' (Aldridge and Becker, 1994, p.25).

This notion was reiterated in a later study:

'...children worry less about themselves and more about their parent's wellbeing (Centre for Child and Family Research (CCFR), 2003, p.3).

Arguably, 'prioritisation' may be maintained by parents and young carers, as well as professionals and can be expressed in various ways. This may include parents prioritising the child's activities to allow sufficient time and energy for them to care:

> Parents successfully controlled their children's lives by prioritising their duties, their social activities and their schoolwork (Aldridge and Becker, 1994, p.8).

Also, two studies found that caring was prioritised over children's social needs (Aldridge and Becker, 1993a, 1994; Tucker and Liddiard, 1998). Interestingly, their young carer's social needs were sacrificed to a greater extent than their educational needs:

In some cases parents had been forced to prioritise activities for their children. Parents made a choice between what they felt was important and what was less important for their children's wellbeing. They had decided school work took priority over any kind of social activity... (Aldridge and Becker, 1994, p.13).

Furthermore, it may be stated that young carers can maintain this system through avoiding discussion of their own future plans, or describing these only in terms of the cared-for person's needs (Aldridge and Becker, 1993a). Lastly, other findings have suggested that the cared-for person's needs are also prioritised over the young carers, by professionals and service providers. Frank (1995, p.30) reported that: 'The research found many situations where the needs of the care receiver were, rightly or wrongly, placed before those of the child'.

This notion relating to the prioritisation of parental need can be understood according to 'Structural Functionalist' theory, and in particular, the work of Parsons (Parsons, 1943; Parsons, 1971). Firstly, Parsons likened family priorities to an 'onion' structure, consisting of various layers. Each successive layer represents greater social distance from and less obligations to the individual at the centre. Those likely to be nearest to the core and thus, of fundamental importance, particularly during childhood and adolescence, are members of one's 'family of origin', essentially the parents (Parsons, 1943, p 27). Typically, such individuals share a relationship of regular contact and reciprocity. Nevertheless, reciprocity may be compromised to an extent or at particular times due to the parental condition, as indicated in 'Sick Role' theory (Parsons, 1971). According to this theoretical view of ill members within society, sickness can exclude individuals from performing their normative social roles and responsibilities, including their parental responsibilities and in addition, gives individuals the right to be cared-for by others. This perhaps implies that sick or ill individuals may be given priority status within their families.

Interestingly, this notion of 'parent as priority' also relates to a model on adult carers (Lewis and Meredith, 1988). According to this, carers deal with their caring responsibilities in one of three ways - which in turn dictates the outcomes of caring. These are a 'balanced mode' in which individuals combine their caring roles with other pertinent elements in their lives; an 'integrated mode' in which caring is incorporated into their lives; or an 'immersed mode' where individuals become so heavily involved with their caring responsibilities, other key areas in their lives are neglected.

Health Impacts Experienced by Young Carers

A range of detrimental health impacts have been reported in relation to adult carers (Haley, Brown, and Levine, 1987; Pruchno and Potashnik, 1989; Dura, Haywood-Niler and Kiecolt-Glaser, 1990; Schulz, Visintainer, and Williamson, 1990). Research conducted by a national carers' organisation asserted that there were commonalities in terms of the experiences and outcomes for adult and young carers alike:

> ...the problem of ill health is not age related... carers of all ages are twice as
> likely to suffer ill-health as the general population... (Clark, 2003, p.1).

Nevertheless, young carers can also experience particular health-related issues due to their specific needs as children.

Regarding young carers' health, various impacts have been described in relation to both physical and mental wellbeing, including: '...impaired health and psycho-social development including physical injury...' (Aldridge and Becker, 2002, p.210).

Effects on Young Carers Physical Health

In relation to physical health, injury due to lifting has been commonly reported in relation to young carers of parents with a physical disability (Aldridge and Becker, 1993a; Hill, 1999). Moreover, in one study, a range of health problems were discussed by former young carers, such as back pain due to lifting the cared-for person, weight loss, allergies and ulcers (Frank et al, 1999). Within this study,

28% of the young carers remarked that their physical wellbeing had been detrimentally affected (Frank et al, 1999).

Effects on Young Carers Mental Health

In terms of mental and emotional wellbeing, again a range of issues have been discussed in various studies. These include **stress-related symptoms** (Elliott, 1992; Aldridge and Becker, 1993a; Landells and Pritlove, 1992; Imrie and Coombes, 1995; Dearden and Becker, 1995, 1998, 2000; Morgan, 2006), **sleeping difficulties** (SCDR and CCS, 1999), and **anxiety** about the actual condition as well as their own and their parent's long-term future (Aldridge and Becker, 1993a; Dearden and Becker, 1998; Becker and Aldridge, 2003, Thomas et al, 2003):

> …who will care for them or where will they live if their parents become incapacitated, before they, the children, are old enough to be fully independent… (Aldridge and Becker, 1993b, p.284).

The findings of one retrospective study of former young carers indicated that 40% of the participants felt their mental health had been detrimentally affected by their caring role (Frank et al, 1999). Difficulties such as emotional traumas, depression, stress and low self-esteem were specified (Frank et al, 1999). Another more recent study set out to investigate the worries and concerns of young carers (Cree, 2003). Particular issues uncovered included fears about the cared-for person's health (which applied to 81% of the sample), concerns about their own health (67%), general worries about the cared-for person (58%) and concerns about who would care for them in the future (53%) (Cree, 2003). Moreover, it was found that these worries presented themselves in terms of a range of observable health-related problems, including difficulties sleeping (60%), eating problems (30%), self-harm (34%) and deliberation of suicide (Cree, 2003). These findings clearly support the assertion that physical health and mental health are inter-related. Nevertheless, it has been acknowledged by the young carers approach that some of these issues are relatively common to many adolescents and thus, 'it is impossible to separate out many of these problems from the range

of adolescent concerns experienced by most children' (Becker and Aldridge, 2003, pp.16-17).

A further recent study which considered the needs of young carers within a specific, socially-deprived area in Glasgow highlighted a range of health impacts and concerns. These were based on both the perceptions of the young carers and the observations by significant family members (SCDR and CCS, 1999). Of the family members, 20% recognised detrimental impacts in relation to the child's physical health and a further 17% specified sleep deprivation as a key concern. Additionally, around 50% felt that the child's mental health had been affected (SCDR and CCS, 1999). In addition to the young carers' perspectives, a control group of non-carers were also surveyed in order to offer comparative element. Both groups undertook a range of psychological measures which indicated levels of self-esteem, depression, self-concept and perceptions around their health status. The scores suggested that the young carers were 'significantly less happy with their lives' than the non-carers and that the young carers experienced 'significantly lower self-esteem' (SCDR and CCS, 1999, p.38). Of particular interest, low self-esteem (or the extent to which one values or likes oneself) has been associated with various difficulties, also linked to young caring. These include social anxiety (Blascovich and Tomaka, 1991), loneliness (Peplau and Perlman, 1982) and alienation (Blascovich and Tomaka, 1991).

Similar findings indicative of low self-esteem, depression and anxiety amongst young carers were reported in a further study (Broadbent, 1999). Interestingly, those caring for a parent with a mental health problem scored higher on depression scales compared to those caring for parents with a physical disability. The caring context however, did not appear to have an impact in relation to the levels of anxiety experienced (Broadbent, 1999).

Nevertheless, it may be questioned whether early experiences of caring in childhood and adolescence have a lasting detrimental impact on health. On the one hand, the achievement of optimal development during childhood has been

strongly correlated with healthy functioning in adulthood (Fine and Hovestadt, 1984). Indeed it has been suggested that former young carers commonly experience psychological problems in adulthood. In support of this assertion, one small-scale study reported that 75% of the former carers involved were found to have some psychological difficulties (Frank et al, 1999).

On the other hand, a range of research evidence may call into question the impact that young caring actually has on health and wellbeing. Firstly, according to the most recent census, the proportion of young carers that identified themselves as having poor health was relatively low. Only three percent of young carers in Scotland and two percent in England and Wales identified that they were 'not in good health' (Census, 2001). Indeed within the general population in the UK, there is a high incidence of mental health problems, which affect an estimated one in five young people aged 5-16. (Holmstrom, 2002). Additionally, one in ten has a clinically recognised mental disorder (Green, McGinnity, Meltzer, Ford, and Goodman, 2005). Thus, these findings relating to young carers may be unremarkable.

Secondly, factors other than the young caring role may contribute to the mental health problems that young carers experience, such as poverty, family violence or homelessness (Cree, 2003). Thirdly, a study conducted in the US with former young carers considered the correlation between young caring and adult depression. The findings of this study may challenge the assertion that young carers experience higher levels of mental health problems (Shifren, 2001). Within this study, a sample of ex-young carers reported positive mental health and only two participants indicated that they were clinically depressed according to specific tests administered (Shifren, 2001). Nevertheless, it is important to observe caution in the interpretation of these findings. Firstly, there may have been cultural differences and secondly, none of the participants were caring in adulthood, which perhaps acted as a protective factor in terms of their health status as adults. Also all had completed secondary school education and half had pursued higher education. This suggested that they most probably had an

adequate income, which was perhaps a further protective factor (United Nation's Children's Fund (UNICEF), 2001).

Effect of Differing Caring Contexts on Young Carers Health

It is also important to consider the health problems and issues experienced by young carers in particular caring contexts. Firstly, within the medical and social literature, health problems experienced by children, has been linked to the nature of their parent's illness or disability. This however, has been explored to a lesser extent within the young carers literature. Within the medical and social research, it has been found that children of parents with mental health problems, substance misuse or learning difficulties, are at an increased risk of developing their own immediate or future mental health problems (Rutter, 1966; Rieder, 1973, Waters, 1980; Beardslee, Bemporad, Keller, and Klerman, 1983; Worland, Weeks and Janes, 1987; Johnson, Boney, and Brown, 1991; Elliott, 1992; Lynskey, Fergusson and Horwood, 1994; Wilens, 1995; Booth and Booth, 1998; Falkov, 1998; Amminger, Pape, Rock, Roberts, Ott, Squires-Wheeler, Kestenbaum and Erlenmeyer-Kimling, 1999; Frank et al, 1999; Stanger, Higgins, Bickel, Elk, Grabowski, Schmitz and Amass, 1999; Weissman, McAray, Goldstein, Nunes, Verdeli and Wickramaratine, 1999; Jones, 2000; Dogra, Parkin, Gale and Frake, 2002; Aldridge and Becker, 2003; Bancroft, Wilson, Cunningham-Burley, Backett-Milburn and Masters, 2004; Hall, 2004). Also living in the context of parental mental health problems has been associated with an increased risk of developing or exhibiting self-harming thoughts and behaviours (Weissman, Warner and Wickramaratine, 1997; Klimes-Dougan, Free and Ronsaville, 1999).

Secondly, it has been found that children living in the context of problem alcohol use are most likely to experience parental violence (Bancroft et al, 2004) and children of parents with drug use are at an increased risk of neglect (Powell, 1995, cited in Tunnard, 2002a; Forrester, 2000; ACMD, 2003). Additionally, a higher incidence of both abuse and neglect has been observed in children of parents with learning difficulties (Schilling, Blythe and Barth, 1982; Tymchuk and Andron,

1990). This is a significant finding as both abuse and neglect may create problems in relation to one's health and wellbeing.

Thirdly, it has been asserted that children of parents with substance misuse problems are more likely to be 'early starters' in terms of their own usage of alcohol and drugs (Velleman and Orford, 1993; Denton and Kampfe, 1994; Walker and Lee, 1998; ACMD, 2003; Velleman and Templeton, 2003). Lastly, as indicated within the young carers literature, those caring for parents with a physical disability are most likely to experience physical injury (Aldridge and Becker, 1993a).

Impacts of Young Caring on Career Prospects and Employment

As acknowledged, illness, disability and poverty are intrinsically linked. Thus, on the basis of living in a family with illness and disability, there is an increased likelihood that young carers will be subjected to poverty, which in itself may be detrimental to their future employment chances:

> ...children raised in poverty are, as adults, more likely to be unemployed, or
> in low paid employment... (Montgomery, Burr and Woodhead, 2003, p.57).

The importance of finding paid employment cannot be understated, as this offers the principal means of escaping poverty and social exclusion (Dearden and Becker, 2000). Additionally, it has been suggested that being in meaningful employment affects virtually every domain:

> ...one's general level of life satisfaction, circle of friends and intimates,
> styles of parenting, income level and standard of living, use of leisure, and
> general level of health all are outcomes of finding a suitable vocational
> niche... (Kroger, 2000, p.70).

The impact of work on health and wellbeing has been an area of particular interest within the literature. It has been proposed that an inability to attain suitable employment is distressing and worrying for young people (Erikson, 1968), which has consequential impacts such as low self-esteem and poor psychological health (Feather and O'Brien, 1986; Patton and Noller, 1990, Feather, 1990; Fryer, 1997;

Prause and Dooley, 1997; Winefield, 1997). In addition to this, on a pragmatic level, employment offers a '...structure for the waking day...' (Kroger, 2000, p.122). In consideration of these factors, research findings that suggest young carers' career and employment opportunities may be severely restricted are of particular concern. Such disadvantages, as well as the impact of caring on young carers' vocational interests, were of particular interest in the current study.

Seeking and Sustaining Meaningful Employment

In terms of finding employment, a range of detrimental impacts and limitations have been reported. It has been found that older young carers with current or previous responsibilities at home may be unable to seek employment. For instance, one study found that virtually all of the young adult carer participants aged 18-25 were in receipt of state welfare benefits and only 25% were in paid employment. It was concluded that difficulties in attaining employment stemmed from two main factors:

> A lack of educational qualifications combined with ongoing caring responsibilities served to exclude some young carers from the labour market (Dearden and Becker, 2000, p.2).

Roots of or Factors Underpinning Career Choices

Within the literature on adult carers, caring has long since been conceptualised as a career (Suitor and Pillemer, 1990; Pearlin, 1992; Lindgren, 1993) '...in which entry and exit periods encompass a span of time during which the "work" of caregiving is carried-out...' (Schumacher, 1995, p.214). In relation to young carers however, the notion of 'caring careers' was coined to describe the apparent phenomenon of young carers pursuing caring-related vocations (Aldridge and Becker, 1993a, p.53). Nevertheless, this potential link between caring and career choices was noted previously by other commentators (Fallon, 1990; Elliott, 1992). Also, this has since been discussed within a number of studies (Dearden and Becker, 1995; Frank et al, 1999, Dearden and Becker, 2000; Lackey and Gates, 2001).

In relation to this, one study of former young carers found that approximately half of the participants linked their caring – related career choice to the acquisition of skills and experience stemming from their young caring role (Frank et al, 1999). Moreover, a further study indicated that all ten of the former young carer participants had worked or studied within a caring-related field (Harrison and O'Rooke, 2003). This link was also highlighted in another study, although it was also found that a lack of qualifications had rendered some caring-related careers unachievable (Dearden and Becker, 2000). The reasons offered to explain this apparent link included the acquisition of skills through caring, deemed key within particular vocations (Lackey and Gates, 2001).

Nevertheless, this has not been viewed in wholly positive terms:

...there may be a danger of young carers moving into caring jobs or professions because they feel these are the only skills they have to offer... the young people had many other qualities which employers would value, such as organisational skills, independence, maturity... (Dearden and Becker, 2000, p.40).

Thus, young carers should be encouraged to consider the range of career choices open to them:

...careers advisors need to be aware of these skills and competencies and try to offer a range of possible options....' (Dearden and Becker, 2000, p.3).

Indeed, it has been found that exploring choices open to them may enable young carers to work towards a career '...more in line with their personality needs...' (Grotevant and Cooper, 1986, p.92).

Effects of Young Caring on Spatial Transitions

Difficulties making spatial transitions or moving away from the parental home is a further area described in the literature. Prior to discussing the precise issues, it is necessary to consider the relevance of this area in a wider sense. It has been proposed that the 'housing transition', or making a permanent move from the parental home, is one of the three key transitions undertaken in late adolescence

and early adulthood, along with the 'school to work transition' and the 'domestic transition'. Together, these three transitions indicate the achievement of adult status (Jones, 1995; Coles, 1995).

In general, where studies have considered this area, findings have suggested that young carers have either hastened or delayed their moves to independent living – and arguably their status as adults - because of their caring situation (Dearden and Becker, 2000). It has been suggested that premature spatial transitions may be instigated by the early attainment of the key skills necessary for independent living:

> ...the transition to adulthood generally depends upon young people becoming self-sufficient, and undertaking domestic labour in the home is an integral part of the process... (Dearden and Becker, 2000, p.16).

In terms of the delayed spatial transitions, it has been proposed that young carers may feel unable to move due to fears and concerns about leaving the cared-for person, particularly where other potential care sources are unavailable. Moreover, findings of an early study which considered the viewpoints of parents' receiving care from their children, suggested that the parents wishes very often restricted the young carers moves away from the parental home:

> ...the parents all expressed that they wanted their children to be happy, none wanted their children to cease caring completely, yet none expressed hopes of their child to make spatial transition or complete independence... (Aldridge and Becker, 1994, p.8).

This relates to a further notion around young caring as a form of short and long-term entrapment. In terms of this, young carers may be prevented from establishing independence from the cared-for person or moving away from home (Tatum and Tucker, 1998).

Additionally, a further type of spatial transition has been described. This relates to the enforced removal of young carers from their families due to care proceedings (Dearden and Becker, 2000). This has been discussed in terms of the

largely unfounded fears of young carers and parents around the initiation of such proceedings because of professional concerns about the young caring role (Wiener, Spencer, Davidson and Fair 1993; Aldridge and Becker, 1994; Fiedler, 1996; Keith and Morris, 1996; Barnett and Parker, 1998; Tatum and Tucker, 1998; Frank et al, 1999; Banks et al, 2002b).

Further, the nature of the parental condition may be a significant factor affecting young carers' moves to independent living. In the young carers literature, one study that looked-at the impacts of young caring during adolescence, found a correlation between parental mental health problems and children's early and problematic moves away from the parental home:

> In families where a parent had a severe and enduring mental health problem...spatial transitions were sometimes premature and traumatic... (Dearden and Becker, 2000, p.2).

Within the body of social literature, it has been suggested that children living in the context of parental substance misuse may be most at risk of premature spatial transitions through their attempts to escape harsh living conditions (Velleman and Templeton, 2003). Moreover, as stated, children of parents with learning difficulties may be at risk of early and traumatic spatial transitions, through their enforced removal from their families. For instance, one study which looked at children of parents with learning difficulties revealed that 40-60% of the children involved had been removed from their families and placed into alternative care. Principally this was due to the low levels of support and provision offered by statutory services which prevented parents from adequately parenting their children (Booth and Booth, 1998).

Impact of Young Caring on Familial Relationships

The impact of parental illness or disability on family functioning and relationships has been an issue of fundamental concern within the social, clinical and young carers literature. On the one hand, early clinical research consistently highlighted the negative consequences of this on parenting abilities and childhood

development. In particular, parents with a physical disability or mental health problems were deemed ineffective parents (Arnaud, 1959; Castro de la Mata, 1960; Anthony, 1970; Power, 1977). On the other hand, the findings presented within the young carers literature have been ambiguous regarding the effects of the parental condition on the parental-child relationship.

The findings of some studies indicated that caring had a positive impact on the relationships that the participants shared with their parents (SCDR and CCS, 1999). For instance, an active involvement in the parent's care management served to allay some of the fears around the parental condition harboured by the children (Aldridge and Becker, 1993a; Aldridge, 2003; Becker, 2005). Positive effects on the relationships shared between young carers and their siblings have also been reported (SCDR and CCS, 1999). Nevertheless, other studies have found that parental-child relationships may be detrimentally affected because of tensions caused by parental guilt over the child's caring role (Aldridge and Becker, 1994). Other studies have also reported that young carers themselves exhibited negative feelings around their relationships with parents (Broadbent, 1999). In addition to the debate around the effects of caring on parental-child relationships, a further area of controversy has related to the occurrence and consequence of 'parentification' or parental-child role reversals (Anthony, 1970; Meredith, 1991a; Frank, 1995; Tatum and Tucker, 1998). This area merits dedicated, critical discussion. Thus, in addition to an overview of the notion of parentification, the relevance of this in relation to young caring will be considered.

Parentification, Parental-Child Role Reversals and Young Caring

The term 'parentification' was coined to describe the phenomenon of adult role assumption by children within the family milieu. This notion was rooted in psychiatry and encompassed a range of psychological theories, such as attachment, social development and object relations (Erikson, 1959; Mahler, 1968; Mahler, Pine and Bergman, 1975; Bowlby, 1980; Zeanah and Klitze, 1991; Alexander, 1992; Jacobvitz and Bush, 1996). Whilst this notion has been

considered in relation to a range of contexts including parental divorce (Ward, 2003) and child sexual abuse (Barnett and Parker, 1998), in recent years, young caring has also been included under this term (West and Keller, 1991; Barnett and Parker, 1998; Chase, 1999; Earley and Cushway, 2002). 'Parentification' is a relatively new term (Broszormenyi-Nagy and Spark, 1973). However, over the past forty years the concept has been described by theorists under alternative headings such as the parental child (Minuchin, Montalvo, Guerney, Rossman and Schumer, 1967), role reversals (Kabat, 1996) and cross-generational boundary transgressions (Ward, 2003).

Despite differences in terminology, all of these labels have shared the fundamental commonality of describing children or adolescents placed in adult roles before they are developmentally, psychologically or emotionally ready. In turn, this may affect their immediate and long-term development and wellbeing (Broszormenyi-Nagy and Spark, 1973; Bekir, McLellan, Childress and Gariti, 1993; Valleau, Bergner and Horton, 1995). Parentification has been commonly described as manifesting in one or a combination of forms which generally involves the adoption of various roles, including parental or spousal roles in relation to parents, 'pseudo-parental' roles in respect to siblings, as well as a range of caring tasks to satisfy the parental needs (Broszormenyi-Nagy and Spark, 1973; Minuchin, 1974; Walsh, 1979; Sroufe and Ward, 1980; Ward, 2003).

In one study the main roles associated with parentification were categorised and further delineated. This included the following areas: 'non-specific adult role taking' which described the child's assumption of domestic tasks; 'spousal role vis-a-vis parent' which involved sharing personal issues and financial concerns with the parent; and 'parental role vis-a-vis parent' which involved the delegation of decision-making responsibilities from the parent to the child (Stein and Riedel, 1999, p.199). Thus, in addition to explicit caring tasks, parentification may manifest in various implicit guises including meeting the emotional needs of the parent or attempting to minimise parental conflict in order to promote equilibrium within the family (Broszomenyi-Nagy and Spark, 1973).

The clinical and social literature highlighted particular risk factors in terms of the family contexts most associated with parentification. These related to families which experienced particular stressors at levels so extreme, parents were unable to adequately undertake their parenting responsibilities (Broszormenyi-Nagy and Spark, 1973; Cates, Grant, Boeglin and Tielker, 1990; Bekir et al, 1993). Thus, unsurprisingly the majority of these studies have been concerned with parental substance misuse (Edwards and Zander, 1985; Goglia, Jurovic, Burt and Burge-Callaway, 1992). Indeed, the nature of substance misuse may be particularly problematic as it can dictate the organisation of all other elements of family life. As a result, the needs of individual members may be neglected or overlooked (Bowen, 1974; Black, 1981; Dulfano, 1981; Cermak, 1986). Moreover, one study asserted that children living within the context of problem alcohol use were three times more likely than others to undertake age-inappropriate roles (Velleman, Copello and Maslin, 1998). Nevertheless, the adoption of such roles is not unique to children and young people living in the context of parental substance misuse. Indeed role reversals in relation to parental mental health problem have been well documented (Bateson, Jackson, Haley and Weakland, 1956; Anthony, 1970; Karpal, 1976, cited in Chase, 1999; Walsh, 1979). Thus, Aldridge and Becker have suggested that:

> The inevitability of atrophied parenting skills was also seen as to be one of the main consequences of parental mental illness, and this in turn is described as leading to significant role modifications for each family member – and children in particular (Aldridge and Becker, 2003, p.5).

Parentification in relation to a specific physical condition, such as HIV/ AIDS, has also been considered in more recent years (Stein and Riedel, 1999). Lastly, in terms of parental learning difficulties, the notion of 'reverse dependency' and patterns of child functioning have been discussed. These modes of functioning have been described as 'rebellion', 'pseudo-retardation' and the 'parent's right hand'. The latter related to patterns of parentification or role reversals within such families (O'Neill, 1985, p.255). However, the assumption of inappropriate roles

and parentification are perhaps not due to the actual caring context, but instead to the severity of the condition, as well as a range of other socio-economic factors, such as the availability of alternative support within the family (Stein and Riedel, 1999).

In terms of the body of young carers' literature, the notion of 'parentification' (or parental child role reversals, a specific type of parentification) has been discussed mainly in relation to parents with physical disabilities or mental health problems (Booth and Booth, 1998). From the outset, studies undertaken by the young carers approach highlighted the increased likelihood of role reversals within the family (Aldridge and Becker, 1993a; Frank, 1995; Tatum and Tucker, 1998). This notion attracted much criticism from disability rights activists, on the basis of two main issues: firstly, the failure to recognise 'parenthood' as being multi-faceted, rather than one-dimensional; and secondly, assertions which apparently equated disability with dependency (Parker, 1994; Morris, 1995; Parker and Olsen, 1995; Booth and Booth, 1998).

Firstly, in terms of 'parenthood', the disability rights approach have argued that references to young carers 'parenting their parent' (Aldridge and Becker, 1993a, p.45; Frank, 1995, p.46) have failed to embrace the complex nature of parenthood, a role which not only involves key tasks, but also an identity (Parker, 1994). Furthermore, whilst some forms of parental condition may render parents unable to perform certain tasks, this does not negate their identity or control as a parent. Thus, whilst the child is responsible for assisting their parent to perform tasks, this does not necessarily equate a reversal of identities between parent and child:

> Even if some children of disabled parents undertake practical and physical tasks that might normally be done by adults, this does not mean that they automatically internalise 'the concern and sense of responsibility that parents have for their children's welfare in all its manifestations (Keith and Morris, 1996, p 84).

However, it may be argued that recognition of this key distinguishing feature was apparent within the young carers literature from the outset. Initially, this was perhaps evident only in implicit terms:

> ...pragmatically, the roles may have been reversed, but emotionally their parents' status as guardians remained intact... (Aldridge and Becker, 1993b, p.283).

Yet latterly, in a much more explicit way:

> ...evidence has suggested that undertaking the care management of a parent is not in itself indicative of role transference among children... (Aldridge and Becker, 2002, p.217).

And further that:

> It seemed that most of the children in our study were able to recognise that their parents retained the status, if not always the task effectiveness of parents...this may be due to the fact that, despite the duality of children's roles when they care, children need secure attachments or parental role models and thus, continue to see parents as parents despite what they might do for their parents when they are ill (Aldridge and Becker, 2003, p.87).

Proponents of the young carers approach now view the notion of role reversal as somewhat misleading, as it does not fully reflect the situation of young carers relationships with their parents. Instead, they now refer to 'role adaptation' as an alternative (Aldridge and Becker, 2003, p.86).

Nevertheless, it may be argued that parental tasks and identity are not as clearly divisible as proposed. For instance, 'parenting' has generally been seen to involve both care and control functions:

> Warmth, nurturance and provision of developmentally appropriate and consistent supervision, structure and autonomy are the universal hallmarks of good parenting, from infancy through adolescence (Oyserman, Mowbray, Mearns and Firminger, 2000, p.296).

Moreover, parents are required to undertake specific tasks, to fulfil these identifiable features of parenthood. Thus, parenting cannot be conveniently split according to parental tasks and parental identity, as the two elements are interdependent. This very notion was discussed in one study, as parents and professionals (yet interestingly, not young carers themselves) suggested that the parental identity was closely bound up with parental tasks and roles:

> 'Parents were more likely to equate their lack of practical (parent-type task) function with loss of power or nurturing capacity' (Aldridge and Becker, 2003, p.87).

However, as argued by proponents of the disability rights approach, children would not be required to undertake 'parental' tasks if the parents needs were addressed through adequate service provision (Keith and Morris, 1996). Thus, the focus of researchers and professionals should be on preventing parents from relying on their children for such assistance (Morris, 1995). Nevertheless, this assertion is discordant with research findings which suggest that parents often prefer their children, rather than professionals, to care for them (Aldridge and Becker, 1994). Also, even where formal assistance is provided, this is unlikely to be adequate to fully meet parental needs or completely remove the need for children to care (Aldridge and Becker, 1997).

Secondly, according to the disability rights approach, the notion of role reversals is underpinned by assumptions of parental dependency (Aldridge and Becker, 1993a). Indeed they have argued that the young carers approach has made reference to role reversals despite an explicit acknowledgement that the young carers' themselves never directly referred to this in their descriptions (Aldridge and Becker, 1993a; Segal and Simkins, 1996). Unsurprisingly, this has attracted accusations of misinterpretation and false descriptions of parental dependency:

> Young carers' do not describe themselves in such terms. Consequently, researchers have imposed their own definitions and perceptions on their subjects (Keith and Morris, 1996, p.85).

It has long been argued that dependency is normal within reciprocal family relationships and that this is both important to adolescents (Josselyn, 1952, cited in Power, 1977; Youniss and Ketterlinus, 1987) and fundamental to the survival of the family unit (Walmsley, 1993). Thus, perhaps this matter should not be perceived in pathological terms. It may also be argued that latterly the young carers approach has embraced this notion of reciprocity within parental-child relationships:

> ...ill or disabled parents may receive care but they also provide care to their children and to others... (Becker et al, 1998, pp 108-109).

And further that:

> Perhaps a more appropriate view of young caring in the context of parental mental illness would be one that recognised the reciprocal nature of parent-child relationships (Aldridge and Becker, 2003, p.58).

Also, the arguments forwarded by the disability rights approach are around parents with physical disabilities and thus, parents with and children affected by other conditions, are overlooked. These differences, however, are also embraced by the young carers approach:

> ...many parents with a physical disability will be healthy and may require only practical support. Others, however, may experience chronic pain, may have remissions of illness and others may be facing death from a progressive, terminal illness. Thus, there are instances where parenting capacity will be compromised as a result of illness or disability (Dearden, 2000, p.2).

Furthermore, it has been argued that failing to recognise that parents are not always in control or the providers of support may obscure the recognition of young carers (Tatum and Tucker, 1998).

In relation to parentification, one of the key areas investigated has been around the impacts experienced by 'parentified' children (Chase, 1999). Of particular relevance, the impacts described in the parentification literature have been largely consistent with those discussed within the young carers' literature. For instance,

in terms of the long-term effects of parentification, multiple studies have highlighted key concerns relating to young people's health (Jacobvitz and Bush, 1996), identity development and personality, as well as their relationships and career opportunities (Earley and Cushway, 2002).

In terms of long-term health impacts, anxiety and depression in adulthood have been associated with childhood parentification (Jacobvitz and Bush, 1996; Stein and Riedel, 1999). For instance, it has been proposed that in the short-term, parentified children 'lose out on their childhood' (Siegel and Silverstein, 1994, p.195). This may be expressed most acutely during adolescence, with tasks relating to development, identity-formation and academic achievement forfeited (Erikson, 1968). Also, the impact of parentification on interpersonal relationships, partnerships and later relationships with one's own children has been considered (Earley and Cushway, 2002). Findings have suggested that these relationships may be affected detrimentally (Earley and Cushway, 2002), particularly in terms of developing intimacy and establishing independence outside the family (Erikson, 1968). For instance, those parentified as children may pursue relationships in adulthood which enable them to continue caring for others, very often to pathological levels (Siegel and Silverstein, 1994). This has been commonly referred to as 'caretaking syndrome' (West and Keller, 1991; Peek and Trezona, 1984, cited in Valleau, Bergner and Horton, 1995).

Moreover, several studies have highlighted a link between parentification in childhood, low academic attainment and adjustment problems within higher education establishments (Held and Bellows, 1983; Chase, Denning and Wells, 1998). With regards to career choices, other studies have indicated a link between parentification in childhood and the pursuit of caring careers in adulthood (Earley and Cushway, 2002). For instance, the findings of one study which involved students undertaking degrees in either psychology or engineering, suggested that the psychology students were parentified to the greater extent (Sessions, 1986, cited in Chase, 1999). Moreover, a large-scale study involving 1577 social

workers discovered that two-thirds had undertaken young caring roles in the past (Lackie, 1983).

Effects of Young Caring on Romantic Relationships

Whilst the impact of young caring and/ or parental illness or disability on family relationships has been identified as an issue of concern within the literature, the impacts on romantic relationships, has received minimal consideration. Although developing relationships is a fundamental concern of late adolescence and early adulthood, this received only fleeting mention within one of the two main studies on young carers transitions to adulthood:

> ...it is interesting to note how often former young carers deliberately excluded themselves from either making wider social contacts, or developing the kind of commitments that might necessarily flow out of externally generated relationships...in such circumstances acts of self-exclusion become easily justifiable, for without them some former young carers would have been unable to cope with the pressures and dilemmas of caring (Frank et al, 1999, p.9).

Again, the prioritisation of the parental needs within the family may explain the young carers' lack of interest in romantic relationships. According to Parsons, two family groups are of fundamental importance to individuals – the 'family of origin', particularly central during childhood and adolescence and the 'family of orientation' or the marital family, usually the key priority throughout adulthood (Parsons, 1943). Whilst contemporary western culture largely encourages the pursuit of marital relationships in early adulthood, perhaps this is unrealistic for young carers. Indeed forming a partnership usually involves spending less time with the family of origin, which may be unrealistic or unacceptable.

Positive Impacts of Young Caring

Advocates of the disability rights approach have been critical of the portrayal of young carers' experiences in largely detrimental terms (Olsen and Parker, 1997). Whilst not a predominant feature of any of the young carers studies conducted,

some have highlighted positive outcomes (Mahon and Higgins, 1995). Positive factors described include: the development of knowledge of particular conditions; an enhanced understanding and the development of caring skills; as well as an increased sense of responsibility and maturity (Tatum and Tucker, 1998; Dearden and Becker, 2000; Banks et al, 2002b; Aldridge and Becker, 2003; Thomas et al. 2003). Further, it has been asserted that caring can have a positive impact on the parental-child relationship (Aldridge and Becker, 1993a; SCDR and CCS, 1999; Aldridge, 2003; Becker, 2005) or on relationships between siblings (SCDR and CCS, 1999).

As has been asserted, such positive outcomes are perhaps more likely in the context of available support, choice over the caring role and having time for outside activities (Tatum and Tucker, 1998). This assertion is perhaps strengthened by the findings of a further study. This found that those children undertaking 'secondary' caring roles in the family were more likely to experience positive outcomes (Beach, 1997).

However, the supposed positive outcomes associated with young caring may be somewhat misleading:

> Often though these young carers had known little other than the caring experience and it was the one area in their lives that they could locate a sense of self-worth or satisfaction (Aldridge and Becker, 1993a, p.57).

Also, some of the apparently positive outcomes noted, such as early maturity (Dearden and Becker, 1995), have been discussed elsewhere as the negative consequences of 'lost childhoods'.

2.5 Hidden-ness Around the Young Caring Role

Arguably, the issue of hidden-ness is a key concept running throughout the body of young carers literature. Indeed this notion has been variously discussed, with references to young carers as a 'hidden army' (Arrow, 2004), as well as the invisibility of young carers, as evident in the titles of various articles such as *'The*

Hidden Cost of Young Carers' (Aldridge and Becker, 1993a); *'The Hidden Face of Community Care'* (Newton and Becker, 1996); *'Hidden Children'* (Elliott, 1992); and *'The Concealed Consequences of Caring'* (Tatum and Tucker, 1998). It may be argued that research and policy interest since the early 1990s has served to increase the visibility of young carers:

> Policy makers now recognise the contribution which young carers make to family and community care, and the needs for their rights and experiences to gain recognition in law and policy (Aldridge and Becker, 1999, p.304).

Nevertheless, such recognition in social policy has not and perhaps cannot fully address the issues surrounding identification of young carers. This invisibility has been maintained through a range of complex systems involving both private and public domains (Frank, 1995). Hidden-ness has been maintained partly by individual young carers, their parents and wider family systems, through their failure to recognise, acknowledge or disclose the young caring role. In addition, this has been further sustained through a lack of awareness or acknowledgement of young caring, amongst front-line workers in contact with young carers and families. This has served to create a milieu of multi-party silence (Frank, 1995; Tatum and Tucker, 1998):

> [young carers are] hidden from public view by the actions and activities of family members...and are largely ignored by welfare agency personnel... (Tatum and Tucker, 1998, p.17).

In addition, others such as peers may be considered key contributors in maintaining this multi-party silence.

Young Carers Lack of Self-Identification and Disclosure

Principally, it has been proposed that the silence exhibited by young carers and parents has originated from '...various kinds of emotional resistance' (O'Neill and Platt, 1992, p.8) including:

> ... a wish for privacy; feelings of shame or stigma; fear of community reaction; concern about intrusive professional intervention... (O'Neill and Platt, 1992, p.9).

Similar findings have been documented elsewhere (Elliott, 1992; Heal, Mapp and Clements, 1995; Aldridge and Becker, 1997; Frank et al, 1999; Dearden and Becker, 2001).

Specifically in relation to young carers, further causal factors have been proposed to explain this 'self-inflicted silence' (Aldridge and Becker, 1993a, p.46) such as:

> ...not liking to be identified as different in any way; not having an identity as a carer; a sense of family responsibility; apprehension about strangers taking over caring roles; pride in the caring role (Banks et al, 2002b, p.19).

Within the literature, it has been asserted that young carers have dismissed the young carer label and have wished not to be recognised as different (Aldridge and Becker, 1993a).

To begin with, as has already been discussed in terms of 'definitional issues', many young carers lack an awareness of their caring identity which may underpin their hidden-ness (Aldridge and Becker, 1993a; Fox, 1995; Banks et al, 2002a). Secondly, in terms of not wishing to be viewed as different on the basis of one's caring status, the notion of 'fitting in' is of key importance. Indeed, young carers' silence has been partly attributed to wishing to 'fit in' with their peer group. Various studies have suggested that young carers fear their situation becoming common knowledge and therefore, strive to hide anything which makes them stand out as different from other children (Aldridge and Becker, 1993a; Frank, 1995). In practical terms, this may involve keeping their social and home life separate, failing to disclose their home situation to others, failing to invite friends to the family home, or leading a double life (Bilsborrow, 1992; Elliott, 1992; Aldridge and Becker, 1993a; SSI, 1996; Frank et al, 1999; PRTC, 1999; SCDR and CCS, 1999; Dearden and Becker, 2000; Eley, 2004). Such silence may exacerbate the social isolation and exclusion commonly reported by young carers (Frank, 1995). It must also be acknowledged that silence can create loneliness even in the context of an otherwise active social life:

Isolation however, can go beyond the practical difficulties of socialising. Some carers manage to maintain a level of social contact, but still experience a sense of being alone since they are unable to talk to people about their situation (Heron, 1998, p.49).

Furthermore, it has been suggested that young carers are careful in terms of who they disclose details of their home situation to (Aldridge and Becker, 2003). Normatively, information is shared with a small number of individuals with similar experiences:

> ...Only one of my friends knows, it's not something I talk about and I wouldn't want anyone else to know... (Frank, 1995, p.32).

This indicates a preference against the home situation and caring role from being 'common knowledge' at school (Frank, 1995, p.32). Similar findings have been evident in other studies:

> ...young carers wanted to limit the amount of people who knew about their situation to family members and possible supporters... (Aldridge and Becker, 1993a, p.46).

Perhaps this also highlights the utility of dedicated young carers groups:

> ...one of the reasons why they value mixing with young people in projects where explanations are not necessary because many experiences are shared (Dearden and Becker, 1998, pp 15-16).

In turn, it has been found that being around others aware of and sensitive to the situation may detract from the 'pain and loneliness' of being viewed as different (Alderson, 1992, p.166).

As well as maintaining silence in order to 'fit in' with peers, the literature has highlighted that hidden-ness can be preserved through young carers failure to disclose their home situations to teachers and other professionals. Firstly, in relation to teachers, findings of one study suggested that embarrassment about one's home situation prevented young carers' disclosure:

...most of them do not wish the school to know about their home situation and often go to great lengths to make excuses for lateness or poor work rather than admit that their parent is ill and needs their help...children were embarrassed to tell teachers about home... (Frank, 1995, p.50).

Also, it has been found that fears about the lack of confidentiality around any disclosed details (in terms of others finding-out) has prevented disclosure in some cases (Underdown, 2002). However, it must be considered that non-disclosure of one's home situation with teachers may be unremarkable. Some sociological research has described this as an unsuitable milieu for disclosure, due to the often problematic nature of relationships between teachers and adolescents (Barber and Olsen, 1997). Also, it must be questioned whether teachers can be considered in a 'blanket' sense in terms of their utility. For instance, a guidance teacher may be more helpful than a class teacher, a point which has not been fully explored in the literature. This was evident in one study, as a young carer expressed that whilst her form tutor was aware of her home situation, other general teachers were not (Frank, 1995).

In terms of concealment and disclosure, it is useful to consider a theoretical understanding underpinned by symbolic interactionism. This concerns the 'presentation of self' in interpersonal interactions (Goffman, 1959) and specifically, the reasons why and the means which individuals employ to present differing personas to the outside world. Goffman's understanding of how social meanings can be attributed within everyday social exchanges was represented in 'dramaturgical' terms. In terms of this, interpersonal interactions were likened to a drama production which consisted of performances and involved actors, audiences, roles, scripts and props, which were played out both on and off stage. Essentially, individuals present personas, interpreted and understood by audiences according to the performances delivered, as well as the expectations of the observers. Nevertheless, performances may not reflect the 'actor's' reality, as individuals may present a 'front', or direct the audience in a particular way. Thus, in relation to young carers, individuals may present different personas to different

audiences portraying a particular 'front' to classmates, teachers and other professionals, in order to conceal their home situation, perhaps to 'fit in' and to avoid 'courtesy stigma' or other negative treatment.

Silence Due to Stigma

Young carers' silence may be partly underpinned by perceived stigma on the basis of their parent's condition. This issue was widely recognised within the clinical and social literature (Goffman, 1963; Hillbourne, 1973; Romano, 1976; Frankenburg and Perry, 1985; Sargent, 1985). More recently, this has been acknowledged within the young carers literature (Elliott, 1992, Newton and Becker, 1996; Aldridge and Becker, 1999; Frank et al, 1999; SCDR and CCS, 1999; Shah and Hatton, 1999; Banks et al, 2002b). In relation to young caring, this has been discussed with reference to Goffman's notion of 'courtesy stigma' (Goffman, 1963, p.30; Newton and Becker, 1996, p.2; Frank et al, 1999, p.18; Morgan, 2006, p.8), or stigma by association (Booth and Booth, 1998). The fear of being stigmatised was clearly demonstrated in one study in which 28% of the 240 young carer participants failed to disclose their caring roles to friends. Half of these attributed this silence to a fear of being ridiculed, and 20% feared abandonment by their friends (Banks et al, 2002b).

It has been proposed that stigma and lack of understanding can result from the naivety and inexperience of others in relation to illness, disability and young caring:

> ...friends, even close friends, do not understand the pressures on children who care or are too young to comprehend the implications of caring and are unable to deal with it sensitively (Becker, 1995, p.9).

It must also be highlighted that the stigmatising practices described here do not necessarily or wholly relate to odious treatment from others outside the family. Indeed, commonly reported experiences described in the literature include: 'harassment from relatives' (Aldridge, 2003, p.33) and 'lack of support or help from the extended family network' (Elliott, 1992, p.18).

Nevertheless, it must be highlighted that courtesy stigma is not universally experienced or acknowledged by young carers. For instance, in one study it was found that '...none of the children admitted feeling stigmatised...' (SCDR and CCS, 1999, p.46). However, perhaps in this case, the young carers felt unable to discuss their experiences of stigma, or did not fully comprehend the concept of 'stigma' or stigmatising treatment. Also, in relation to this particular study, arguably stigma was actually perceived, yet avoided through non-disclosure of one's situation to others:

> ...but it seemed that they did fear disapproval and so some sought to keep the situation secret, thus, they avoided talking with anyone outside their families...did not disclose even to best friends in some cases (SCDR and CCS, 1999, p.46).

The Visibility of Caring According to Different Caring Contexts

Furthermore, the particular caring context may account for the differing levels of courtesy stigma perceived or experienced by young carers. In the literature, various findings suggest that stigma and secrecy are most severe in relation to families with mental health problems, substance misuse and particular physical conditions such as HIV and AIDS (Stafford, 1992; Frank, 1995; Alexander, 1995). This substantiates findings from earlier clinical research which discussed the detrimental impacts of parental mental health problems on the development and social functioning of children:

> Children of mentally ill parents are often vulnerable, partly because they may not receive adequate nurturing and partly because they feel stigmatised by their parents' disabilities (Sargent, 1985, p.617).

In terms of this, the degree of visibility and acceptability of particular conditions may be of critical importance, with the less visible conditions generally seen as less acceptable:

> ...Such problems [mental health problems and substance misuse] are much less visible than physical ones such as Multiple Sclerosis or arthritis, and, arguably, much less socially acceptable. People with mental health

problems can sometimes be irrational, unpredictable or violent, and their behaviour, if witnessed by others outside the caring environment, may make their children objects of ridicule. Those who abuse or misuse drugs or alcohol may have a lifestyle bordering on the illegal which is likely to be in direct contradiction to the values taught in schools and wider society... (Dearden, Becker and Aldridge, 1994, pp.4-5).

This assertion was further corroborated by the findings of other studies. For instance, one study found that young carers of parents with a mental health problem (which included problem alcohol use), were hidden to a greater extent than those within other caring contexts:

In these families an extra layer of experiences helped to support and maintain a conspiracy of silence. The feelings of embarrassment generated meant that the outside world had to be kept at arm's length... (Frank et al, 1999, p.12).

Also, in a further study it was concluded that:

More children caring for a relative with a 'visible' illness, e.g. a physical disability, were identified than those caring for a parent with a mental health problem, or drugs or alcohol related illness (Frank, 1995, p.56).

Similarly, in various other studies, these particular issues were acknowledged as key reasons for the lack of identification of young carers (Elliott, 1992; Dearden and Becker, 1999; Banks et al, 2002a; Aldridge, 2003). In terms of substance misuse, it has been proposed that children and adolescents living in the context of drug use are more likely to experience stigma than those living with problem alcohol use, perhaps due to the legality and greater social acceptability of the latter (Bancroft et al, 2004).

Parental Contribution to Hidden-ness

As highlighted in the literature, a further reason which may underpin young carers' silence or non-disclosure relates to parents' fears of stigma. As a consequence of this, children may be prohibited from sharing 'family business' (Aldridge and Becker, 1994; Banks, et al, 2002b). However, the extent to which

this actually affects young carers' decisions to disclose can be questioned. For instance, in one survey conducted by the Princess Royal Trust for Carers (PRTC, 1999), only three percent of the young carer participants stated the *cared-for person's* preference for others not to know, as the reason for their failure to discuss their home situation with friends (Banks et al, 2002a). It has also been indicated that silence has been compounded by the non-disclosure of care-receivers who 'felt unable to control their emotions sufficiently to talk to school about illness' (Frank, 1995, p.50). Alternatively, some parents with physical conditions they may be unable to attend key school events such as parent's evenings, because of environmental barriers such as a lack of access to the school building (Frank, 1995).

Professional Contribution to Hidden-ness

In relation to key professionals, it has been indicated that young carers and parents have actively attempted to conceal the young caring role from social workers due to concerns about being negatively judged over the child's caring role (Wiener et al, 1993; Fiedler, 1996; Keith and Morris, 1996; Barnett and Parker, 1998; Frank et al, 1999; Watson, 1999; Banks et al, 2002a; Becker and Aldridge, 2003). Indeed, it has been suggested that social workers are generally not trusted by young carers and their families, despite being the most commonly received external service (Aldridge and Becker, 1993a, 1994; Dearden and Becker, 1995; Dearden and Becker, 2004; Morgan, 2006). Nevertheless, there have been some documented accounts of young carers who have disclosed details of their home situation to professionals such as teachers, social workers and doctors. For instance:

> ...for some, this occurred in a crisis when they 'blurted it out'. For others, regular contact with professionals meant that someone was aware of the situation and was in a position, in theory at least, to offer some support... (Dearden and Becker, 1995, p.28).

In one early study, it was found that young carers who were living in a home situation of relative stability were most prepared to talk about their caring role (O'Neill and Platt, 1992).

Elsewhere, there have been accounts where professionals across health, education and social services have contributed to this hidden-ness, through their lack of awareness, recognition or acknowledgement of young caring (Aldridge and Becker, 1993a; Jenkins and Wingate, 1994). One study found that the professionals involved only showed an interest where there was some pathological concern, such as a 'psychological or physical disorder' exhibited by the child (Jenkins and Wingate, 1994, p.733). Indeed, the notion of 'professional ignorance' was coined to describe the apparent unawareness of professionals regarding their legal duties to young carers within local authority children's services and an inclination of adult services' to overlook children (Dearden and Becker, 2001). According to one study, the causal factors which underpin this professional ignorance may include firstly, a lack of awareness of the existence of young caring; secondly, a failure to identify particular young carers and thirdly, presuppositions that relatives are providing care, rather than the child (Dearden and Becker, 2001). This was corroborated by the findings of a further study which asserted that there is a 'tendency of many agencies to focus solely on the needs of their patient and not to consider the needs of children/ young people within families' (Banks et al, 2002b, p.22). Indeed, as was asserted in an early study, the treatment endured by young carers due to uninformed professional practices, may be so damaging and detrimental, it could be conceptualised as punishment (Aldridge and Becker, 1993a).

Specifically in relation to teachers' practices and treatment of young carers, a range of problematic issues have been identified, relating to a lack of support, understanding, recognition and identification (Watson, 1999; Aldridge and Becker, 1994). Firstly, an awareness of young caring does not necessarily equate to an understanding of the issues around young caring or the identification of young carers. For instance, in one study, it was found that even where teachers were aware of the young carers' situation, they were still perceived as unhelpful (Shah and Hatton, 1999). In another study, teachers with a working knowledge of young caring and the associated issues could not actually identify any young

carers within their schools, for the purposes of recruitment for the research (Frank, 1995). Moreover, a further study reported that only two of the former young carers surveyed had an understanding teacher whilst at school (Frank et al, 1999).

Such a lack of understanding has been expressed through teachers 'overlooking' the young caring role or 'colluding' with young carers by ignoring problems such as frequent absences, lateness, or homework difficulties (Elliott, 1992; Frank, 1995; Malcolm, Thorpe and Lowden, 1996; Dearden and Becker, 1998; Bibby and Becker, 2000; Dearden and Becker, 2000). This may arise from teachers being unaware of the young carers' home situation (Frank, 1995; Marsden and Lund, 1995; Shah and Hatton, 1999). Indeed, it has been found that schools and pastoral staff are slow to acknowledge or recognise the young caring roles undertaken by some pupils (Bibby and Becker, 2000). Nevertheless, what young carers actually perceive as understanding practices needs to be clarified. For instance, perhaps colluding with young carers over their frequent absences or late homework may be perceived by young carers in positive terms, as letting them 'off the hook'. However, as has been highlighted in the literature, this may result in an exacerbation of the already poor educational outcomes commonly experienced by young carers:

> Children's well-being can be affected even within situations intended to promote their best interests... (Montgomery et al, 2003, p.18).

Moreover, it has been found that a lack of understanding may be expressed through 'punishing' young carers for experiencing such difficulties (Aldridge and Becker, 1993a; SCDR and CCS, 1999), perhaps through assigning the label 'problem children' to young carers, due to their particular difficulties (Underdown, 2002, p.58).

Additionally, in terms of other professionals, young carers have consistently reported feeling ignored, overlooked or disregarded by social workers and nurses in contact with their parents (Tucker and Liddiard, 1998; Shah and Hatton, 1999; Corlyon, 2001). Accounts of this lack of acknowledgement or consultation have been evident even in contexts where regular home visits are made by

professionals or where the needs of the care-receiver have been assessed (Aldridge and Becker, 1993a; Frank, 1995; Newton and Becker, 1996). Moreover, it has been indicated that some agencies and professionals are reluctant to identify young carers due to firstly, a lack of the skills required to address issues presented by young carers (SSI, 1996) and secondly, because of scarce resources (Banks et al, 2002a). It has also been proposed that professionals such as GP's and nurses may feel that identifying and addressing the needs of young carers is outside their professional remit (Frank, 1995; Banks et al, 2002b), as indicated in the following statement:

> If there is no resources, time, money or staff 'ignoring the situation may seem wiser (Shifren, 2001, p.189).

Contribution of Other Factors to the Hidden-ness of Young Carers

Arguably, two further factors which may contribute to the hidden-ness of young carers relate firstly, to the hidden nature of certain caring tasks and secondly, to becoming accustomed to the caring role. A range of tasks and roles have been described in the literature, such as domestic help, general and nursing care, intimate personal care and childcare (Dearden and Becker, 2004). Emotional support, however, is perhaps the most significant type of assistance in terms of hidden-ness.

Emotional support has been variously described (Frank, 1995; Aldridge and Becker, 2003), with references to 'emotional labour' or 'feeling responsible for the parent' (Mahon and Higgins, 1995, p.36). Despite differences in terminology, this refers to a range of tasks such as 'sitting with parents...helping when parent's upset...being there when things are bad...' (Becker and Aldridge, 2003, p.15). Additionally, parenting the parent has been described under emotional responsibilities. Emotional support is usually undertaken in addition to other caring responsibilities (Newton and Becker, 1996) and mainly in the context of parental mental health problems or substance misuse (Frank, 1995; Dearden and Becker, 1999).

Indeed as these tasks are much 'less visible' (Frank, 1995, p.38), 'difficult to define' (Newton and Becker, 1996, p.24) and 'less easy to quantify or measure' (Aldridge and Becker, 2003, p.64), emotional support arguably represents the 'hidden elements of care' (Aldridge and Becker, 1993a, p.25). As a result, where the main form of support is emotional care, there may be ambiguities around the identification of young carers amongst both young carers themselves (Becker and Aldridge, 2003) and professionals (Dearden and Becker, 1999).

Nevertheless, the findings of the latest national survey indicate a growing acknowledgement of emotional support amongst young carers (Dearden and Becker, 2004). A total of 82% of the participants stated that they were providing this form of assistance. The validity of this finding however, may be questioned. If emotional support is provided mainly in the context of parental mental health problems and substance misuse, the finding that 82% of young carers provide such emotional support seems high. Nevertheless, 'emotional support and supervision' were considered under a single category in the survey which may explain the high figure. Even so, this conflated category is misleading as it represents a failure to acknowledge the distinctiveness of each. Indeed, 'supervision' surely also encompasses physical and spatial guidance. Also, the very concept 'emotional support' is ambiguous, as supporting parents' emotional wellbeing is expected and healthy within any normative, reciprocal parental-child relationship and exactly how this differs in terms of 'nature' or 'amount' is unclear.

Secondly, the impact of becoming accustomed to the caring role is an important factor which contributes to hidden-ness. Whilst highlighted in the literature, its contribution to the invisibility of young carers has been overlooked. This notion has been variously discussed, including references to the notion of being *'used to it'* in direct quotes by young carers:

> I didn't feel as if I had any choice, but it didn't bother me – I'd been used to it since I was so young. Sometimes it does get to you – not very often 'cause I'm used to it (Aldridge and Becker, 1993a, p.16).

This notion has also been highlighted elsewhere (Aldridge and Becker, 1994; Newton and Becker, 1996; Shah and Hatton, 1999; Thomas et al, 2003), including quotations which refer to caring as 'routine' or 'normal' (SCDR and CCS, 1999; Aldridge and Becker, 2002). Arguably, if young carers are so accustomed to the caring role and the potential restrictions that this may impose, they can fail to notice or discuss the inimitability of caring in childhood.

Addressing Hidden-ness – Spotting Cues

To redress the issue of hidden-ness, the importance of professional recognition and identification has been highlighted:

> ...unless young carers and their families are actively encouraged to make themselves known, the welfare professionals might have a much bigger problem on their hands when those children become adults (Thompson, 1995, p.13).

Nevertheless, as has been acknowledged, identification is circumscribed by the secrecy exhibited by young carers (Aldridge, 2003). In response, it has been proposed that all health, education and social services professionals require to be aware of and vigilant to potential signs or cues displayed by young carers indicative of young caring responsibilities:

> ...because young carers can appear in so many locations – social services departments, adult or children's services, primary health care services, youth or voluntary projects or schools...professionals in all these settings need to be alert to signs of distress such as ill health, depression or poor school performance... (Fiedler, 1996, p.13).

This was recognised in one study and addressed in a practicable manner via 'a checklist' of possible indicators to show if a child was caring. This checklist outlines various observable indicators of caring, such as poor academic performance and poor social skills (Frank, 1995, pp 66-67). Indeed, other findings suggest that the most visible cues presented relate to an educational context, including poor school attendance (Frank, 1995; Newton and Becker

1996), behavioural problems, tiredness and concentration problems, as well as difficulties completing assigned class work or homework tasks (Fallon, 1990). In addition, parental absences from key events such as parents' evenings are commonplace (Aldridge and Becker, 1993a; Frank et al, 1999). Other studies have highlighted a range of other cues. For instance:

> The child may be tired, oversensitive and withdrawn, with low self-esteem. They may also be bullied, untidy or unclean, or have symptoms such as headaches, back pain, anxiety or depression (Sadler, 2003, p.181).

Arguably the exhibition of such cues places teachers (both guidance and class teachers) in a prime position to identify of young carers.

In terms of other key professionals, both health and social workers have a role in the identification of young carers due to their potential contact with them. More recently, it has been suggested that evidence of self-harming may act as a further cue to the presence of a caring role:

> ...self-harm may be seen as an indicator of other problems which may be less visible (Cree, 2003, p.308).

In relation to this, school nurses are perhaps ideally placed in terms of observing such cues and identifying young carers (McLure, 2001; Sadler, 2003). All nurses however, have a potential role in their identification and support:

> Community nurses and health visitors have a front line role, working in the homes of young carers...hospital nurses also have an important role...it may be that a hospital admission is the first time that an individual and his/her carers have been in contact with health professionals, thus, they may be the first people to enquire about the young carers needs (Watson, 1999, p.38).

Difficulties 'Reading' Cues - Mixed Messages

Nevertheless, it may be difficult to accurately 'read' the cues presented. Firstly, these can be misconstrued (Watson, 1999) as being linked to young caring when there is an alternative explanation. Accurate interpretation may be less problematic where professionals are aware of the basic details around young

carers' home situations. Secondly, particular cues may be extremely subtle. For instance, potential cues (such as low self-esteem, depression, back pain or depression) are particularly difficult to interpret due to their subjectivity and outward invisibility. Indeed, these may be best described as subjective 'symptoms' rather than outward signs.

2.6 Conclusion of the Main Points from the Review of Literature

The available body of young carers' literature based on empirical work conducted from the early 1990s onwards has been extremely valueable. Primarily, this has served to highlight the existence of young carers' as well as the scale of the issue and the circumstances and needs of such children. Ultimately, this body of work has shaped policy and practice in relation to young carers and their families.

Based on the findings of a range of studies, it may be argued that defining 'young carers' is integral in terms of quantifying the scale of the 'problem', identifying young people with caring responsibilities and their resultant needs, as well as delimiting agency responsibility for addressing the needs of young carers. However, the lack of a universally agreed working definition of 'young carer' has created problems in terms of identification and support of young carers and their needs. Ambiguity around the definition has been underpinned by the apparent incompatibility of young carers as both children and carers. In addition, there has been much disagreement over how young carers should be defined, as well as the implications of labelling young people as young carers - for the individual, family and the wider political system.

Nevertheless, a degree of parity does now exist between the two main definitions. Both both policy-makers and the young carers approach acknowledge the key emphasis of the other definition, within their own. However, this acknowledgement has been implicit and thus, each definition is still viewed as being quite distinct. This has created widespread confusion amongst young

carers, their families and professionals and has ultimately manifested in the lack of recognition or self-recognition of young carers and their needs. Whilst professionals have been mainly responsible for the identification of young carers, arguably, an element of self-recognition may facilitate this process. In this current situation of definitional ambiguity, the extent to which young carers comprehend the definition or conceptualise themselves according to the definitions proposed is key, yet an element not previously investigated. Therefore, this was an issue of primary concern within the current study.

The body of research on young carers has highlighted fundamental gaps in knowledge, as well as methodological issues of concern. These guided the design of the current study. In terms of such gaps, firstly the actual scale of the issue or the number of young carers in the UK is still largely unknown. However, it was felt that conducting a further study to attempt to quantify the issue would be unconstructive. Indeed such studies have been beset with difficulties and offered little in terms of knowledge around the experiences and needs of young carers.

Particular issues around the experiences of young carers received minimal attention in the past, including the experiences of young carers according to different caring contexts. As stated, research has concentrated on the impacts of young caring in relation to either one or a range of areas, such as education, health, social life, relationships and/ or spatial transitions. Such impacts, however, have been considered in relation to a single condition or diagnosis, or alternatively, in relation to a range of different conditions. In terms of the latter, previous studies made no attempt to discriminate young carers' experiences according to the condition of the cared-for person. Therefore, within the young carers literature, there has been very limited evidence of the experiences and impacts of young caring in relation to a range of caring contexts.

However, the clinical and social literature has indicated that the experiences of children and young people (though not necessarily young carers) may differ according to the nature of their parent's condition. Those in the contexts of

parental mental health problems and substance misuse endure the most detrimental effects. On this basis, if the experiences of young carers are at least partly guided by the nature of the caring context, this has serious practice implications in terms of intervention with young carers and their families. Rather than treating all young carers in a 'blanket' sense, it is necessary to be aware of and sensitive to particular issues which may arise in specific caring contexts. Such awareness may better facilitate the planning and delivery of intervention with young carers and their families. Nevertheless, it must be questioned whether and the extent to which 'impacts' can be attributed to the young caring role rather than other socio-economic factors. Critical consideration of the roots of these apparent impacts is thus, integral to ensure the delivery of appropriate support.

In terms of the methods and sampling techniques adopted in previous studies, firstly, the principal method used most often within previous qualitative studies has been semi-structured interviews. As well as being intrinsically valuable in small-scale studies due to the sensitivity and flexibility it affords, this method has countered some of the difficulties apparent in relation to other methods, such as low response rates as evident in postal questionnaires. Secondly, in terms of sampling techniques, researchers have primarily recruited their participants through young carers' services because of difficulties accessing participants through statutory agencies. Also as discussed, researchers have encountered various problems when using professionals as proxies to gain an insight into the experiences and circumstances of young carers. Such accounts have been found to be inconsistent with the young carers' situations. Lastly, it has been demonstrated that using a 'retrospective' sample of former as opposed to current young carers can adversely affect the accuracy of findings, due to factors such as poor memory recall of past events and 'ex-post facto' rationalisation.

In consideration of these factors and to ensure that the current study was valuable on a conceptual level, the area of investigation concentrated on the experience of young caring according to a range of different caring contexts. In terms of practical considerations, as will be described in the following chapter, the

methods used in sampling and data-collection were at least partly influenced by insights from the literature.

Chapter 3 – The Methodology and Methods Used in the Study

3.1 Introduction to the Methodology Chapter

The present chapter sets out to explore, describe and critically discuss the methodology and approaches employed within the current study. Firstly, the research process will be outlined in order to contextualise the study. Therafter, a range of ethical considerations involved in the planning and conducting of the study will be discussed. This will be followed by a description and appraisal of the methodological and philosophical assumptions which underpinned the research. The study was set within the qualitative domain and underpinned by the constructive-interpretive paradigm, with its theoretical foundations rooted in symbolic interactionism. As congruent with this overall approach, the study employed grounded theory methods to facilitate the collection and analysis of data, all of which will be highlighted and critically considered throughout this chapter. In addition, the researcher's role as the principal research tool and the implications that this posed will be discussed, followed by a description of the research process and pertinent issues relating to this. Lastly, issues pertaining to the trustworthiness of the research study, the researcher and the findings will be considered.

3.2 An Overview of the Research Process

As outlined in Table 3.1., the study began with an exploratory phase. In terms of this, firstly, the body of relevant literature was investigated which facilitated the identification of gaps in knowledge and secondly, two young carers from a local

dedicated support project were consulted to ascertain some of the key issues around for young carers. It became evident during this exploratory phase that the nature of the parental condition affected the experience of young caring. However, this was an area which had received minimal research interest and attention. Thus, it was decided that this would be the broad focus of the investigation. Thereafter, the research was conducted in two further phases, each of which pertained to specific areas of interest. Within the first phase, the principal concern was to understand the meaning of young caring to young carers. In the second phase, the main aim was to understand meaning according to different caring contexts. This involved utilising different samples of young carers within each phase of the study. Therefore, the first phase involved young carers supporting parents with a physical disability. Within the second phase, it was necessary to involve young people caring in two other contexts – parental mental health problems and substance misuse - in order to understand the meaning of young caring to those in different situations. Various tools facilitated the exploration of this, which included semi-structured interviews, a diary method, a self-esteem tool and observations.

Table 3. 1 - Overview of Research Process and Procedure

Phase of the Project	Period Undertaken	Identified Objectives	Participants Involved	Tools Utilised
Exploratory Phase - Study Design	May 2003	To uncover issues of concern and potential 'gaps' for study	Two randomly selected young carers	Semi-structured interviews and consultation of the literature
Phase One – Data Collection	June 2003 – December 2003	To understand the meaning of young caring to young carers	Ten young carers supporting parents with a physical disability	Semi-structured interviews; Rosenberg self-esteem scale; observations and a diary method
Phase Two – Data Collection	February 2004 – March 2005	To discriminate in relation to the identified research problem	Ten young carers caring for parents with a mental health problem and a further ten, for parents with problem alcohol or drug use	Semi-structured interviews; Rosenberg self-esteem scale and 'ad-hoc' observations

3.3 Ethical Considerations and the Procedures Adopted

Prior to discussing the research process in further detail, it is necessary to outline the research and professional ethics which underpinned the study. These will be discussed according to the formal procedures adopted for access, as well as the principles of good practice adhered to throughout the study, to ensure the safety and wellbeing of the participants and the researcher.

Formal Procedures Adopted for Access

As will be discussed, social work professionals employed within a range of statutory and voluntary settings were approached in order to identify a sample of young carers for the study. As such, it was imperative to seek ethical approval as appropriate. However, this process was complicated as it involved seeking permission from various sources for different aspects of the study. Whilst National Health Service Research Ethics Committees (NHS RECs) were available to scrutinise proposed research within health contexts, there was no such system pertaining to research in local authority settings. Therefore, in the current context it was not feasible to gain endorsement for the entire study from an established and independent body equivalent to NHS RECs. However, the research was approved by various other relevant sources including The Robert Gordon University, Aberdeen City Council Social Work Department and the Association of Directors in Social Work (ADSW). In addition, and of fundamental importance, the doctrines of good ethical practice were adhered to throughout the study. Each of these aspects will be discussed in turn.

Firstly, the project was endorsed by the Robert Gordon University research degrees committee (which was responsible for overseeing all research degree activity undertaken in the university) and at a departmental level, by the School of Applied Social Studies. This took account of issues relating to feasibility, practicability as well as ethical considerations. Moreover, the research plan and progress was reassessed annually both by the research degrees committee and the School.

Secondly, permission to involve statutory social workers and young people who used their services was sought initially at a local level from Aberdeen City Council social work department and latterly, at a national level from the ADSW Standing Committee for Standards Training and Research. Approval from the ADSW was applied for in September 2003 and permission to proceed was provided verbally via a telephone conversation in March 2004, and later confirmed in an email correspondence (a copy of which can be found in Appendix 3). The need to access approval at a national level arose due to difficulties identifying a sufficient sample of young carers from the Aberdeen City area as had been originally planned. This necessitated a need to recruit across a number of local authority areas.

Furthermore, whilst an element of the study required access to an NHS employee (a health visitor), it was not necessary to gain ethical approval from the local NHS REC. The reason for this was two-fold. Firstly, in addition to her role as a practitioner, she also occupied a position as a university lecturer and it was in this capacity that I contacted her. Secondly, the purpose of her involvement was to discuss her observations relating to the notion of hidden-ness of particular young carers. As this one-off involvement did not require access to patient records or any confidential or sensitive details, this was classed as an 'audit' rather than 'research', for which ethical approval was not required according to COREC, the national body responsible for co-ordinating the 190 NHS RECs throughout the UK.

Thirdly, and of critical importance, both before and beyond securing the relevant ethical approval to progress with the study, the doctrines of 'good ethical practice' ultimately informed every step of the research process (Glesne and Peshkin, 1992).

Good practice was informed by various relevant professional and research codes which included: the *'Social Research Association's (SRA) Ethical Guidelines'*

(SRA, 2003); the *'British Association of Social Workers (BASW) Code of Ethics for Social Work'* (Bolton, 2003); the *'British Sociological Association (BSA) Statement of Ethical Practice'* (BSA, 2002); and the *'Scottish Social Services Council (SSSC) Code of Practice for Social Services Workers'* (SSSC, 2002). As well as being bound by these codes due to professional membership within the governing organisations (BASW, BSA and SSSC), adopting these measures was fundamental in terms of upholding professional integrity. Below an attempt is made to link the conduct and good practice fostered, to the relevant points within the various codes (which can be found in Appendix 4).

Collectively, these codes have been guided by the fundamental principle of 'do no harm' to the physical, social and psychological health and well-being of research participants and those connected to them. It has been suggested that such 'harm' could manifest in '...undue stress through participation, loss of self-esteem, psychological injury or other side effects' (SRA, 2003, p35).

In order to safeguard against harm as far as practicably possible, it was important to reflect on - not only at the design stage, but throughout the entire process - the potential sources of harm that could have affected the participants and those linked to them, as well as the researcher, the University and the wider research community (BSA, 2002, points 2, 9, 24 and 26; SSSC, 2002, point 26; BASW, 2003, point 6; SRA, 2003, points 2, 3 and 9). This was assessed according to various criteria including '...the probability of risk, the number of people at risk and the severity of the potential harm...' (SRA, 2003, p.35). The nature and source of potential forms of harm as well as harm-reduction strategies were constantly reflected on and accordingly, appropriate strategies were devised. These included: seeking voluntary participation and informed consent; respecting privacy, anonymity and confidentiality; striving towards a milieu of transparency and open-ness; and ensuring personal competence to undertake the research. In addition, issues relating to the safety of the researcher were relevant.

<u>Ethical Issues Pertaining to Voluntary Participation and Informed Consent</u>

Safeguarding the rights and wellbeing of individuals was partly achieved through firstly, ensuring as far as possible, that participation was voluntary and secondly, accessing their informed consent prior to their taking part (BSA, 2002, point 12; BASW, 2003, point 15; SRA, 2003, point 12). In addition, in terms of key social work values, it was recognised that as well as protecting the rights and interests of individuals, seeking informed consent was also underpinned by a need to support individuals to make informed choices and exhibit control and independence over their lives (SSSC, 2002, points 3 and 14).

In terms of voluntary participation, it was ensured that involvement in the research was on the basis of free and informed choice. Thus, prior to their agreement to participate, individuals were fully briefed on the goals of the study, their potential involvement as well as their rights and expectations, such as their right to refuse to participate, to opt-out of the study at any stage or to withdraw information supplied (BSA, 2002, points 12 and 13; BASW, 2003, point 14; SRA, 2003, points 12 and 20).

However, the potential danger of coercion was recognised due to the imbalances of power, authority and control between the researcher and the participants because of their status as children (BSA, 2002, points 10 and 27; SSSC, 2002, points 21 and 27). Nevertheless, in retrospect it could have been queried whether a degree of coercion was evident. In the first phase of the study, each of the ten individuals identified as potential participants were sent a letter requesting their involvement. In this it was indicated that they should contact the researcher if they wished to take part. However, as this request proved to elicit no response, it was necessary for the researcher to initiate telephone contact to request their participation. However, this action was perceived as being 'persuasive', rather than 'coercive' (SRA, 2003, point 16). Moreover, as acknowledged within the SRA's guidelines, an enhanced 'degree of persuasion' may be required when recruiting 'vulnerable' participants such as children into research (SRA, 2003, points 16 and 18).

Further concerns which stemmed from the age of the participants were apparent in relation to obtaining informed consent and thus, necessitated the adoption of additional measures '*...to protect their rights...*' (SRA, 2003, p.30). Such measures included gaining parental consent for those participants under the age of 16 and ensuring that the information offered about the research was presented in a manner accessible to the young people (BSA, 2002, point 28).

To begin with, those participants over the age of 12 years were deemed to have 'legal capacity' and thus, presumed to be competent to consent to their involvement in the study. However, due to their legal status as children, as a measure of good practice, written parental consent was obtained for every participant under the age of 16. This was pursued for the protection of the participants and the researcher. For instance, the bounds of confidentiality pertaining to child protection concerns were fully and sensitively explained to participants (and parents where applicable) and were documented in the consent form (see Appendix 5 for a copy of the consent form used) (BSA, 2002, points 14, 15, 28 and 34; SSSC, 2002, point 15; BASW, 2003, point 20; SRA, 2003, point 19). If such issues regarding the safety or welfare of a child arose and thus, disclosure to the relevant authorities had been necessary, having secured parental consent would have addressed any doubts about whether the child had fully understood or was aware of the limits of this procedure.

Secondly, in order to facilitate informed consent, it was fundamental that the relevant information regarding the purpose and procedures of the study as well as the potential readership was presented in an appropriate and accessible manner, taking into account the age and levels of comprehension of the participants (SSSC, 2002, point 8; BASW, 2003, point 15). This was achieved through providing potential participants with both written and verbal information (SRA, 2003, point 22). In terms of this, it was important to reflect on what and how much information was required, as there was a danger of giving either too much, which could have caused confusion, or indeed, too little which could have

inadvertently removed the individual's right to pursue a fully informed choice over their participation (SRA, 2003, points 13, 14 and 15). For instance, the information booklet provided to the participants was presented in a 'child friendly' format (see Appendix 1). Also in discussing the particular areas of focus within the study, the notion of 'parentification' was introduced sensitively as it was a term possibly unfamiliar to the participants and potentially problematic in its implications for family dynamics.

The Limits of Confidentiality, Anonymity and Privacy in Practice

It was recognised that a further possible source of harm could have resulted from the disclosure of either confidential information or the identities of participants. Such harm could have manifested in a threat to the rights of individuals and their families to confidentiality, anonymity and privacy (SSSC, 2002, point 4). Thus, the importance of assuring the confidentiality of information provided - aside from instances where child protection concerns were apparent - was fundamental to good practice (BSA, 2002, points 14, 31 and 34; SSSC, 2002, point 28; BASW, 2003, point 20; SRA, 2003, point 11). Additionally, this was also recognised as a means of facilitating the development of trust and rapport with the adolescent participants:

> Additionally, confidentiality of all data affects the ease and completeness of children's and adolescent's responses. Adolescents are especially concerned with confidentiality, as they are often experimenting with new ideas and ways of presenting themselves (Faux, 1988, p.185).

Assuring confidentiality was achieved through the adoption of simple measures such as ensuring that the personal details and raw data pertaining to participants were kept securely in a locked cabinet, as well as using pseudonyms in place of real names (BSA, 2002, points 31, 32 and 33; SSSC, 2002, point 9; SRA, 2003, point 23). However, ensuring anonymity was more complicated. Although the identities of the participants were obviously not directly disclosed, potentially these could have been deduced by others on the basis of their distinct characteristics or combinations of characteristics presented in the thesis, such as

their age, family and caring situation (BSA, 2002, point 32). The risk of this was perhaps heightened as the research relied on a relatively small sample of young carers from a fairly limited geographical area. Thus, to minimise this risk as far as possible, it was decided to present only the very basic background details relating to each participant, rather than comprehensive individual case histories similar to those evident in other young carers studies (Dearden and Becker, 2000) (BSA, 2002, point 33; SRA, 2003, points 25 and 26). This necessitated a careful reflection on what information was actually required by the reader. For instance, in terms of the family members, initially the age of any siblings was included. However, this could have served to identify an individual and thus, instead, merely an indication of whether the siblings were younger or older than the young carer was offered. Indeed it was found to be the birth order of children in the family – rather than their chronological ages - that was potentially significant in the assumption of caring responsibilities.

In accordance with both data protection legislation and good practice (BSA, 2002, point 17; SRA, 2003, point 1), to facilitate informed consent individuals were advised of their rights to confidentiality and anonymity, including the data storage arrangements and their right to reject the use of tape-recording equipment (BSA, 2002, point 14). Additionally, the potential limits of confidentiality and anonymity, as well as the strategies adopted to minimise the risk of disclosure were highlighted (BSA, 2002, points 14, 15 and 33; SSSC, 2002, point 9; SRA, 2003, point 24).

Maintaining Transparency, Open-ness, and Trustworthiness

Arguably, the need for transparency and open-ness runs throughout good ethical conduct and within the current study this was reflected as being particularly important on two key levels – firstly, with participants and secondly, in relation to the reporting of data.

Firstly, transparency involved being open and honest about the research and ensuring that participants were fully informed about aspects which could have

affected their participation (SSSC, 2002, points 7 and 8; BASW, 2003, points 12 and 13). On reflection, exhibiting such open-ness from the outset proved to be useful in developing rapport with the participants, which possibly increased their willingness to share details regarding their caring roles. Also, in relation to open-ness and in line with good practice, the observations undertaken were overt as the young people were made aware of this element of the research from the outset (BSA, 2002, point 30; BASW, 2003, point 8; SRA, 2003, point 21).

In addition, the importance of developing rapport with the professionals who referred young carers to the study was recognised and again, essentially achieved through open-ness and transparency about the study, the extent of their potential role and the involvement of the young people as well as general expectations (SRA, 2003, point 6). This was recognised as key in fostering the relationships which existed between the participants and the professionals and in ensuring that these were in no way compromised by the research (BSA, 2002, points 22 and 23). Not only were these relationships key in terms of providing ongoing support to the young people and their families, these provided opportunities for follow-up support relating to issues raised by the research (SSSC, 2002, point 40; SRA, 2003, point 17). In addition, forging good working relationships with professionals and establishing networks had more wide-reaching impacts. This was fundamental in terms of the reputation of the individual researcher, the institution affiliated to (which in this case was The Robert Gordon University) the wider social research community, as well as the social work profession (BSA, 2002, point 37; SRA, 2003, point 7).

Secondly, transparency related to the accurate reporting and appropriate dissemination of research findings (BSA, 2002, points 2, and 8; SSSC, 2002, point 8; BASW, 2003, point 17; SRA, 2003, point 8). In terms of this and in line with the social work duty of integrity, it was necessary to '...report findings accurately, avoiding distortion whether by omission or otherwise...' (BASW, 2003, p13). This was achieved through a variety of methods which included the triangulation of data and cases, as well as confirming the accuracy of

interpretations with the participants. On reflection, striving towards transparency at all stages of the research with participants, professionals and where applicable. with families, as well as in the presentation of the findings, was most useful in achieving and maintaining the trust of participants and professionals (BSA, 2002, point 10; SSSC, 2002, point 7).

Ensuring the Competence of the Researcher to Undertake the Study

The competence of the researcher to conduct the study was recognised as integral to the safety and welfare of all those involved. Thus, in terms of this it was necessary to reflect on the knowledge, technical abilities and skills required to successfully and appropriately complete the research, and identify gaps and training needs. As the Ph.D. process was regarded as an apprenticeship, such knowledge and skills were fostered and developed throughout the research period. This was achieved through extensive reading, consultation with colleagues and supervision sessions, undertaking various training courses (such as training in computer-assisted packages including 'NVivo') as well as working toward a postgraduate certificate in research methods (BSA, 2002, point 3; SSSC, 2002, point 41; BASW, 2003, point 9). Arguably, personal competence in the research capacity also drew on already established social work knowledge and skills, including interpersonal, communication and interviewing skills.

Promoting the Safety and Welfare of the Researcher

As well as protecting the wellbeing of the research participants, consideration of the safety and wellbeing of the researcher was also necessary (BSA, 2002, point 4). This was of particular relevance with respect to the interview sites chosen. Within the second phase of the study, it was intimated by two of the professionals who referred young carers to the research that the parent had demonstrated repeatedly violent behaviour and thus, it was inadvisable to conduct home visits (SRA, 2003, point 10). On the basis of both this advice and the expressed wishes of the young people involved in the second phase, interviews were conducted at various places outside the family home, normally within the premises of the referring agencies. However, had the young people requested to be interviewed at

home, this could have created potential conflicts between firstly, the wishes of the young person and the interests of the researcher (BSA, 2002, point 9) and secondly, between the interests of the research and the interests of the researcher (SSSC, 2002, point 12). In relation to the latter, difficulties identifying possible participants in the second phase of the study would have made it difficult to simply reject willing participants on the basis of requiring to be seen at home. However, research is the 'art of the possible' and therefore, the researcher would not have placed herself at any significant risk (SSSC, 2002, point 32). Such a situation could have been managed by attempting to persuade the young person to meet elsewhere.

If declined, the actual level of risk posed to the researcher in conducting a home visit would have been assessed in a manner similar to that routinely undertaken by social workers conducting home visits (SSSC, 2002, point 16). Additional information would have been requested from the referring agency about the parental behaviour, such as the circumstances surrounding previously exhibited violent behaviour. If the risk to the researcher was deemed low, the measures used when conducting the home-based interviews in the first phase of the study would have been adopted, such as informing a colleague of the location and expected duration of the visit, providing a mobile telephone contact number, and reporting back to them following the visit.

3.4 The Paradigm and Approach within the Current Study

The current investigation, because of its focus on young peoples *experiences* of caring, was firmly placed within the qualitative domain and consequently, the methods utilised were mainly qualitative in nature. In justification of this, it is necessary to make brief reference to the various research paradigms.

Key Divergences between the 'Constructive-Interpretive' and the 'Positivist' Paradigms

According to Denzin and Lincoln (1994) research may be underpinned by one of four types of paradigms, namely positivist and post-positivist; constructive-interpretive; critical and feminist-poststructural. Fundamental distinctions between these have related to the differing epistemological positions or the assumptions made regarding the nature of knowledge and reality (Jeon, 2004). Whilst positivism has perceived knowledge as largely objective, those subscribing to a constructivist approach have viewed knowledge as the product of an inter-subjective process between the researcher and the subject:

> Constructivism assumes the relativism of multiple social realities, recognizes the mutual creation of knowledge by the viewer and the viewed, and aims toward interpretive understanding of subjects meanings. (Charmaz, 2000, p.510).

Accordingly, the focus of the constructive-interpretive paradigm has been very much on how people fashion meaning to their own Worlds through their interactions, interpretations and construction of meanings. Therefore, this paradigm has been particularly useful where the aim has been to describe and understand the multiple social realities and how people ascribe meaning to their own situations (Creswell, 1998), as was the case in the current study.

The epistemological stance in the current context was heavily influenced by the constructive-interpretive paradigm as firstly the aim was to describe, interpret and

understand the meanings attached to young caring and the experiences of young carers according to different caring contexts, rather than simply to test any existing theories. Secondly, the experience of young caring was recognised as being subjective and thus, knowledge regarding this resulted from an interpretive and interactive process between the researcher, the researched and their social contexts.

The Influence of Symbolic Interactionism

In terms of this broad constructive-interpretive philosophy, the study was set within the 'Symbolic Interactionist' tradition, an approach founded on concepts such as 'human society', 'objects', 'actors', 'action' and 'interconnection' between individuals (Blumer, 1969). In terms of this, the meanings attached to young caring by the participants were recognised as deriving from their face-to-face interactions with others around them including their parents, family members, friends, partners and professionals, as well as the wider society in which they were placed.

According to this approach, words and actions can be understood and experienced in a collective sense, by people at a given place and time. However, these also have personal meaning for individuals based on their own biographies, life experiences and histories and thus, meanings are modified according to individual interpretations (Blumer, 1962). For instance, the term 'young carer' has been socially constructed and holds a particular meaning and particular connotations within contemporary western society, yet has also been interpreted according to individual experience.

The ultimate goal of this tradition - to understand *the complex world of lived experiences from the point of view of those who live it'* (Schwandt, 1994, p.118) - was particularly fitting within the current study, where the overarching aim was to understand the meaning of caring to young carers and how young carers themselves defined their situations and caring experiences. Moreover, to access this understanding, particular tools were utilised which included interviews,

observations, a diary method and a self-esteem scale[6], all of which depended on the interplay between the researcher and the participants.

Moreover, as knowledge was recognised as the product of an inter-subjective process, as well as the young carers own interpretations of their situations, the researchers' understanding and interpretation of these were critical. This was influenced by the researcher's biography in terms of her professional background and personal history, her own experiences and comprehensions of areas such as family life, relationships, educational and health issues. This in turn influenced the interpretation of some of the key notions which were described and discussed by the participants. To ensure that the interpretations reflected the young carers lived experiences, the findings were validated by various measures including the triangulation of data and through consultation of the young people themselves (this will be further discussed in *'Establishing 'Trustworthiness' in the Research Process and Findings'* later in this chapter). Additionally, the researcher's personal biography informed other elements of the research including the data-collection tools used, the questions posed and the language used, the direct interactions with the young people and methods used to develop rapport.

<u>The Role and Influence of Grounded Theory within the Study</u>

Within this interactionist framework, a range of grounded theory methods were utilised. In line with the interactionist tradition, the emphasis within grounded theory has been to uncover meanings 'embedded in data' (Bryman, 1992, p.84) in the words, behaviour and actions of people's their everyday lived experiences (Strauss and Corbin, 1998), which as stated, was the general aim within this study.

Additionally, utilising this approach was particularly appropriate due to firstly, the real-life nature of the research problem investigated within the current study:

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[6] The Rosenberg Self Esteem Scale is a standardised tool. The implications of using this in the current study will be discussed later in the chapter (see section 'The Data-Collection Methods Employed in the Study').

A human problem and the social-psychological or social-structural processes arising from it are the fodder of GT research (Crooks, 2001, p.17).

Secondly, the emphasis within grounded theory has been on making new discoveries (Goulding, 1999), which was feasible within a relatively 'new' area of research interest such as young caring. Lastly, and perhaps most importantly, the methods offered by this approach facilitated a critical and analytic approach to the execution of the study and offered a practical guide to the collection and analysis of data.

Whilst useful, this approach has been beset with contention regarding its philosophical position, as well as various practical concerns (Glaser, 1978; Glaser, 1998; Strauss and Corbin, 1998). Some of these were evident in the current context and ultimately rendered the adoption of a purist grounded theory approach unworkable. In terms of this, firstly, the theoretical frameworks proposed by the co-founders of grounded theory have diverged over the years and as a result, variations in approaches - all labelled 'grounded theory' - have been evident (Goulding, 1999; Glaser, 1992; Stern, 1994). Whilst the approach used in the current study most closely relied on that proposed by Strauss and Corbin, (1990; 1998), the methods described by other proponents were also employed. Secondly, it was not possible to use theoretical sampling - the preferred sampling strategy – due to difficulties accessing young carers. The implications of this will be elaborated on later.

Thirdly, in line with the notion that theories should be allowed to emerge inductively from the data, it has been argued that researchers should commence their work free from preconceived ideas which may bias both the research process and the findings (Glaser and Strauss, 1967). However, it has not been implied that researchers should be 'atheoretical' (Goulding, 1999, p7) as knowledge of relevant theory can essentially serve to sharpen 'theoretical sensitivity' (Miles and Huberman, 1984; O'Callaghan, 1996; Goulding, 1999). Indeed, within the current context the researcher's own 'personal biography' and in particular, her professional experience. increased her awareness of some of the key issues

relating to young caring. Despite this, it has been suggested that detailed reviews of the literature relating to the immediate area of interest, should be avoided until the final stages of data analysis to ensure that this does not influence the perceptions of the researcher. In the current context, this was impractical as it was paramount that the researcher had a detailed knowledge of the existing work within this area at an early stage, to ensure that the study would actually contribute to the established body of knowledge on young caring, rather than merely replicate an area already exhausted (Charmaz, 2000). Therefore, she immersed herself in the literature from the outset.

Thus, due to these identified restrictions and issues, grounded theory was used in the research insofar as it provided a 'modus operandi' or a method to conduct the study. The methods prescribed by this approach as they applied to the current study will be discussed later.

3.5 The Researcher as the Research Instrument and the Use of Self in the Study

As stated, advocates of the grounded theory approach have recognised that the life experience, knowledge and theoretical awareness of the researcher can serve to enhance theoretical sensitivity. Indeed, in the current study the researcher's own knowledge and experience influenced every element of the research, from the choice of the topic area, to the design and execution of the study, as well as the interpretation of the findings. Nevertheless, utilising some of the key tools prescribed by the grounded theory approach went some way to ensure that the effects of this were controlled for as far as possible, by making the researcher aware of her own biases and the potential effects of these on the study. As will now be discussed, this was critical considering the central role that the researcher held as the principal research tool.

Addressing Subjectivity in the Research Process

In relation to this, one of the key characteristics of qualitative design has pertained to the researcher becoming their own research instrument (Janesick, 1994; Ely, Anzul, Friedman, Garner, McCormack, Steinmetz, 2006). Therefore, whilst the current study was aided by the use of formal tools for data collection and analysis, including an interview schedule, a self esteem scale and a computer assisted data analysis package (NVivo), the researcher occupied the central role of primary research instrument. Thus, the researcher's 'self', particularly in terms of her 'personal biography' or her history, experiences, knowledge, values, attitudes, beliefs, interests and needs at the particular time when the study was conducted, impacted on every element of the research. This included the topic area selected, as well as the research methods and sample, her interactions with the participants, the interpretation of data and the presentation of findings (Glesne and Peshkin, 1992; Punch, 1994). Indeed, this notion of 'subjectivity' (Glesne and Peshkin, 1992, p.93) has been widely acknowledged throughout the qualitative research community:

> ...we are the primary instruments, but we are not cool, automatised instruments...while we try to maintain distance and perspective, we too, have personal responses to what we see and hear... (Ely et al, 2006, p.108).

Whilst the presence of subjectivity was accepted, it was also recognised that this could create bias and adversely affect the reliability of the data. In order to minimise the effects of this, it was important to firstly, reflect on and determine the relevance of elements of the self such as personal biases, prejudices, assumptions and limitations to the current context and ultimately, their potential in 'clouding or distorting the perceptions of others experiences' (Ely et al, 2006, p.122). Thereafter, it was necessary to consider and adopt various measures to address the effects of subjectivity, including the triangulation of data to counter bias and the confirmation of participants regarding the interpretation of data.

This ongoing reflection proved a challenging process even though there was an already established level of self-awareness as necessitated by the social work role.

Indeed, whilst working as a social worker (prior to undertaking the research), the self was the principal tool utilised in interactions with others. Thus, within this capacity, it was important to have an awareness of both the existence and potential impact of personal attributes. Nevertheless, within a research capacity, it was recognised that such factors were likely to differ according to role and context, and thus, the impact of the self had to be revisited and reappraised.

Being the principal research instrument enabled a great deal of personal responsibility and control over the process. On the one hand, this was viewed as exciting as it facilitated much creativity within the research process (Ely et al, 2006). One the other hand, it was also viewed with trepidation, particularly in terms of the interpretation of data, as there was an ongoing fear of 'getting it wrong' or misinterpretation. Nevertheless, such worry decreased with both a growing trust in oneself as a flexible research instrument and one's own abilities, as well as the acceptance that others - with their own subjectivity - would interpret the data differently. This concern was further minimised through the triangulation of data and cases and 'checking' the accuracy of the findings with the participants.

Roles and Relationships within the Research Context

The research was initiated and informed by professional experience with young carers' within a local carers and young carers' organisation, initially as a social worker and latterly - whilst undertaking the research - as a volunteer worker. The decision to volunteer within the same organisation was based on three factors: firstly, to assist in providing a much-needed service to the young carers; secondly, due to reasons of personal interest and fulfilment; and thirdly, to have access to potential participants for the study. The transition from social worker to volunteer worker was in itself relatively straightforward, even though this necessitated the adoption of a different role and responsibilities. However, as the first phase of the study progressed and young people from the service became involved as research participants, this required negotiation of a new dynamic – the researcher and the researched.

The occupation of multiple and diverse roles created both opportunities and a whole set of new tensions and ambiguities. On the one hand, having an established relationship with the young carers offered some key opportunities due to a familiarity with them, their backgrounds and histories. Such benefits included gaining access to research participants, developing rapport with them and avoidance of appearing naïve (Ely et al, 2006). On the other hand, whilst these very issues could be construed as 'positives', they also presented problems for both the researcher and the young carers alike. Principally, this related to ambiguities over boundaries, role and purpose. Some of the issues and dilemmas encountered were similar to those documented elsewhere, particularly by feminist nurse researchers in discussions around the dilemmas and implications of undertaking research in one's own professional milieu (Estabrook, 1987; Field, 1991). For instance, one study conducted by a postgraduate student who had previously occupied the position of head nurse in an intensive care unit, was concerned with how 'touch' was used by intensive care nurses with their patients (Estabrook, 1987). In relation to this, the researcher recounted her difficulties in separating her various roles as a researcher and a nurse and her over-riding need to intervene in issues relating to the treatment of patients, whilst conducting the fieldwork. She also discussed issues relating to over-familiarity with the patients as participants. Below, an attempt is made to explore some of these dilemmas encountered in the current study. In particular, the changed nature of the roles and relationships of and between the researcher and the participants and an over-familiarity with the participants, as well as the development of rapport, will be considered.

Renegotiating Roles and Relationships between the Researcher and the Participants

Within the capacity as both social worker and volunteer worker, the relationship shared with the young people had been characterised by on-going support and 'near-friendship'. However, this posed potential problems within a research context. Firstly, previously the main purpose of contact was to help and support the young carers and thus, direct intervention and advocacy were expected.

However, within the research context this had to be renegotiated, as neither was desirable nor intended:

> The relationship you and your others develop [within a research context] should be marked by reciprocity, trust, mutual respect, and learning, but, at this point, not by advocacy and action... (Glesne and Peshkin, 1992, p.36).

Instead, the purpose of contact in the research capacity and the necessity to develop good rapport with participants was geared towards gathering relevant information. Thus, the relationship between the researcher and the researched was ultimately determined by the needs of the researcher, rather than the needs of the participants. This represented the converse of the purpose of the relationship between social worker and service user:

> ...the function of rapport [in social work relationships] was based on the need for clients to feel adequately comfortable in order to disclose information and thus, intent is to attain ends shaped by their clients' needs, as they and the clients ascertain them. Researchers to the contrary traditionally establish rapport to attain ends shaped by their own needs. In qualitative research, rapport is a distance-reducing, anxiety-quieting, trust-building mechanism that primarily serves the interest of the researcher... (Glesne and Peshkin, 1992, p.94).

Whilst the researcher experienced this change of purpose as unfamiliar and somewhat uncomfortable, it was necessary from the outset to establish boundaries and clarify roles and expectations with the participants as well as the professionals, based at the young carers centre. Fundamentally, this involved dealing with the dual role in an open and honest manner. For instance, it was ensured that visits to the young carers centre for research purposes (to undertake interviews), were organised for times which did not coincide with volunteering duties and where possible, following each session the researcher would physically leave the building in order to reinforce boundaries. Additionally, it was agreed that issues that were raised by individuals that necessitated some form of support or intervention would be followed up after, rather than during the interviews or

observations. This again served to reinforce boundaries and also allowed the researcher to concentrate more fully on the research:

> ...letting go means that a qualitative researcher is more able intensely to 'be with' what is happening and to respond to that instead of worrying about what should or could be happening. This means that the person who is the research instrument is more in line with the needs of the study and can reflect more realistically upon possible next steps... (Ely et al, 2006, p.46).

This system worked well and there were only a few instances where the participants attempted to use the interview sessions to access support or therapy. Nevertheless, whilst the objective of the interviews was to gather relevant information, rather than to provide therapy to participants, this was perhaps an unintentional outcome as several of the young carers in both phases of the study, commented on how positive the experience of engaging in the interview process felt. Nevertheless, observations were undertaken at various times and as opportunities arose, mainly whilst the researcher was working with the young people in a volunteering capacity. However this was viewed by the researcher as less intrusive.

Secondly, previous interactions – particularly in the capacity as volunteer worker – had been based on a quality of relationship characterised by 'near-friendship'. This had been fostered by both the relaxed culture of the organisation and the type of work latterly undertaken, which largely involved fun activities and outings. In a social work context, this was perceived in a positive sense. However, the distinct differences between rapport and friendship were recognised, particularly in terms of personal affection and power dynamics:

> ...friendship means mutual liking and affection and implies a sense of intimacy and mutual bonding...a relationship characterised by rapport is marked by confidence and trust, but not necessarily by liking...control over the relationship also distinguishes the two concepts...the rapport relationship is more asymmetrical, with control in the hands of the researcher... (Glesne and Peshkin, 1992, p.94).

This notion of 'friendship' was somewhat one-sided, although admittedly, from a personal viewpoint, there was much positive regard for particular individuals. On the one hand, this was recognised as being potentially beneficial in terms of fostering rapport:

> ...feelings of intimacy and warmth towards one's research participants are not only natural, but in general positive. The task of successfully stepping into the shoes of another person is greatly facilitated by feelings of sympathy, compassion and unconditional acceptance... (Ely et al, 2006, p.112).

On the other hand, involving such individuals in the study could have been problematic as it was recognised that such 'friendship' or 'favouritism' could have created bias and thus, compromised the data (Gold, 1969; Miller, 1952 as cited in Glesne and Peshkin, 1992; Shaffir, Stebbins and Turowetz, 1980; Van Maanen, 1983). For instance, in terms of selection, it would have been most straightforward to target such individuals, as they would have been more likely to agree to participate and to provide full and complete accounts of their caring situations. However, it was recognised that this would have created an outright bias in the data and thus, such a sampling strategy was avoided (the actual sampling strategies employed will be discussed later). Whilst the participants in the first phase were targeted on the basis of their convenience and availability through their contact with the young carers centre, the sample was not merely restricted to those individuals deemed most likely to participate due to their familiarity with and to the researcher.

Thirdly, whilst contact within a social work and volunteering capacity was ongoing, contact for the purposes of the research was time-limited. Thus, this necessitated clarification of the length of contact with the participants and consideration of appropriate closure. Such closure differed within each phase. Within the first phase, the participants were involved with the researcher on a number of occasions, to facilitate interviews and observations. Additionally,

some of the participants had ongoing contact with the researcher in her capacity as volunteer worker. In contrast, contact was limited to a single session within the second phase.

Challenges Due to Over-familiarity with the Participants

As the individuals selected within the first phase were known to and familiar with the researcher, this presented a particular difficulty in the reporting of sensitive findings. In addition, two further issues were evident within both phases, which again derived from familiarity with either the participants or the topic area. These related to assumptions made by the researcher and 'intellectual flexibility' (Ely et al, 2006, p.132).

Firstly, being familiar with the setting and the young people posed a difficulty in terms of what and how to report. Knowing and respecting the individuals engendered a heightened sense of concern regarding their privacy. Whilst good ethical practice concerning confidentiality and privacy were upheld as far as possible, conflicts could have presented between preserving privacy where a participant revealed some particularly sensitive information - such as the disclosure of abuse or neglect - and reporting relevant information fully and deeply. In addition, if such concerns about child welfare had become apparent, this information would have been disclosed to the agency that referred the young person to the study. Again, this demonstrated the limits of confidentiality – this could have not been 'absolute' in situations relating to child welfare. Additionally, a degree of familiarity meant that the researcher was privy to additional information gained outside the research context. This created difficulties in deciding if and how such information should be used. Following careful consideration, it was accepted that whilst such information would undoubtedly inform the researcher's own understanding and offer further triangulation of data, any information gained outside the research context could not be published as the young people had not explicitly consented to this.

Secondly, a further difficulty stemming from the researcher's familiarity with the subject area and with some of the young people involved in the study, concerned her presumed understanding. For instance, it had been assumed that the young carers viewed themselves as young carers according to their caring role at home and thus, that their responses to a question about their understanding of the term 'young carer' would be organised around this comprehension. However, instead a range of alternative understandings were revealed. Indeed, it was not until these responses came to light that such personal assumptions on the part of the researcher were recognised. On reflection, this area had never previously been explored with the young carers:

> The point here is that the familiar, when observed from a different stance or a new perspective, may frequently turn out to be quite unfamiliar... (Ely et al, 2006, p127).

Thirdly, whilst the researcher strived to remain open to emerging data, preconceived notions based on a familiarity with the field had initially threatened to affect this open-ness. However, recognition of this enabled a guarded and reflective approach.

The Necessity and Role of Rapport in Accessing Information

As well as subjectivity, rapport was a further key ingredient that determined the success of the researcher as research instrument. Undoubtedly, rapport was key in terms of both gaining access to the participants and thereafter, throughout the fieldwork. Within the first phase of the research, familiarity with the young people at the young carers' centre facilitated access to them as participants. This was aided by the trust of and rapport that had developed earlier between the researcher and the young carers, in her capacity as a social worker and volunteer. Ultimately, this aided fuller and more accurate disclosure from the participants (Glesne and Peshkin, 1992). However, it was not simply taken for granted that rapport and trust had been achieved and thus, required no further consideration. Rather, it was recognised that amongst the participants in the first phase, different levels of trust in and rapport with the researcher were evident and even where

much trust and rapport existed, this still needed to be nourished in order to be maintained.

In the second phase of the research, the participants (or the professionals approached as gatekeepers to the young carers) were not familiar with the researcher, which perhaps accounted for greater difficulties in recruiting a sample and also meant that trust and rapport were initially absent. Thus, these had to be developed in order to facilitate disclosure. This proved to be a real challenge within a one-off contact lasting only 90 minutes, and thus, it was questionable whether this affected the completeness of the data. In resolution of this, various strategies were considered. For instance, the interview data could have been collected over two sessions rather than one, which may have facilitated opportunities to build greater levels of rapport (Glesne and Peshkin, 1992). However, this was impractical due to other constraints such as lack of time and the geographical spread of participants. Instead, rapport was fostered as far as possible within the single session by allowing additional time prior to the interviews for introductions and familiarisation with and between the researcher and the participants.

In addition, various other measures to foster rapport were adopted within each of the phases of the study. These measures related to the order of the questions in the interview schedule (for instance, the biographical questions were followed by subject-specific enquiries), the awareness and presentation of the self as well as communication with the participants. Also, as the direct or immediate benefits of partaking in the research were largely unapparent to the participants, it was recognised that this too could have affected their motivation and rapport. Whilst it was pointed out to the participants that they were unlikely to gain *directly* from their involvement in the research, it was important that they perceived some benefit from their participation. Each of the measures adopted will now be considered.

Rapport-Development Techniques Adopted

Firstly, the interview questions progressed from factual and non-threatening, to increasingly personal and sensitive items to facilitate an opportunity to build rapport and gain some level of trust, prior to the disclosure of emotive information (Faux, 1988).

Secondly, the potential effects of the personal attributes of the researcher on the development of rapport were considered. For instance, a naturally friendly disposition was judged to be a favourable trait, whilst a personal pitfall relating to difficulties with time-management was recognised as a factor that could have undermined good rapport. However, acknowledgement of the latter meant that strategies were put in place to ensure good time keeping for interviews and meetings with the participants. Moreover, in addition to this, it was perceived that some of the researcher's personal characteristics could be manipulated in order to foster rapport, such as showing patience. However, whilst other personal factors, such as age and gender were out of the researcher's control, arguably these were also manipulated. For instance, age was perceived by the researcher as being particularly important due to knowledge surrounding adolescent perceptions of authority figures (Faux, 1988). Thus, the relative youth of the researcher was viewed positively in terms of rapport and thus, appearing youthful was further manipulated by choice of dress and use of language.

Thirdly, rapport was fostered by a conscious and careful use of verbal and non-verbal communication, skills learnt and developed during social work training and practice. For instance, this included knowing what questions to ask and how to ask them, as well as showing an interest in what the person had to say by nodding, smiling and making affirmative sounds. Additionally, an awareness of the body language of the participants was critical. In several cases during the interviews, it was perceived on the basis of their posture or avoidance of eye contact that the participant felt uncomfortable when asked to respond to a particular question. This was addressed by demonstrating empathy, understanding and reassurance,

which was achieved through measures such as reflecting on the question, giving illustrative examples, or moving on to the next question.

Lastly, in order to foster rapport and motivation of the participants, it was important to reflect on ways to ensure that the young people also got something out of their involvement in the research. This was particularly important as the ultimate purpose of both establishing contact and the development of rapport was to serve the needs of the researcher, and within the current context there were no immediate, direct benefits to the actual participants. In order to address this, the importance of their participation was emphasised in relation to the development of knowledge and the future implications of this in terms of service development. Also, all of the participants were provided with a small gift (a voucher for a music store) to show that their time and participation was appreciated. In addition, perhaps other 'unspoken' factors motivated the participants and fostered rapport, such as access to the undivided time and attention of the researcher during the session; the recognition associated with being asked to participate in the study, as well as being treated as 'experts' in relation to their lives and caring roles. Indeed, the positive experiences derived from 'telling one's story' or being the recipient of another person's focused attention, have been highlighted elsewhere in relation to children and young people:

> The interview experience itself can be a gratifying one to children of all
> ages; their feelings of status are enhanced by receiving the full attention of
> an interested adult (Yarrow, 1960, p.568).

A Reappraisal of the Appropriateness of the Volunteering Role

In retrospect, it was questionable whether the dual role of volunteer and researcher was appropriate or whether it would have been advantageous to have either recruited young people from outside of the agency in the first phase of the study or to have ceased involvement with the young carers centre in any work-related capacity. On the one hand, perhaps the researcher was 'too close for comfort' in terms of undertaking research in a familiar setting, which created heightened emotional reactions and dilemmas for both her and the participants.

Although it was felt that this familiarity had enabled access to the young people, perhaps such access would have been permitted anyway - on the basis of the rapport already established in the previous capacity as a social worker. Nevertheless, it was decided to continue working in the volunteering capacity, because this did not present such issues in the second phase as the young people were recruited from sources outside of this agency.

3.6 The Sampling, Data-Collection and Data-Analysis Methods Utilised in the Current Study

In line with the grounded theory methods used, data-collection, analysis and the development of theory were undertaken concurrently rather than as discrete phases, in recognition of the reciprocal relationships between these processes. This concurrent approach facilitated the full exploration and development of ideas apparent within the data which in turn, guided the direction of the subsequent data-collection insofar as the interview questions posed and the observations undertaken (Glaser and Strauss, 1967; Glaser, 1978; Charmaz, 1983; Strauss and Corbin, 1990; Glaser, 1992; Stern, 1994; Strauss and Corbin, 1994; Begley, 1996; Strauss and Corbin, 1998; Allan, 2003). Nevertheless, in order ensure clarity, the sampling, data-collection and analysis methods will be discussed in turn.

The Sampling Techniques Employed

In terms of previous research conducted within the young caring field, a well-documented methodological concern related to difficulties accessing young carers as research participants, mainly due to their unidentified status as young carers:

> ...researchers continue to find difficulty in identifying young carers as research participants, in part because their profile in health, education and welfare agencies is generally low, but also because the young people themselves and their families may wish to keep their caring role a secret (Thomas et al, 2003, p.36).

Therefore, taking this issue into account it was necessary to consider the most practicable means of recruiting young carers into the study and which sampling strategies could be employed. For instance, due to their invisibility and because a 'register of young carer' did not exist, it would not have been possible to obtain a random sample of young carers and as will be discussed below, it was not possible on practical grounds to use the sampling strategy prescribed the grounded theory approach. Instead, various purposive sampling methods were employed including convenience and snowball sampling.

Difficulties in Using Theoretical Sampling

Within a grounded theory approach, 'theoretical sampling' (Glaser, 1978; Strauss and Corbin, 1998) has been the recommended sampling strategy. It has been prescribed that this should involve moving from a sample containing a broad range of experiences that allows the exploration and development of emerging ideas, towards a more discriminatory sample that serves to strengthen findings and refine theories developed (Glaser, 1978). According to this, the sample should be guided by emerging concepts and theory, rather than predetermined at the outset (Strauss and Corbin, 1998).

Sampling on this basis proved largely impracticable in the study because of difficulties accessing young carers to participate. Instead, it was necessary to engage any suitable young carers who fitted the stated criteria (as described below) and were willing to participate. Thus, the participants were recruited largely on the basis of their availability and convenience. This was particularly apparent in the first phase of the study, as participants were accessed through the local young carers' organisation at which the researcher volunteered.

Nevertheless, proponents of the grounded theory approach have acknowledged that sampling on the basis of convenience may be necessary due to difficulties recruiting participants using theoretical sampling strategies:

> ...the ideal form of theoretical sampling might be difficult to carry out if a researcher does not have unlimited access to persons or sites...realistically,

the researcher might have to sample on the basis of what is available (Strauss and Corbin, 1998, p.210).

<u>Purposive Sampling and the Stated Criteria for Involvement</u>

The study relied on a range of purposive sampling strategies. Firstly, in order to access and compare a range of caring experiences, the key characteristics of the participants - in terms of age, caring contexts and relationship to the care receiver – were determined at an early stage. These sought characteristics were determined by the early research questions (which evolved over the course of the study) and in response to existing professional knowledge, the identification of a 'gap' in the literature and preliminary discussions with young carers around issues important to them.

In terms of family relationships, it was decided to involve young people caring for parents, rather than other family members. In particular, this decision was based on findings of previous studies which consistently found that children caring for parents experienced the most marked effects in terms of their own health, wellbeing and development because in this context they were most often required to assume primary caring responsibilities (Dearden and Becker, 1998). Additionally, this facilitated the exploration of parentification or parental-child role reversals. In relation to caring contexts, the specific areas of interest were parents with a physical disability, mental health problem, learning difficulties, or problem alcohol or drug use. As will be discussed, however, it became impracticable to include those caring for parents with learning difficulties. In terms of age, it was decided to involve young people between the ages of 11 and 25, in order to gain an insight into the broad and diverse range of issues typically associated with this period. In normative development, adolescence and early adulthood have generally reflected a period of transition bridging childhood and adulthood, associated with an increased independence from the family of origin, paralleled with the development of relationships outside the family. The current study had set out to explore these issues.

Also, the approximate number of participants involved in the study was stipulated at the outset – ten young people from each of the four caring contexts were initially sought. This was considered adequate to allow the development of categories and emerging concepts, whilst also being manageable in terms of the time constraints that bound the study. This number was in keeping with the assertion that most studies achieve saturation in 8 to 24 interviews (Riley, 1996). Arguably saturation was achieved, as by the tenth interview in relation to each of the caring contexts no new evidence emerged. However, whilst the number of participants was predetermined, there was flexibility in relation to this. If the categories had required further development, additional young people would have been sought. Also, the other elements critical in terms of achieving saturation were addressed in the study. Firstly, the data was fully interrogated; secondly, the negative cases - or those which did not support the emerging ideas - were taken into account (Goulding, 1999); thirdly, the interview questions were continually amended to facilitate the exploration of emerging concepts; and lastly - and arguably most critically - the data collected was adequate in addressing the research questions (Ely et al, 2006).

Snowball Sampling

Additionally, in the second phase of the study, a further form of purposive sampling - 'snowball sampling' - was employed (Lindlof, 1995, p.127). This was necessary due to the inaccessibility of young carers within the stated caring contexts. Such young carers could not be accessed through the local young carers' project used in the first phase due to its limited contact with young carers in these contexts. Therefore, a total of 264 professionals from a range of statutory and voluntary agencies including health, social work and education, were contacted in order to either identify potential participants (a service user or child of a service user) or other agencies that had contact with young carers. These professionals were located through a combination of local knowledge and previously established professional networks, as well as 'Grampian Caredata', a database of local social care and health contacts. Initially, the researcher wrote to

each professional detailing the aims of the research, their potential role and the involvement of the participants. This was followed up by telephone contact if there was no response after a period of two weeks. Establishing contact with such a large number of agencies involved a huge investment of both time and effort on the part of the researcher and perhaps demonstrated the determination, perseverance and flexibility required when conducting 'real world' research.

However, only ten of those 264 professionals contacted, actually referred young carers to the study – see Table 3.2 for a breakdown of numbers by agency type and referrals according to caring contexts. As a result 20 rather than the planned 30 young carers were involved in the second phase and the data-collection and analysis spanned a period of thirteen months (February 2004 - March 2005), instead of nine months as originally planned. This was somewhat frustrating, as it had been envisaged by the researcher that these professionals were in a prime position to identify young carers due to their contact with children and families affected by illness, disability or substance misuse. Nevertheless, such difficulties in securing professional co-operation for research purposes have been well documented elsewhere (Becker et al, 1998; Rackham, 1999; Thomas et al, 2003).

Table 3. 2 - Breakdown of Agencies that Referred Young Carers in the Second Phase

Agency	Agency Type	Number of Young Carers Referred to the Study	Caring Context
Young carers' project A	Voluntary	2	1 – Mental Health 1 – Substance misuse
Young carers' project B	Voluntary	6	5 – Mental Health 1 – Substance misuse
Young carers' project C	Voluntary	3	2 – Mental Health 1 – Substance misuse
Young carers' project D	Voluntary	1	1 – Substance misuse
Mental Health Organisation	Voluntary	2	2 – Mental Health
Drugs and Alcohol Team	Statutory	1	1 – Substance misuse
Alcohol Organisation	Voluntary	2	2- Substance misuse
Careers Organisation	Statutory	1	1 – Substance misuse
Social Work	Statutory	1	1 – Substance misuse
Self Referral	N/A	1	1 – Substance misuse

The Process Involved in Securing a Sample

Various issues prevented the full support or participation of the professionals contacted. These included: a lack of professional awareness and knowledge of young carers; fears and suspicion surrounding their service-users involvement in the research; preconceived notions that their service-users would not wish to participate; a lack of familiarity with the researcher resulting in their reduced commitment; as well as a lack of time to assist due to their own extensive workloads.

In recognition of their own workload commitments, the researcher strived to minimise the extent of their role in the recruitment of participants. For instance, in the first phase the young carers were contacted directly by the researcher through their contact addresses supplied by the young carers' project. Making direct contact was permissible due to the researcher's position as a volunteer within the agency. However, in the second phase, due to data protection

restrictions, it was necessary for the professionals take a more active role in recruiting suitable young people.

In terms of the process involved in the recruitment of the participants, in the first phase ten identified individuals were supplied with an information pack detailing the background and aims of the study as well as a request for their involvement (see Appendix 1 for a copy of the information pack used). Whilst they were encouraged to reply to these written requests (a fast food meal voucher was supplied to each individual who responded, as indicated in the letter in Appendix 6), the majority did not initiate further contact. Thus, it was necessary for the researcher to 'follow up' this with telephone contact. Of the ten originally sought, six agreed to participate and four declined. Therefore, a further four individuals who met the stated criteria were subsequently identified and recruited into the study.

Within the second phase, the researcher initially wrote to the identified professionals to request their cooperation in identifying potential participants or other professionals in contact with young carers (see Appendix 7 for a copy of the letter sent to a range of professionals). Additionally, they were each supplied with information packs to pass onto relevant service-users (see Appendix 1 for a copy of the information pack[7] used). Due to the lack of response to written requests for their participation by young carers in the first phase of the study, the procedure for recruiting participants was amended in the second phase. Thus, a more proactive role was assumed from the outset. Thus, rather than merely distributing the information packs, the professionals were asked to gain the consent of any interested and suitable young people, to allow their contact details to be passed onto the researcher (this was achieved through the mandate form illustrated in

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[7] The information sheet was supplied to potential participants in both phases one and two of the research. However, this was updated periodically in response to various changes. For instance, with regards to the procedures for their involvement, the young carers were initially encouraged to initiate contact with the researcher (as indicated in the pack outlined in Appendix 1). However, due to a poor response in the first phase, potential participants in the second phase were informed in the information provided, that they would be contacted directly by the researcher.

Appendix 8). Following this, the researcher pursued contact with the individuals and arranged interviews.

In recognition of the role that the professionals assumed as 'gatekeepers' to the young carers (as described in other young carers' research, such as Eley, 2004), it was important to ensure good rapport with them to facilitate their engagement. Ultimately this ensured that sufficient young carers could be recruited. This was partly achieved through offering training sessions on young caring with staff from a range of agencies. This served to both raise awareness of young carers' issues and increase familiarity with potential 'gatekeepers'. Whilst this enabled contact with a number of young carers, it did not completely resolve problems relating to the identification and recruitment of participants. Thus, it was necessary to firstly, undertake additional advertising and secondly, make modifications to the original design and sample sought.

Advertisements outlining the research were placed in five agency newsletters (such as the 'Carers News' and the 'Aberdeen Council of Voluntary Agencies Bulletin) with readership of professionals, service-users and carers – including young carers. This resulted in establishing contact with only one young carer who actually self-referred to the research. In addition, a range of relevant professionals and agencies (in social work, education and health) were approached and briefed on the study (during staff team meetings, committee meetings and special interest groups) as a further method of recruitment. This proved more successful with a total of ten referrals to the study following this personal contact.

Required Changes to the Sample Sought

The sample and design of the study required to be modified due to difficulties accessing young carers. This related to both the caring contexts studied, the geographical context from which young people were recruited and the sequence in which the young people were recruited.

Caring Contexts

Whilst young caring in the context of parental learning difficulties was an initial area outlined for exploration, it was possible to identify and recruit only one participant in relation to this context. This may have been because they were less visible than other young carers, perhaps because their parents had less professional intervention. Other means of accessing data relating to this were considered, which included recruiting former young carers. However, this was rejected on the basis of recognised recall difficulties associated with retrospective samples. Additionally, the researcher contacted several key professionals in order to get an insight into some of the issues surrounding young caring within this context as well as the apparent hidden-ness of this group. However, as the research was rooted within the constructive-interpretive paradigm, and thus, was concerned with the young carers' interpretations of their worlds, it would have been inappropriate to attempt to compare the voices of the young carers themselves with the perspectives of the professionals. Therefore, the findings relating to this were relegated to an appendix, as a source of additional information (see Appendix 9 for a discussion of the key findings). The voice of the one young carer in this context has also been included within this section presented in the Appendix. Again, it would have been inappropriate to compare this with the other young carers within the main body of the findings chapter.

Geographical Area

Initially it had been planned to involve young carers only within Aberdeen City. However, as it was impracticable to recruit an adequate number from within this specific location only, the geographical area was extended to include two further areas within the North-East of Scotland, namely 'Aberdeenshire' and 'Moray'. Incidentally, this resulted in the researcher spending a great deal of time travelling to meet with participants.

Sequence of Sampling

Furthermore, the design of the second phase had originally involved recruiting and interviewing participants and analysing the resultant data in relation to each of

the particular caring contexts sequentially. The rationale for such an approach was based on conceptual considerations. It was felt that it would be more manageable to develop concepts and ideas about young caring in relation to particular caring contexts if each was focused on in turn. Nevertheless, in practice it transpired that such an approach was impractical, mainly because those agencies that referred young people to the study mainly provided generic services across service-user groups, and thus, they had contact with young carers in a range of caring contexts. Therefore, contact with young carers' was not established on a systematic basis according to caring context.

The Choice of Research Methods and an Appraisal of Alternative Approaches

Prior to discussing the methods actually employed to collect the data, it is important to briefly highlight the various alternative approaches and methods that were explored and discounted. For instance, as has been highlighted in other studies, a longitudinal design would have perhaps facilitated the most comprehensive understanding of young carers' experiences. However, undertaking repeated observations of participants over a period of time would have been impracticable due to the limited timescale available. Additionally, a survey method, such as a large-scale postal questionnaire, would have offered both a high degree of rigour and generalisability in terms of the findings (McQueen and Knussen, 2002). Nevertheless, this would have been unsuitable due to pragmatic difficulties such as problems identifying an adequate number of young carers due to their invisibility, as well as the relatively low response rates typically associated with this method. This could have resulted in few returns and limited data (McQueen and Knussen, 2002) and perhaps, most critically, would have failed to obtain the expressive richness of the participants' language (Lindlof, 1995), which was of key importance within the current study.

The Data-Collection Methods Employed in the Study

Firstly, in keeping with the grounded theory approach, multiple methods (i.e. qualitative and quantitative) were employed throughout the study. These were mainly qualitative and included interviews, observations and a diary method. In addition, with respect to quantitative methods, The Rosenberg Self-Esteem Scale (Rosenberg, 1965) was used. This will be referred to as The Rosenberg Scale for reasons of brevity. Essentially, the purpose of utilising a multi-method approach was to facilitate triangulation of the data and to counter the weaknesses inherent within each individual method, ultimately, to increase the overall reliability of the findings. For instance, during one interview a young carer intimated that he felt uncomfortable in social situations, which was clearly evidenced at a later stage during an observation at a social event.

Within the first phase of the study, the full range of these methods was used. The interviews provided the most detailed, rich data and the other methods provided supplementary evidence to support the interview data. However, it was unnecessary and impractical to utilise the full range of methods in the second phase. Firstly, as the purpose of the two phases differed, there was no actual requirement for the same methods to be employed within each. To reiterate, the first phase was concerned with understanding the meaning of young caring to young carers and thus, necessitated a range of methods to fully investigate this. In the second phase, the purpose was to discriminate in relation to this, which was addressed adequately through semi-structured interviewing and use of The Rosenberg Scale. Secondly, the interviews produced the most useful data and thus, it was most effective to proceed with these. Thirdly, the diaries failed to produce the kind of information sought. Whilst these had provided some insights and served to corroborate the other data to some extent, their overall value to the study was limited. Therefore, excluding this method in the second phase created no particular difficulties. Fourthly, it was deemed impracticable to undertake numerous observations in the second phase. Nevertheless, observations of the behaviour, actions and body language of the participants were made throughout the interview sessions (in both phases), which provided an indication of the

congruence between the spoken word and inner feelings. Thus, although fewer methods were used in the second phase, the triangulation of data was still achieved through the use of multiple cases and multiple methods, namely interviews and The Rosenberg Scale, as well as ad-hoc observations.

The methods employed were selected in response to a range of considerations including: the scope and aim of the study; the research questions; a critical evaluation of the various methods adopted in previous related studies; their feasibility and validity (Hall and Hall, 1996); as well as pragmatic issues, such as time constraints and access to participants. For instance, the researcher had fully anticipated some difficulties in gaining access to potential young carer participants, due to well-documented accounts of such problems in the literature (Page, 1988; Frank, 1995; Newton and Becker, 1996; Tatum and Tucker, 1998; Dearden and Becker, 1999; Banks et al, 2002b). This rendered some methods such as large-scale postal surveys unworkable and in the current study, necessitated ongoing modifications to the research design. The methods used within the study will now be discussed.

Semi-structured Interviews

Interviewing was utilised within both phases of the research, and was deemed suitable due to the qualitative focus, the small number of participants and the over-arching aim of the study which was to explore how and in what ways young carers conceptualised their caring contexts and experiences (Yarrow, 1960; Gillham, 2000).

It was important that the design of the interview schedules - particularly in terms of the format, structure and types of questions posed – could effectively access data which reflected the lived experiences of the participants. The interviews were structured around two broad themes, firstly, socio-demographic information about the young carer and their family and secondly, their experiences and the impacts of caring (see Table 3.3 below for a broad overview of the interview schedule and Appendix 10 for a copy of the interview schedule).

Table 3. 3 – Overview of the Interview Schedule

		Content
SECTION A	**About You**	*Sex, age, ethnicity, family composition, vocation, income, housing.*
SECTION B	**Parental Condition**	*Nature and effects of the condition on the parent*
SECTION C	**Young Caring Role**	*Definitional issues, caring role, formal and informal support, issues of responsibility.y*
SECTION D	**Impacts of Caring**	*Education, friendships/ relationships, work, spatial transitions, financial issues, health.*

The interviews were semi-structured, rather than completely structured or unstructured, because of the flexibility that this afforded. It allowed the participants to raise and discuss issues which were important to them (Faux, 1988), yet still achieved a comparative element across cases:

> Totally unstructured interviews cause confusion...structured interviews may be merely an extension of the researcher's expectations...the art lies therefore in finding a balance which allows the informant to feel comfortable enough to expand on their experiences, without telling them what to say (Goulding, 1999, p.8).

To ensure that the questions posed reflected the areas of concern defined by the participants, the interview schedule was initially developed in response to a period of consultation with young carers during the preliminary phase. This served to highlight major themes and concerns that merited further investigation. At this stage, the interview questions were broad. Thereafter, the schedule was amended on a continuous basis to embrace developing concepts and ideas and thus, the interview questions became increasingly focused (the interview schedule in Appendix 10 reflects a version utilised in later interviews). In illustration of this, in questions around definitional issues, participants in the first phase were initially asked '*What does the term 'young carer' mean to you?*' However, as an understanding and concepts relating to this area evolved, the question was altered to reflect this: '*Do you feel that the term young carer is used to mean something other than a young person caring for someone else at home?*' This increasingly

focused questioning also reflected the interviewing process prescribed within a grounded theory approach (Strauss and Corbin, 1998).

Lastly, in practical terms, participants were consulted with regards to the location and timing of the interviews. As well as being good practice in terms of embracing the notion of partnership in decision-making and control, it was important that the young carers felt as comfortable and relaxed as possible, to allow them to participate fully. In the first phase, seven of the ten participants chose to be interviewed at their home, and the other three, at their local young carers' project. Home visits maximised observational opportunities and the gathering of supplementary data, particularly as family members were also very often around. Within the second phase, none of the interviews were undertaken at home. This reflected the expressed preferences of the participants, which was underpinned by concerns that sensitive information could have been overhead by parents. Alternatively, a range of locations were utilised including agency premises and schools. Within both phases of the research, the interviews with the young carers were tape recorded and subsequently transcribed in full.

Direct and Participant-Observations

Observation has been stated as the preferred method of researchers working within the interactionist tradition, as it has been asserted that an understanding of people can be most successfully derived from what they *do*:

> ...we need to see what they see and see or observe how they act... (Mead, 1962, p.134).

Thus, an understanding of what others 'do' perhaps can be best facilitated through observing and partaking (Crooks, 2001). Nevertheless, within this tradition, the importance of interviewing to access data has also been noted (Charon, 1995). Within the first phase of the study, a variety of direct observations and participant-observations were undertaken, which involved individuals and groups of young carers in a variety of informal settings. These were conducted both prior to and following the interviews usually as opportunities arose. However, when the

researcher was an active participant in the observations, she directed the discussions with the participants. Due to convenience, the observations were sometimes undertaken in the researcher's capacity as a volunteer worker, particularly at weekly homework group sessions at the young carers centre, at a residential weekend away and in the young people's own homes. Nevertheless, the observations were as unobtrusive as possible. These proved useful in a number of ways: firstly, they informed the general direction of the study; secondly, they facilitated opportunities to build or foster rapport with those subsequently interviewed; and thirdly, they served to corroborate the other data gathered, particularly during the interviews which further developed the themes and categories. Where observations provided contradictory evidence, this triggered a re-examination of the data.

In the second phase of the study, opportunities to observe the participants were limited. This was because the researcher was not involved with the young people in a work-related capacity and thus, opportunities did not arise to observe. Secondly, the researcher did not have any opportunities to observe them in their home environments as there were concerns about the researcher's safety and the participants all expressed a wish to be seen outside their homes. Nevertheless, as facilitated by the researcher's social work training, observations of the actions and body language of the participants were made throughout the interviews. This was useful insofar as it offered an indication of their inner feelings and the congruence between these and the interview data. Thus, the observations undertaken in both phases acted as a valid source of knowledge and a source of triangulation.

Before discussing the utility of the observations undertaken, it must be highlighted that in line with good ethical practice, the researcher's role as observer was wholly overt (SRA, 2003; BSA, 2002; BASW, 2003) and thus, each participant was fully informed of the purpose and process of the observations prior to taking part in the study. Indeed, it has been suggested that covert observation is appropriate in only very limited situations:

...covert observation and any other forms of research which use deception can only be justified where there is no other ethically sound way of collecting accurate and appropriate data (SRA, 2003).

Although undertaking overt forms of observation avoided ethical concerns relating to informed consent and privacy, it perhaps did to an extent affect the findings as particular young people appeared to 'perform' when observed. To address this concern, the majority of the observations that were made by the researcher were direct, rather than as a participant. It has been suggested that covert methods may be used in circumstances where individuals change their behaviour patterns when observed (BSA, 2002). However, the need to respect individual privacy and informed choice far outweighed any benefits to the research in obtaining data using covert methods.

Diary Method

In addition to the methods already outlined, participants involved in the first phase of the study were also requested to complete a diary for a period of seven consecutive days prior to their interview. In terms of this, they were asked to record their caring responsibilities and their resultant thoughts and feelings (see Appendix 11 for an excerpt of the diary utilised). Thereafter, these were reviewed and discussed with the participants during the interviews. Of the ten participants involved in the first phase, six submitted a completed diary.

As has been successfully demonstrated within other studies which have utilised this method (Hilton, 1989; Coxon, Davies and McManus, 1990), diaries can access '...rich illustrative material...' (Oppenheim, 2001, p.252), which justified their usage in the current study. Whilst they had been employed to gain information about young people's caring roles and the impacts that these had, they transpired to be of minimal utility. In terms of this, the material accessed was limited as diary entries were sparse. It also became apparent that within these entries, the participants had under-estimated the extent of their caring roles and

the impacts that these had on other domains within their lives. In illustration of this, several participants stated that caring had little impact on their education, but later in the interviews, revealed regular absences or concentration difficulties at school. Such issues were reflective of the general difficulties associated with the diary method:

> ...the researcher must remember that he or she can never be sure that what the informant says represents the full story. This uncertainty is greatest for events that occur so regularly and routinely in the life of the person or group that they elude awareness (Lindlof, 1995, p.166).

Thus, due to their limited value in the current study, the diary method was discarded in the second phase.

The Rosenberg Self-Esteem Scale

In addition to the semi-structured interviews, a further quantitative tool utilised within both phases of the study was The Rosenberg Scale (Rosenberg, 1965), a ten-item self-completion self-esteem scale (see Appendix 12 for a copy of The Rosenberg Scale used). This scale was designed to gauge feelings of global self-worth or self-acceptance, rather than domain-specific self-esteem or particular aspects of the self, such as school performance or physical appearance. This particular dimension of the self was selected for study rather than alternative constructs such as self-efficacy[8], because of the reported correlations between low self-esteem and other problems commonly reported by young carers, including social anxiety, depression and loneliness (Peplau and Perlman, 1982; Blascovich and Tomaka, 1991; Brennan and Shaver, 1995). Within the current study, The Rosenberg Scale was employed firstly, to consider the proposition that young carers generally experience lower self-esteem than young people without caring roles and secondly, to gauge whether there were any differences in young carers self-esteem according to different caring contexts. The data produced by this tool also acted as a source of triangulation, as scores were compared with other data

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[8] 'Self-efficacy is the 'belief in one's capabilities to organise and execute the courses of action required to manage prospective situations' (Bandura, 1995, p.2)

indicative of feelings of self-worth, such as statements made by participants in the interviews and observations.

This particular measure was selected rather than an alternative scale on the basis of its brevity, suitability for usage with adolescents and good reliability and validity (Blascovich and Tomaka, 1991), as well as its remit in assessing global self-esteem (overall feelings of self-worth) rather than specific elements of self-esteem (such as self-worth deriving from personal appearance or athletic abilities). The latter issue was fundamental considering that the objective was to assess general feelings of self-esteem rather than those relating to specific aspects. However, as self-esteem can be considered context-specific, this differs according to one's situation. For instance, perhaps the young carers exhibited different levels of self-esteem at school, at home, and in social contexts and thus, within the current study, the findings produced by this measure may have been affected by factors such as the interview location. In practical terms, The Rosenberg Scale was completed by 26 of the 30 participants immediately after the interviews, which allowed them to clarify any issues concerning the scale with the researcher. Four individuals declined to complete the test.

Critical Appraisal of the Choice of Methods

In terms of the methods selected, it was fitting to use interviews, observations and the diary method as these were open-ended and exploratory in nature. This was congruent within the constructive-interpretive approach which guided the study. Whilst The Rosenberg Scale was more positivist and deductive in nature (as it was used to 'test' the proposition that young carers experienced lower levels of self-esteem than other young people), this tool was used to collect more standardised data, which was deemed appropriate due to the following reasons. Although the study was inspired by a constructive-interpretive approach, it was not constrained by it and thus, it was suitable to adopt an eclectic or mixed methods approach in order to gain knowledge. Additionally, in relation to the broad area of interest concerning young carers' health, it was appropriate to assess

the proposition that young carers experience low levels of self-esteem and this measure adequately achieved this.

Data Analysis Methods Used

Within this section, analysis of the interviews will be discussed initially because this was the principal method used and provided the richest source of data. This will be followed by a discussion of the analysis of the subsidiary methods employed.

<u>Analysis of Interview Data and the Utility of Grounded Theory Procedures</u>
The form of thematic analysis prescribed by the grounded theory approach was used in the current study. Unlike many other qualitative approaches, this offered formal tools and procedures to aid both data-collection and analysis (Bryman, 1992; Strauss and Corbin, 1998), which was viewed as particularly useful. As stated, the researcher was fully aware that her own biases, preconceptions and knowledge of relevant literature could have influenced her analysis of the data. However, the tools offered served to guard against this by sensitising the researcher to what was actually in the data and thus, improved rigour in terms of the analytic process and the findings. Moreover, the prescribed techniques allowed the researcher to explore the conditions, contexts and relationships pertaining to the themes within the data, rather than regarding and presenting these as disjointed entities. This facilitated a deeper and more holistic understanding of the young carers' worlds. Lastly, the availability of formal tools enhanced the confidence of the researcher in undertaking the analytic process.

Some of these tools and techniques were used throughout the process of analysis whilst others were adopted at particular points in the main coding stages - 'open coding', 'axial coding' and 'selective coding' (Strauss and Corbin, 1998). The particular procedures and issues pertaining to each of the three coding stages will be outlined, followed by a brief description of the application of specific tools employed throughout the process. On a practical level, 'NVivo', a computer-assisted programme based around a grounded theory framework, was used to

facilitate the collection, coding, organisation and reporting of data obtained from the interviews and observations.

The Main Coding Phases

The main coding stages within the grounded theory approach - 'open coding', 'axial coding' and 'selective coding' - were loosely followed and cumulatively involved 'reducing', 'elaborating' and 'relating' data in order to 'conceptualise' (Strauss, and Corbin, 1998, p.8). Whilst these are outlined here as a somewhat systematic and linear process, it is important to highlight that these were used flexibly and creatively.

Open Coding

Initially, the interview transcripts were subjected to 'microanalysis' (Strauss and Corbin, 1998, p.105) or coded openly, line-by-line and word by word, to identify 'chunks or units of data…as belonging to, representing, or being examples of some more general phenomena…' (Spiggle, 1994, p.493). Whilst microanalysis was critical within the early stage of analysis to get a feel for what was in the data, such intricate analysis on thirty lengthy transcripts was highly time-consuming. Also, this process created a degree of confusion as individual words which were highlighted as representative of particular concepts, became lost when out of the context of the surrounding paragraphs.

Thereafter, the data was organised according to emerging ideas and categories. These categories were then further delineated according to their 'properties' (or key characteristics) and 'dimensions' (or the variations within the properties) were identified (Strauss and Corbin, 1998, p.57). In illustration of this early coding process, all of the text in the interview transcripts which referred to 'definition' was placed under a heading and labelled *'definitional issues'*. This code was then further delineated according to the properties and dimensions which related to this. For instance, the property *'definitional ambiguity'* represented confusion and ambiguities surrounding the definition of 'young caring'. In terms of this, a particular issue related to an *'association of the term with membership of a young*

carers group', to which there were varying degrees of association, from *'complete association'* to *'no association'*. An awareness of these evolving concepts informed the direction of the interview questions, which in turn produced data which refined the categories.

Axial Coding

The initial stage of open coding was followed by axial coding, or coding around the 'axis' or core of a category. This involved developing the relationships between and across the identified categories at the level of their properties and dimensions. The purpose of this was to facilitate the exploration of conditions and consequences relating to the phenomenon studied (Strauss, 1987; Strauss and Corbin, 1998). In illustration of this, it was necessary to establish the nature of the relationships between the various major categories identified - such as *'educational difficulties'* and *'problems with social life'* - and their subcategories. It transpired that both of these categories were underpinned by the young carer *'worrying about the parent'* whilst away from home. Such worry ranged in intensity from *'extreme and constant'* to *'low and sporadic'*.

Selective Coding

The final phase of analysis involved further refining the categories and finally integrating these into a larger theoretical scheme (Strauss, 1987). This was achieved by determining a central theme or a 'core category' to which all of the other categories could be related (Merriam and Simpson, 1995; Goulding, 1999; Byrne, 2001; Jeon, 2004).

Nevertheless, identifying a central category proved a challenging process, as several of the categories appeared pivotal to the others. Again, this process was facilitated by a procedure specific to this approach, which consisted of a list of criteria used to determine centrality (Strauss, 1987). Conditions stated within this included *'frequency of mention'* and *'high connectedness'* (Strauss, 1987). This allowed the strength of the relationships between the potential central categories and all of the other categories to be critically assessed (Strauss, 1987). The

outcome was the identification of both a 'core' and a 'near-core' category (Strauss, and Corbin, 1998, p.270). The core category which was identified - 'Hidden-ness' – was central to the majority, but not all of the other categories. In particular, this related to the invisibility of the young caring role; the invisibility of particular parental conditions, namely mental health problems and substance misuse; as well as the unquantifiable and hidden nature of particular roles and tasks. The 'near-core category' which related to the concept of 'Parental Needs as Priority' over the young carers own needs, served to explain and link all of the remaining categories, particularly the difficulties presented by the young carers across areas such as their education and social functioning.

Furthermore, the process of uncovering a core and near-core category was facilitated through the usage of 'NVivo' (QSR, 2002). In particular, the 'modelling' function enabled the development of diagrammatical representations of the categories and the relationships which existed between these (see Appendix 13 for an illustrative example of a model showing the relationships between the various categories).

Tools and Procedures Utilised Throughout Analysis

In addition to the tools which pertained to specific stages within data analysis, various other procedures, characteristic of the grounded theory approach were employed throughout the analytic process. These included the constant comparative method, memo-writing and the analysis of specific words and phrases to uncover meaning. These will now be discussed in turn.

The Constant Comparative Method

Firstly, and of utmost importance, was the constant comparative method. In terms of this, concepts and ideas were categorised according to similarities and differences, which were uncovered through the making of constant comparisons (Glaser and Strauss, 1967; Goulding, 1999; Spiggle, 1994). This was facilitated by the asking of key questions whilst scrutinising the data, such as 'what is happening here', 'why' and 'what accounts for this', 'what patterns are evident',

'what else could be going on here' and in 'what circumstances did particular incidents occur' (Strauss and Corbin, 1998, p.128). This involved scrutinising the interview transcripts for terms such as 'since', 'due to', 'when' and 'because' (Strauss, and Corbin, 1998, p.128), a process assisted by the search facility in 'NVivo'. Essentially, this allowed the researcher to see what was grounded in the data and to develop concepts and categories based on this (Jeon, 2004) and to remain open-minded, rather than blinded by her own preconceptions and biases (Allan, 2003). In turn this served to refine the research questions. For instance, initially it had appeared that the young carers strived to 'fit in' with their peers, but on closer inspection of the data it became apparent that some merely wished not to 'stand out' from others. On reflection, the researcher's interpretation of this had been influenced by her own professional experience and knowledge of similar issues outlined in the literature.

Memo-writing

Secondly, memos were noted throughout the process to record analytical ideas and thoughts, which were then used to map out and develop a theoretical scheme (Goulding, 1999). Additionally, memo-writing allowed the researcher to explicate her own knowledge and assumptions and the ways in which these could impinge upon the interpretation of the data. However, one drawback of recording multiple memos on each individual related to keeping track of these due to the sheer volume which were gathered.

Waving the Red Flag

Thirdly, an important tool utilised - 'waving the red flag' (Gibbs, 2002, p.97), involved scrutinising the interview data for explicit signs of bias exhibited by the participants. In terms of this, terminology such as 'Always', 'Never', 'Everyone', and 'No Other Way' was suggestive of partiality in terms of the participants accounts (Gibbs, 2002, p.98). In illustration, it appeared that the participants were downplaying the level of impact experienced as a result of their caring responsibilities. Indeed, by utilising this tool through searching the transcripts for the suggested key terms, repeated references to 'always' and 'never' within

several interview transcripts was evident. This suggested that some of the participants had presented a somewhat incomplete or more optimistic representation of their situations. Thus, such statements were observed with a degree of caution. For instance, several young carers stated that they were 'never' absent from school, yet at later points during the interview revealed caring-related absences. (See Appendix 14 for a copy of a coding report which shows excerpts of a transcript and the categories developed and assigned in relation to this).

Analysis of Data from the Subsidiary Methods

As mentioned previously, the subsidiary tools utilised in addition to the interviews, were observations, diaries and The Rosenberg Scale. As supplementary methods their main purpose was to offer triangulation.

Analysis of the Observation Data

Firstly, in relation to the direct and participant-observations, detailed notes were scribed both during and after each session and later scrutinised for ideas and concepts similar to those derived from the interview data. In addition to data which appeared to support emerging ideas and concepts, the value of contradictory ideas was also recognised in terms of refining the 'properties' and 'dimensions' of the categories developed. For instance, growing evidence suggested that the presence of a second parent at home, acted as a protective factor in terms of minimising the extent of the caring responsibilities assumed by young carers and the impacts of these. This notion, however, was later challenged by the findings of one particular interview. In terms of this, the young carer described both major caring responsibilities and impacts resulting from his role, even though he had a second parent at home. Nevertheless, it transpired that his parent was unwilling to take on any caring responsibilities and thus, had assigned these to him. On the basis of this and later findings, it was discovered that in addition to the presence of a second parent at home, the availability of that parent to provide care was fundamental. Additionally, notes were made during and after the interviews regarding observations of the participant's behaviour and body

language, which in some instances, offered an indication of the congruence between what they communicated verbally and their inner feelings.

Analysis of Diaries

Secondly, whilst of limited utility, the qualitative comments in the diaries used in the first phase of the study were scrutinised for elements that supported or indeed, contradicted the findings from the interviews. These were noted in turn.

Analysis of the Rosenberg Scale

Thirdly, The Rosenberg Scale, completed by 26 of the 30 participants, was scored according to the specific guidelines for this measure. This suggested that the ten questions which were responded to according to a four-point scale (from 'strongly agree' to 'strongly disagree'), should be graded and assigned a score from a potential of thirty. The suggested average score for all age groups is twenty-two, with scores between fifteen and twenty-three indicative of moderate self-esteem (Heatherton and Wyland, 2003). Following this, the results were further scrutinised using a computer-assisted statistical analysis package, 'Statistical Package for the Social Sciences' (SPSS) (SPSS, 2004). This was used to consider the overall scores for each individual and the entire group, as well as the scores for each of the ten questions. These were then compared and contrasted according to the three different caring contexts.

3.7 Establishing 'Trustworthiness' in the Research Process and Findings

Rigour, or the credibility and trustworthiness of the research process, the researcher and the findings, was increased through various measures. These included being aware of and countering the effects of subjectivity as far as practicably possible; the use of grounded theory methods (such as coding, memo-writing, undertaking constant comparisons); the triangulation of data and cases; the development of an 'audit trail' or explicating how the findings emerged (including a clear indication of procedural modifications made during the research

process); as well as cross-checking the interpretations made by the researcher with participants and other researchers. The rationale underpinning the 'member-checking' sessions and the process involved will now be described.

Member-Checking Sessions

Acutely aware that the interpretations made were influenced by the researcher's own professional background, knowledge and experience, it was necessary to verify that these actually reflected the descriptions and lived realities of the participants (Glesne and Peshkin, 1992). In terms of this, 'member checking' sessions (Lincoln and Guba, 1985; Riley, 1996), were undertaken with fifteen - or half - of the original participants. Within these sessions, the findings and interpretations were presented, but the actual theories developed were not, as these would lacked meaning to the individuals (Goulding, 1999).

As had been agreed during the fieldwork stage, the young people were contacted directly and asked to participate in the validation sessions. As previously explained, it was not feasible to involve all of the original participants in this process, as several of the young people had relocated to other geographical areas or had ceased contact with the referring agency.

The fifteen young carers involved were organised into three groups of five and each met on a single occasion with the researcher, within a different geographical area. Each group was mixed in terms of gender, age and caring context and consisted of both those referred to the study by young carers' organisations as well as other agencies. Thus, the young carers in each group were largely unfamiliar with one another.

Much thought and reflection was put into the format and delivery of the member-checking sessions. Firstly in term of the format, whilst validation could have been achieved with participants on a one-to-one basis, holding group sessions was assessed as being more suitable. As well as being much more time-efficient, the group milieu also allowed for the interpretations to be cross-checked in a holistic

sense and enabled the sharing, reflection and development of ideas amongst the participants. Indeed, whilst one-to-one sessions would have allowed more privacy, the lack of this did not appear to hamper discussion, personal reflection or disclosure amongst the group members. In some respects, the level of openness noted was remarkable, particularly as the members had previously been unfamiliar with each other. However, this perhaps reflected the highly supportive nature of each of the groups.

Moreover, the delivery of the sessions also perhaps facilitated this open-ness. These were designed to be as non-threatening and relaxed as possible. For instance, as the majority of the participants within each of the groups had not known each other previously and had limited contact with the researcher, an 'ice-breaker' task was undertaken at the start of each session. This was based on a 'therapeutic' board game 'All About Me' [9] (Barnardos, 1991). Although normally played with children and young people as a board game to facilitate the exploration of painful personal experiences such as death and divorce, several cards were pre-selected by the researcher to facilitate discussion. Each individual (including the researcher) chose a card and was asked to complete various statements about their experiences. These included, "My best ever day was...", "My best thing at school is..." "My worst thing at school is..." and "The best thing about my mum/ dad is..." Whilst this did not necessitate the young people to discuss their caring roles, the majority actually did as the game progressed. For instance, several of the young people stated that the best thing at school was getting a break away from home. Thus, as well as building rapport, the 'ice breaker' served to confirm several of the key interpretations.

Following this, three case studies were introduced and used to instigate discussion. Whilst these were based on fictional young carers, they incorporated some of the key issues which related to the findings. This method worked well.

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[9] A board game designed to be used within a therapeutic relationship to address painful experiences in a non-threatening way. Players select cards and respond to the printed statement, to progress round the board (Barnardos, 1991).

Using fictional cases removed any expectation on the young people to discuss their own situations, which in turn appeared to enhance rapport and their open-ness. Indeed, the young people largely related the key points within the case studies to their own situations and discussed these. In the majority of the cases, the interpretations made were accurate and were deemed by them to reflect their own experiences or accepted as perhaps relating to other young carer's situations. This also served to develop some of the categories, particularly around the other socio-economic factors which partly underpinned the problems, issues and experiences originally attributed to caring. However, some of the findings were recognised as being highly sensitive and were approached with caution by the researcher, particularly the notion of parental-child role reversals.

In retrospect, perhaps the member-checking sessions could have allowed the young people an opportunity to remark on which verbatim quotations they wished to include in the thesis and how they wanted these to be presented, particularly in terms of their use of colloquial language. However, as only half of the young people were involved in the sessions, it would not have been possible to get feedback from all of the participants in relation to this.

As it was not practicable to involve all of the participants in these member-checking sessions, additional means of validating the findings were employed. Perhaps individual reports could have been sent to all of the participants for comments. However, perhaps it was unlikely that the young people would have read these and returned their comments. Also, on a practical level, the contact details of some of the young people (particularly those that had moved on) were unknown. Accordingly, to address this, the interpretations and theories developed were discussed with colleagues from both within and outside the university, including the researcher's Ph.D. supervisor, as well as delegates and members of a postgraduate forum at a national sociology conference. In addition, sections of five randomly selected transcripts were scrutinised and coded by a fellow qualitative researcher. A comparison between these revealed only very slight differences, but the alternative meanings offered and the reasoning for these were

reflected on and discussed. Lastly, the key findings and interpretations were discussed with five of the professionals who had referred young people into the study. This allowed open discussion of some of the more sensitive issues, particularly around parental-child role reversals, as well as the theories developed. Interestingly, all five agreed with the interpretations made, which was perhaps reflective of their social work backgrounds.

Issues of Generalisability

However, in relation to generalisability, due to the small sample size and the non-random sampling methods employed, no firm assertion could be made regarding the transferability of the data. Whilst the sample was not representative of young carers in general, this did produce valid and reflective accounts of the experiences of the participants. This implied a wider, shared experience among young carers that requires further investigation.

3.8 The Presentation of the Findings within this Thesis

The findings were presented according to the major issues discussed by the participants and were based on the data gathered through all of the tools utilised. Thus, data from the interviews, the observations and the limited material accessed through the diaries were all used. However, the verbatim quotations presented were from the interviews only, as the other forms of data-collection did not lend themselves to record the spoken words of the young carers in verbatim fashion. For instance, the observations were not tape-recorded as the aim was to ensure that these were as non-invasive and naturalistic as possible. The findings of The Rosenberg Scale can be found in a separate sub-section.

Whilst this was a qualitative study, basic numerical data has also been included. Specifically, the responses made to particular questions were quantified in order to give an indication of the extent or scale of particular issues. The corresponding numbers have been presented both in narrative form and within tables. However, in no way did this represent an attempt to demonstrate generalisability, as the

findings of this study were socially, rather than statistically significant. For instance, a category was developed either because it presented in the data numerous times or in relation to most of the participants or because it was assessed as being analytically powerful even where it presented only once or a few times.

Justification for the Inclusion of Verbatim Quotations

It has been suggested that verbatim quotations in qualitative social research can be used for one or more of the following purposes: as the matter of enquiry; as evidence; as explanation; as illustration; to deepen understanding; to give participants a voice; and to enhance readability (Corden and Sainsbury, 2006). Within this thesis, quotations were used for one or more of these reasons at different points throughout the findings chapter.

Principally, they were used for two reasons: to explain how the participants made sense and understood their own situations in their own words and to illustrate and provide evidence of the interpretations and categories developed by the researcher. Indeed, in terms of the latter it was felt that the inclusion of verbatim quotations allowed the reader to determine the accuracy of the interpretations made which thus, enhanced both the transparency and credibility of the research and the researcher. It has been questioned whether verbatim statements should be presented as evidence as there may always be scope to find a statement to fit a point made (Corden and Sainsbury, 2006). This however, was countered by a commitment to present the findings in an honest and transparent manner.

Also, at various points, quotations were selected in order to deepen the understanding of the reader. This was deemed particularly important where participants discussed issues in highly emotive terms which could not have been captured adequately within the researcher's own narrative. Lastly, the quotations served to enhance the readability of the entire chapter by breaking up large chunks of text and adding some colour and interest.

Presentation of the Quotations – What Was Included

Various considerations were taken into account in selecting which and the number of quotations used. Firstly, in relation to some categories, the number of quotations presented could have been selected to reflect the 'balance of feeling' amongst the participants, an approach advocated elsewhere (Corden and Sainsbury, 2006, p15). Thus, perhaps five statements from different participants could have represented a majority viewpoint and one for a minority stance. However, this would have been impracticable as the statements would have occupied too much space. Instead, a maximum of three quotations were selected to illustrate various points. Where two or three quotes were presented, this was because either cumulatively they served to deepen understanding or each offered a different emphasis in relation to the same point. Additionally, to promote an inclusive approach it was important to incorporate quotations from all of the participants. This also ensured that the voices of those participants who were perhaps less articulate were included.

In terms of the practical selection of the quotations, initially those interesting or apparently significant points were grouped and then developed into categories. Each of the statements across the participants which related to particular categories were then pulled out and listed. This process was facilitated through the usage of the mapping function within NVivo. This enabled the development of a visual representation of the categories and the relationships between the categories, which were then cross-referenced with one or several verbatim quotations from the transcripts.

Presentation of the Quotations - How These Looked

In addition to deciding which quotes to use, it was also important to consider how these should be presented and attributed. In terms of presentation, one of the key decisions concerned the extent to which the statements should be edited in relation to colloquialisms and expletives. It was recognised that such editing would be inappropriate in relation to some approaches such as narrative or biographical analysis, (Corden and Sainsbury, 2006). Within the current context, however, it

was appropriate to conduct a *'light tidy up'* (Corden and Sainsbury, 2006, p18). This served to enhance legibility and preserve the confidentiality and anonymity of the participants and others that they referred to. However, as the verbatim quotations were used as evidence, explanation and illustration, such editing was kept to a minimum in order to prevent distortion of the participants' voices. Thus, firstly, and most importantly, identifiers such as the names of people and places referred to were replaced with a general explanatory term contained within a square bracket and secondly, 'ums' and 'erms' were removed as these offered very little in terms of understanding and were judged as making somewhat tedious reading. Whilst none of the participants spoke in the regional dialect 'doric', some did use colloquial terminology. Such terms were included in the verbatim statements in order to minimise any distortion of the young people's voices. In recognition of this, it has been stated that:

> ...if research participants would not recognise words as their own, this would be wrong, even though it was unlikely that they would actually see the report... (Corden and Sainsbury, 2006, p19).

Additionally, in terms of the presentation of the verbatim statements, firstly, these were indented within the text to demarcate them from the surrounding narrative; secondly, punctuation marks were used to enhance readability and thirdly, ellipses (three dots) were used where one or more words, unrelated to the point being made, had been removed. For instance, often in their narrative, the participants momentarily diverted from a particular point and then returned to this.

Lastly, the attributions used at the end of each verbatim quotation included the pseudonym assigned to each participant, their age, the parent they were caring for and the caring context. It was recognised that these attributions assigned to the words of the participants could have potentially compromised their anonymity (Corden and Sainsbury, 2006) and thus, it was necessary to reflect on the information actually required by the reader. In terms of this, firstly, attaching a name (pseudonym) to each participant and presenting this in relation to each statement was deemed as a helpful. This provided the reader with a sense of

continuity in relation to each participant and also demonstrated spread, in terms of the use of the participants' words. The caring contexts were highlighted as this was central to the aim of the investigation and age was also deemed significant in terms of the analysis. Whilst the gender of the participants was not explicitly stated in the attributions provided, the pseudonyms selected by the researcher were gender-specific.

In retrospect, some of the key issues in relation to the use and presentation of verbatim statements could have been addressed through discussions with the actual participants. Whilst each participant was informed that their own words would be used to illustrate various points, further discussion around this could have been undertaken in the validation sessions which were used to explore and verify the accuracy of the researcher's interpretations. For instance, the participants could have taken a more active role in the selection of the quotations used and the extent to which these were edited.

3.9 Conclusion of the Main Points from the Methodology Chapter

In conclusion, the methodology and methods within the current study were influenced by the epistemological position of the researcher and her own 'personal biography', as well as the assessed utility and appropriateness of different methods in addressing the aim and scope of the study and a range of ethical considerations. The study was firmly grounded within the qualitative domain and influenced by a constructive-interpretive paradigm, specifically, symbolic interactionism. As congruent with this overall approach, the study employed grounded theory methods to facilitate the collection and analysis of data. This involved using both multiple participants and multiple methods, which included semi-structured interviews, diaries, observations and The Rosenberg Scale. This enabled triangulation as well as the full exploration and development of key ideas and categories which arose from the data. The specific tools prescribed by this approach facilitated both a high degree of creativity and

flexibility, whilst making the process manageable. Arguably this proved to be a useful combination for a novice researcher.

Critically, these tools also served to sensitise the researcher to her own biases and to actually see what was in the data, rather than being blinded by these preconceived notions. This was particularly important given the researcher's own professional background in the field and her knowledge and familiarity with the subject area and some of the participants. Whilst in some ways the researcher's position, knowledge and experience was useful in terms of gaining access to participants and developing rapport, it was important to be clear about her role and purpose within the study. This meant that the relationships already established with some of the participants had to be renegotiated in line with the research context.

Essentially the approach adopted ensured that as far as possible, the findings were valid and reflective of the lived experiences of the participants. Indeed, the credibility and trustworthiness of the research, the researcher and the findings were increased through the adoption of various measures. Nevertheless, it was not the aim of the study, nor was it possible to provide findings that were generalisable across the entire population of young carers. Indeed the study relied on non-probability sampling methods because of inherent difficulties accessing a random population of young carers. The difficulties recruiting young carers into the study necessitated changes to the design of the study, which required a high degree of flexibility and creativity on the part of the researcher.

Chapter 4 – The Key Findings of the Current Study

4.1 Introduction to the Findings Chapter

As outlined, of the 30 young carers involved in the research, ten were caring for parents with physical disabilities, ten for parents with mental health problems and ten for parents with problem alcohol use or drug use. Whilst it had been planned to consider a further 'category' – parents with learning difficulties – it was not possible to pursue this, as only one young carer in this context could be recruited. Additionally, a range of professionals working with young carers and/ or families with parental learning difficulties were contacted to provide an insight into some of the issues around this. Nevertheless, as stated, as the study was interested in young carers' own understandings of their worlds, it was not appropriate to present this data alongside that from the young carers themselves. Thus, a summary of the findings based on the interviews with the professionals, along with an outline of the case of the sole young carer in this context can be found in Appendix 9.

Accordingly, the present chapter will outline and explore the following issues. Firstly, a critical reflection on the interpretation process will be offered. Thereafter, the 30 young carers involved in the study will be described in terms of their personal, family and caring characteristics. This will be followed by the presentation of the main findings, discussed according to four main themes: 'Young Caring in Context'; 'Definitional Issues'; 'Problematic Issues Resulting from Young Caring' and 'Parental-Child Role Reversals'. Significant differences in the findings according to the caring context, the gender and age of the young carers and situational factors such as the presence of support networks, will be highlighted where apparent.

4.2. A Critical Reflection on the Interpretation Process

As the researcher occupied the pivotal position of the principal data gathering tool, it was important to critically consider the impact that this had in terms of the interpretations process. On the one hand, the interpretations were evidence-led and derived from what the participants had communicated. On the other hand, these were filtered through the researcher's own understanding and interpretation of the world. Thus, the process was influenced by the researcher's perspective and her personal biography, particularly her background in social work and professional experience working with young carers. For instance, the researcher's experience and knowledge which derived from this, explained why particular conditions were grouped together, under the broad categories of mental health problems, physical disability and substance misuse. Prior knowledge around young caring also explained the origins of the core category of 'hidden-ness'.

Nevertheless, it has been accepted by proponents of the grounded theory approach that researcher's experience and knowledge can serve to sensitise them to what is in the data. Moreover, throughout the process, the researcher reflected on the potential influence of her own assumptions and biases. Reflective memo-writing greatly facilitated this process. Being aware of her subjectivity ensured that biases could be identified and countered as far as possible and essentially served to generate trustworthy interpretations (Glesne and Peshkin, 1992). Lastly, and most fundamentally, the trustworthiness of the interpretations was assessed through several methods. This included validating the interpretations through 'member-checking' with the participants, adopting multiple methods and cases to allow triangulation; utilising the constant comparative method throughout data-analysis; and presenting the theories developed to relevant professionals. Essentially, this enabled the interpretations to be judged according to criteria such as thoroughness, coherence, comprehensiveness, credibility, dependability, confirmability and utility.

4.3 Young Caring in Context – a Profile of the Participants

As already outlined, the research focused mainly on the individual accounts of a mixed group of young carers. As will be described, they differed in terms of their caring contexts, as well as a range of other variables including gender, age, family structures, housing and socio-economic status. Details pertaining to each individual are available in Tables 4.1, 4.2 and 4.3, and are also summarised below.

Caring Contexts

In terms of the thirty participants, the group comprised of 10 young people in each of the following caring contexts: parental physical disability; parental mental health problems and substance misuse (problem alcohol use and/ or drug use). The majority of the young people – 22 – were caring for their mother; five for their father and three for both their mother and father.

Gender, Age and Ethnicity

Within the sample of young carers, there were 10 males and 20 females. This was not reflective of the actual gender divide in relation to young carers, as large-scale, national surveys have found a relatively equal proportion of male and female young carers. Moreover, the gender divide was unequally distributed across each of the three caring contexts. In relation to physical disability, there were five males and five females; in terms of mental health problems, there were four males and six females; and with regards to substance misuse, there was one male and nine females.

The age range of the participants was broad and spanned from 11 years to 25 years. For the purposes of analysis, the young carers were split into two subgroups according to age – those aged 11-17 and those 18-25. A total of 23 of the 30 participants were aged 11-17 years and seven aged 18-25 years. In terms of ethnicity, all of the young people were white.

Family Structures

Regarding their family structures, 17 of the 30 young carers were living in lone-parent households; five in two-parent households; one in a reconstituted household and seven were living independently of their parent, which included three who resided with foster parents. Of the other four that were living independently, two had previously resided in lone parent households and the other two, with both parents. 25 of the 30 had one or more siblings, although seven of these did not live with any of their siblings.

Housing

The majority of the participants - 21 - lived in local authority housing either with their parents or in their own tenure. Of the others, six lived in privately owned housing, two in homes owned by a Housing Association and one in supported accommodation which provided 24-hour care for his mother.

Education or Employment Status

Of the young carers, 22 were in some form of education. Of these, one was at primary school; 18 at secondary school (two of which also worked on a part-time basis); one attended college and two school leavers were awaiting confirmation of college places. Of the others, four were employed on a part-time basis, one worked full-time, two were non-employed due to their caring responsibilities and one was engaged with a support service which offered vocational training. Two of the young carers in full-time education also had part-time jobs. Of the parents, two of the cared-for parents worked on a part-time basis and in a further two cases, the second parent in the household was employed, one on a full-time basis and the other, on a 'casual' basis. In all of the other cases, the parents were non-employed.

Welfare Benefits

28 of the young people stated that their parent was in receipt of some form of financial assistance or welfare benefit, although only one could categorically

define which benefit and how much they received. The remaining two stated that their parent was not in receipt of any such welfare assistance.

In summary, the sample of young carers in the current study was selected through non-random methods and thus, the findings were not generalisable to all young carers. Nevertheless, key commonalities were noted in terms of the socio-demographic characteristics of this sample and those used in other larger-scale studies, particularly in terms of their ethnicity, family structures and parental employment patterns (Dearden and Becker, 2004).

4.4 Origin of the Young Caring Role

The length of time engaged in caring ranged from two years to 17 years. Five of the 30 young carers were born into households with illness or disability and had been socialised into the caring role from a very early age. Of these four individuals, two were siblings. In all but one of these families, there had been a second parent present, but due to their own ill health or work commitments, they were unable to undertake all of the care required.

A further 14 participants recalled the approximate length of time they had been caring for and also indicated why they had started caring. The main reason offered related to the parent becoming unwell or due to their condition worsening. However, in three cases the caring role was necessitated by the unavailability of the second parent due to a relationship breakdown or their work commitments. This suggested that these young people had been either directed into the caring role by the parent who was unavailable to care or had simply assumed the role due to the unavailability of other sources of care.

As evident, eleven of the young carers had difficulties identifying exactly when they had started caring or how long they had been caring for. This was particularly evident in relation to those caring for a parent with a physical disability or a mental health problem. This could have been linked to the lack of a

firm diagnosis of the parental condition or the chaotic lifestyles associated with parental substance misuse. However, some did refer to specific events as preceding the onset of their caring role, such as their parents splitting up or a second parent seeking employment outside the home. Again, this suggested that they had been either elected into the caring role or had assumed the role due to a lack of other sources of care.

Table 4. 1 - Young Carers of Parents with a Physical Disability

YOUNG CARERS DETAILS

	James~	Peter	Lewis+	Mark+	Raymond	Chloe	Jane	Charlotte	Grace	Jenny~
Age	18	14	21	25	11	13	14	15	25	17
Cared-for Parent	Mother and Father	Mother	Foster-Mother	Mother	Father	Mother	Mother (as well as Father and Brother)	Mother	Mother	Mother and Father*
How long providing care	6 years	Since Birth	5 years	9 years	2 years	Unknown	Since Birth	4 years	10 years	Since Birth
Current education	N/A	Secondary School	N/A	N/A	Primary School	Secondary School	Secondary School	School Leaver – awaiting confirmation of college place	N/A	N/A
Current work	Vocational Training Project	N/A	Works part-time	Works part-time	N/A	N/A	N/A	N/A	Non-employed	Non-employed
Person cared for										
Condition	Mother – M.S.; Father – Back problem and depression	M.S.	M.S.	M.S.	CVA	M.S.	Mother – Epilepsy; Father – Polio; Brother – Autism.	M.S.	Dystonia	Mother – Arthritis and depression; Father Cancer and depression.
Current work of parent and parental figures in household	Non-employed	Non-employed	Non-employed	Non-employed	Non-employed	Non-employed	Mother – Part-time and (Father - full-time)	Mother: not employed; (mother's partner – employed on casual basis)	Non-employed	Non-employed
Housing	Local Authority	Supported Accommodation	Housing Association	Housing Association	Private	Local Authority	Private	Local Authority	Local Authority	Local Authority
Family Members Living with or Significant to Young Carer										
Brother(s)	None	None	Foster-brother (O)	Foster-brother (Y)	None	None	Brother (O)	Brother (O) ~	Brother (Y)	None
Sister(s)	None	Sister (Y) ~	None	None	Sister (Y)	Sisters (Y)	None	None	None	Sister (O)~
Parent(s)	Mother and Father	Mother	Foster-mother	Mother	Mother and Father	Mother	Mother and Father	Mother and Mother's Partner	Mother	Mother

All names have been changed to protect the participants' identities

* now deceased
~ not living with the parent
+ sibling pair
O sibling older than young carer
Y sibling younger than young carer

Table 4.2 - Young Carers of Parents with Substance Misuse

YOUNG CARERS DETAILS

	Caroline~	Pamela	Rose~	April	Katrina	Janice	Julie~	Abbie	Grant	Emily~
Age	23	14	18	16	16	11	15	13	16	16
Cared-for Parent	Mother*	Mother	Mother	Mother	Mother	Mother	Mother	Mother	Mother	Father
How long providing care	Unknown	6 years	Unknown	8 years	10 years	Unknown	7 years	Unknown	Unknown	4 years
Current education	N/A	Secondary School	School Leaver	School Leaver – Awaiting confirmation of college place	Secondary School	Secondary School	Secondary School	Secondary School	Secondary School	College-linked Training Course
Current work	Works full-time	N/A	Works part-time	N/A	N/A	N/A	N/A	N/A	N/A	Works part-time
Person cared for										
Substance	Alcohol	Heroin	Alcohol	Alcohol (and resultant physical condition)	Alcohol and prescription drug	Heroin	Alcohol	Alcohol and heroin	Alcohol	Alcohol
Current work	Non-employed	Works Part-time	Non-employed	Non-employed	Non-employed	Non-employed	Non-employed	Non-employed	Non-employed	Non-employed
Housing	Private	Local Authority	Local Authority	Local Authority	Local Authority	Local Authority	Local Authority	Local Authority	Local Authority	Local Authority
Family Members Living with or Significant to Young Carer										
Brother(s)	None	None	Brother (Y)~	Brother (O)	None	None	Brother (Y)	None	None	Brother (O)~
Sister(s)	Sisters (Y)~	None	None	None	Sister (Y)	Sisters (Y)	None	Sister (Y)	None	Sister (O)~
Parent(s)	Father	Mother	Foster Mother and Foster Father; Mother and Father	Mother	Mother	Mother	Foster Mother and Foster Father; Mother and Father	Mother	Mother	Mother Father

* now deceased
~ not living with the parent
+ sibling pair
O sibling older than young carer
Y sibling younger than young carer

All names have been changed to protect the participants' identities

Table 4.3 - Young Carers of Parents with a Mental Health Problem

YOUNG CARERS DETAILS

	Kayleigh	Cameron+	William	Rachel+	Donald	Douglas	Susan+	Nicole+	Tina	Fiona
Age	15	22	16	15	14	12	13	11	14	15
Cared-for Parent	Mother	Father	Father	Father	Mother	Mother	Mother	Mother	Mother	Mother
How long providing care	Unknown	Since Birth	13 years	Since Birth	Unknown	Unknown	Unknown	Unknown	6 years	10 years
Current education	Secondary School	N/A	Secondary School	Secondary School	Secondary School	Secondary School	Secondary School	Secondary School	Secondary School	Secondary School
Current work	N/A	2 part-time jobs	Works part-time (after-school and weekends)	N/A	N/A	N/A	N/A	N/A	N/A	N/A
Person cared for										
Mental Health Problem	Depression	Schizophrenia	Schizophrenia	Schizophrenia	Depression	Depression	Depression (and physical disability)	Depression (and physical disability)	Depression	Manic-Depression
Current work	Non-employed	Non-employed	Non-employed	Non-employed	Non-employed	Non-employed	Non-employed	Non-employed	Non-employed	Non-employed
Housing	Local Authority	Private	Private	Private	Local Authority	Local Authority	Local Authority	Local Authority	Local Authority	Local Authority
Family Members Living with or Significant to Young Carer										
Brother(s)	None	None	None	Brother (O)	Brother (O)~	Brother (Y)	None	None	None	Brother (O)~
Sister(s)	None	Sister (Y)	None	None	None	Sister (Y)	Sisters (1xO, 2xY)	Sisters (1xO~, 1xO 1xY)	Sister (O)~	Sister (O)
Parent(s)	Mother	Mother and Father	Father	Mother and Father	Mother	Mother	Mother	Mother	Mother	Mother and Father

* now deceased
~ not living with the parent
+ sibling pair
O sibling older than young carer
Y sibling younger than young carer

All names have been changed to protect the participants' identities

Tables adapted from Aldridge and Becker (1993), 'Children who Care'

Role and Tasks of the Young Carer

The roles and tasks described by the young carers could be categorised into six areas: domestic tasks (general housework); cooking; mobility tasks (physically supporting the parent to get around or assisting the parent to utilise mobility aids); nursing care (administering medication and treatments when required); and emotional support. As indicated in Table 4.4 below, 27 of the 30 young carers offered multiple forms of care, with the vast majority undertaking domestic tasks. For instance, James provided three types of care (domestic, nursing and emotional) and as illustrated in the following statement, indicated that he found some tasks easier or more acceptable than others:

> I would help her [mother] with her jabs [injections] and that...I didn't like that though...I would do the cleaning, well sometimes my dad would help and it might be okay and that...the worst bit, was listening to him, and he would sometimes be all quiet and then he'd shout at me and I'd have to try to help him, just get him to calm down and that (James, 18, mother, physical disability; father, physical disability and mental health problem).

Also, there was a link between the nature and 'type' of the parental condition and the types of roles and tasks undertaken. For instance, those caring for parents with a substance misuse or mental health problem were most likely to offer emotional support. All of those caring for parents with a mental health problem and nine of the ten caring in the context of parental substance misuse provided this form of support. This compared to only three caring for parents with a physical disability, two of which (James and Jenny[10]) had parents with dual diagnoses of both physical disabilities and mental health problems. Indeed they attributed their parents need for emotional support to their mental health problem, rather than their physical disability. In contrast, tasks associated with mobility and personal care were most frequently undertaken by those caring for parents

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[10] Jenny and James were identified as caring for parents with physical disabilities. It later transpired however, that their parents had both physical and mental health problems. As a result, the impacts reported may have also related to their parents mental health problem.

with a physical disability. Five of the ten young carers in this context assisted or supported their parent to move around and six of the ten provided personal care. In comparison, fewer participants caring for parents with non-physical conditions were required to undertake such tasks. For instance, only two of those with parents with substance misuse problems assisted with their mobility needs and only one with personal care. In terms of those with parents with mental health problems, one young carer assisted with their mobility and a further one with personal care tasks.

Table 4. 4 - Types of Assistance Provided by Young Carers

	Participants	Domestic	Cooking	Mobility	Personal Care	Nursing	Emotional Support	TOTAL
		TASKS CARRIED OUT BY YOUNG CARERS						
Physical	James	✓				✓	✓	3
	Peter		✓	✓	✓	✓		4
	Lewis			✓	✓			2
	Mark		✓	✓	✓			3
	Raymond	✓	✓					2
	Chloe			✓	✓			2
	Jane	✓				✓		2
	Charlotte	✓						1
	Grace	✓	✓	✓	✓		✓	5
	Jenny				✓		✓	2
Substance Misuse	Pamela		✓				✓	2
	Rose	✓	✓				✓	3
	Caroline	✓	✓		✓	✓	✓	5
	April	✓	✓	✓		✓		3
	Katrina						✓	1
	Janice	✓	✓				✓	3
	Julie	✓					✓	2
	Grant	✓	✓				✓	3
	Emily	✓	✓	✓			✓	4
	Abbie	✓	✓				✓	3
Mental Health	Kayleigh	✓	✓				✓	3
	Cameron						✓	1
	William	✓					✓	2
	Rachel	✓					✓	2
	Donald	✓	✓				✓	3
	Douglas	✓	✓				✓	3
	Susan	✓		✓			✓	3
	Nicole	✓			✓		✓	3
	Tina	✓					✓	2
	Fiona	✓					✓	2

Support Networks

All of the young carers reported that they and/ or their parent received some type of formal or informal support, although the type and number of sources, as well as the quality and regularity of support varied greatly. In relation to both formal and

informal care, the reliability of care sources was an important determinant of its quality. Both formal and informal assistance will now be discussed in turn.

Formal Assistance

As outlined in Table 4.5, various formal support services and professionals were accessed by the young carers, parents and/ or families, including social workers, home carers, community psychiatric nurses (CPN), general practitioners (GPs), counsellors and young carers' workers. The most frequently accessed services were dedicated young carers' projects (accessed by 20 participants) and social work (accessed by 17 participants and/ or parents). Only one young carer indicated that she and her mother received no formal assistance.

Table 4. 5 – Sources of Formal Assistance Received by the Parent and/ or Young Carers

	Participants	Young Carers' Worker	Social Work	Home Care	Home Help	Counsellor	Support Group	CPN	Psychiatrist	GP	Nurse	Foster Parent	Respite	TOTAL
Physical	James	✓	✓P;											2
	Peter	✓	✓P; YC	✓							✓			4
	Lewis			✓	✓						✓		✓P	4
	Mark			✓	✓						✓		✓P	4
	Raymond	✓									✓			2
	Chloe	✓	✓YC	✓					✓YC		✓			5
	Jane	✓												1
	Charlotte	✓	✓YC											2
	Grace		✓P				✓P		✓P	✓P				3
	Jenny	✓	✓YC											2
Substance misuse	Pamela					✓FA								0
	Rose		✓P; YC							✓P; YC				2
	Caroline		✓P; YC											1
	April		✓YC						✓P					3
	Katrina	✓				✓P								2
	Janice	✓				✓P								3
	Julie	✓										✓		2
	Grant	✓	✓YC			✓FA								3
	Emily		✓YC			✓P						✓		2
	Abbie		✓P; YC			✓P								2
Mental Health	Kayleigh	✓	✓P			✓P	✓P	✓P	✓P	✓P				6
	Cameron	✓					✓P	✓P	✓P			✓		7
	William		✓P; YC	✓	✓	✓P	✓P	✓P	✓P	✓P				5
	Rachel													1
	Donald	✓	✓P											2
	Douglas	✓	✓YC											3
	Susan	✓	✓YC	✓										3
	Nicole	✓	✓YC	✓						✓P				2
	Tina	✓						✓P	✓P					2
	Fiona	✓												3

Key
✓   Receiving service
YC Young carers in receipt of service
P   Parent in receipt of service
FA Family in receipt of service

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Interestingly, social work assistance evoked much reaction and discussion particularly in terms of the quality and regularity of the service received, which varied considerably. Where the usefulness of social work support was commented on, this was discussed mainly in terms of negative or unsatisfactory experiences. In comparison, only three described their experiences of social work intervention in positive terms. 'Helpful' social work support was discussed with reference to the practical assistance offered to the young carer and/ or their family. In some cases, this was also viewed as a useful means of accessing other types of help, as highlighted in the comments below:

> The social worker...aye she's helpful, she's great, she helps me with my shopping...and stuff like that (Chloe, 13, mother, physical disability)

> 'Cause like my social worker is hopefully going to maybe find me a job for the time being (William, 16, father, mental health problem)

Where social work support was viewed as unsatisfactory or 'unhelpful' this was mainly attributed to sporadic contact or passive, rather than proactive support as illustrated in the following statements:

> No, I've not seen any of the social workers in a long time (Nicole, 11, mother, mental health problem);

> ...my social worker would come round and that, but she'd only just sit and speak to us (Pamela, 14, mother, problem drug use).

Informal Assistance

As indicated in Table 4.6 below, the majority of the young carers, parents and/ or families were in receipt of some form of informal support from others *outside* the immediate family. However, nine young carers and/ or parents received no such assistance, and five of these also stated that there was no additional support available within the family unit from second parents or siblings. In terms of the sources of support from within the family, eight recognised the contribution of a second parent or parental figure and 15 indicated that one or more of their siblings

assisted. Whilst four recognised that both were sources of support, eleven had neither the support of a second parent nor a sibling.

	Participants	SOURCES OF INFORMAL SUPPORT							
		Help from Family			Help from outside the family				
		Other Parent	Sibling(s)	Total for Family	Grandparent(s)	Aunt(s)/Uncle(s)	Parental Friend(s)/Neighbour(s)	Total for Outside Family	Total for all informal help
Physical Disability	James			0	✓2			2	2
	Peter			0		✓		1	1
	Lewis		✓	1				0	1
	Mark		✓	1				0	1
	Raymond	✓	✓	2				0	2
	Chloe		✓	1	✓	✓		2	3
	Jane	✓		1			✓	1	2
	Charlotte	✓	✓	2	✓			1	3
	Grace	✓		1		✓		1	2
	Jenny			0				0	0
Substance misuse	Pamela			0				0	0
	Rose	✓		1	✓	✓		2	3
	Caroline		✓2	2				0	2
	April	✓		1	✓		✓	2	3
	Katrina			0				0	0
	Janice			0	✓			1	1
	Julie			0				0	0
	Grant		✓	1	✓			1	2
	Emily			0	✓		✓	2	2
	Abbie		✓	1	✓	✓	✓	3	4
Mental Health Problems	Kayleigh			0	✓	✓	✓	3	3
	Cameron	✓	✓	2	✓		✓	2	4
	William			0	✓			1	1
	Rachel	✓	✓	2	✓		✓	2	4
	Donald		✓	1	✓2			2	3
	Douglas			0				0	0
	Susan		✓2	2		✓2	✓	3	5
	Nicole		✓2	2		✓2	✓	3	5
	Tina		✓	1	✓2	✓		3	4
	Fiona		✓	1	✓			1	2

Table 4. 6 – Informal Support for the Parent/ Family

Where provided, informal support was described as being available mainly on an 'as and when required' basis, to assist the whole family. The types of assistance provided included help with domestic tasks, sitting with or 'keeping an eye' on the parent, as well as taking the parent, young carers and/ or other children in the family out, which essentially offered the family respite. In terms of assessing the utility of informal care sources, an important factor related to the proximity of the care source. This was discussed in relation to both 'physical' and 'emotional' proximity. Physical proximity related to the physical distance between the

potential care source and family. Those sources that lived closest to the family were viewed as most helpful, as illustrated in the quotations below:

> ...she's her main contact cause she's the closest, rather than my other auntie that lives in C [coastal village in South Aberdeenshire] it's a lot more convenient (Peter, 14, mother, physical disability);

> And plus she's [grandmother] 600 miles away so she can't do anything (Caroline, 23, mother, problem alcohol use).

In addition, there appeared to be a further association between emotional proximity describing the emotional availability of particular care sources (such as extended family members) and the value of their assistance. In relation to this, four participants described how their relatives had failed to care and had simply 'turned their backs' or 'turned a blind eye' to both the presence of the parental condition and the family's situation. This was perhaps due to factors such as 'courtesy stigma', guilt, embarrassment, or a lack of understanding. This notion was discussed exclusively by young carers of parents with substance misuse problems. Arguably, as substance misuse presents few outward signs it can be concealed and thus, others (such as extended family members) may be able to simply ignore or overlook the situation, as illustrated in the quotations below:

> ...and there's his mother, but she tries to act like she's oblivious to what's going on, so she didn't help him (Emily, 16, father, problem alcohol use);

> Well they don't actually talk just now, it's just because of her problem, they just don't want to know...they don't speak to her and haven't done for a while (Julie, 15, mother, problem alcohol use).

Finally, a novel type of support was discussed by one participant caring for her father who had a history of problem alcohol use. The young carer discussed how she was able to go out socially, because the barman at her father's local public house 'kept an eye on him' and ensured his safety, until she picked him up at the

end of the evening. This was perhaps an indication of 'social capital' in the young carers' home area (see Putnam, 1993).

Issues Relating to the Parental Condition

Three key themes were raised by the participants about the nature of the parental condition, which related to firstly, the assignment of 'blame' or sympathy to the parent, secondly, the 'predictability' of the parents symptoms or behaviour; and thirdly, various 'cues' to the parent's state of health. As these issues will be referred to at several points in the current and subsequent chapters, they will now be described.

Blame and Blamelessness

Interestingly, the notions of blame or sympathy for the parent were highlighted exclusively by those caring for parents with substance misuse or mental health problems. Societal perceptions of these particular types of conditions were widely discussed in terms of the lack of sympathy and misunderstandings associated with these, as illustrated in the statements below:

> Yeah...also more sympathy gets directed for somebody who's physically disabled, whereas for someone like my dad, they are seen as absolute axe-wielding maniac kind of thing (Rachel, 15, father, mental health problem);

> 'Cause a lot of people don't like drugs, they think that if someone's on drugs, all the nice people don't really like that (Pamela, 14, mother, problem drug use).

Furthermore, two participants explicitly blamed their parent for the development or course of their condition. Both of these participants indicated that deteriorations in their mothers' health had been self-inflicted:

> And like, she lost weight, she was upset, she was like 'Oh, I've lost weight, I've went down to this' and it was hard not to say, it's your own fault. (Rose, 18, mother, problem alcohol use);

I think that I get really mad at my mum whenever she has to go into the hospital because she'll do something really crude that'll put her in there and I'll like go 'If you really loved us, you wouldn't do that' (Fiona, 15, mother, mental health problem).

In contrast, generally the young carers expressed sympathy for the parent and a sense of blamelessness. In illustration of this, two female participants suggested that the condition was outside of their parent's control and instead had just 'happened' to them, as indicated in the following statement:

Well, I do feel sad and kind of annoyed that this has happened to my mum, 'cause you couldn't meet a nicer person (Tina, 14, mother, mental health problem).

In a similar thread, a further eight participants cited various reasons as the parental condition, which thus, excluded parental blame or responsibility. In terms of this, as indicated in Table 4.7, causal factors included: experiences of domestic abuse; side-effects of, or poorly controlled medication; the negative influence of peers; loss or bereavement; as well as an inherited predisposition to the condition. Five of the eight participants attributed the parental condition to more than one of these factors.

Table 4. 7 – 'Causes' of the Parent's Condition

FACTOR DISCUSSED	EXAMPLE OF SUPPORTING STATEMENT
Domestic abuse	But that was all because of my dad, that's what started it all off, my dad used to hit my mum (Tina, 14, mother, mental health problem)
Medication	One of the biggest things I realised recently is now I think it's actually his drugs that affect the way he is more...his drugs are vital to his freedom as a human being, but the drugs have side effects which degrade him as well, he can't think straight basically... (Cameron, 22, father, mental health problem)
Influence of Peers	Her friend, she comes through sometimes and...she drinks a lot and she's starting to take drugs her friend (Abbie, 13, mother, problem alcohol use) She was off it for 9 months, then she met up with some boy and he got her taking it again (Pamela, 14, mother, problem drug use) But it doesn't help as well, that he visits people in Aberdeen, 'cause he's got a lot of friends who are actually constantly in the Forensic unit [at psychiatric hospital] they're constantly in, so he visits quite a lot, which could also trigger it, we don't know what triggers it, it's sort of every 2 years (William, 16, father, mental health problem)
Bereavement and Loss	I think it was also because my uncle died like about 8 years ago (Kayleigh, 15, mother, mental health problem)
Genetic factors	But he's [maternal grandfather] like that [a drinker] as well, so that's genetic from him. (Rose, 18, mother, problem alcohol use)

Manifestations and Predictability of the Parental Condition

Furthermore, the manifestations and symptoms of the parental condition were described and discussed. Unsurprisingly, all of the participants caring for a parent with a physical disability had noted mobility problems, whilst those caring in the context of parental mental health problems or substance misuse frequently mentioned their parent's mental and emotional problems. In addition, one participant whose mother had a history of problem alcohol use also had an associated physical condition which caused mobility problems. A further two siblings reported that their mother experienced mobility problems on an intermittent basis, in addition to her mental health problem.

All of the participants caring for parents with a physical disability had a clear knowledge of the actual diagnosis, which in six cases was multiple sclerosis. Similarly, all ten of the participants caring in the context of parental substance misuse were aware of and could clearly define the nature of their parent's

condition. However, there was a degree of ambiguity and uncertainty over the parental diagnosis in relation to mental health problems. Indeed, in many cases, the parental condition appeared to be undiagnosed, as indicated in the following statement:

> Well, she gets depressed from time to time, but she's never had it diagnosed as any specific thing...it's just every so often she gets down (Tina, 14, mother, mental health problem).

Interestingly, it appeared that 'depression' was viewed as being relatively insignificant, as the young carers' descriptions of this was frequently prefixed with 'just', as indicated in the statement below:

> Just depression, she just suffers from depression like now and again (Donald, 14, mother, mental health problem).

This perhaps reflected the general perceptions in society around mental health problems being less serious or less legitimate than physical conditions.

Moreover, a further issue highlighted by the participants related to the unpredictability of either the parental behaviour or the course of the parental condition. Inconsistent and unpredictable behaviour exhibited by the parent was discussed exclusively by those caring for parents with non-physical conditions. Variability in the course of the condition was discussed by participants across all three of the caring contexts. However, with some of the conditions, there was a level of predictability regarding the typical course of the condition. For instance, parents with multiple sclerosis largely exhibited 'relapsing-remitting' patterns. Whilst the timing of the relapses was unpredictable, these commonly involved particular stages and sequences, as illustrated in the following statement:

> Every few months or years it will start up...it starts in her eye, she can't see the TV and has to wear sunglasses to watch it...and then her leg goes...after that she usually gets better...(Chloe, 13, mother, physical disability).

In contrast, living in the context of parental substance misuse was described in terms of extreme unpredictability and stress. Indeed the only element of

predictability evident within this context was in relation to problem alcohol use, where the young people exhibited an established knowledge of the typical stages that the parent went through when intoxicated, as indicated in the statements below:

> if she has too much, she like starts crying and that, but normally when she's got a bit of drink in her she's like alright, but just drunk (Julie, 15, mother, problem alcohol use);

> The stages, there's the just a few drinks and then there was getting funny and then there was getting emotional, like crying, then she goes to nasty...the worst stage was the emotional, she was crying all the time (Rose, 18, mother, problem alcohol use).

Cues as Clues in Terms of the Parental Condition

Lastly various 'cues' (i.e. outward signs) revealed both the presence and nature of the parental condition (that is, physical or non-physical) and indicated deteriorations in the parent's health. Cues were described as being explicit or implicit, with explicit cues most evident in relation to parents with a physical condition, due to the outward visibility. Indeed, amongst the ten participants in the first phase, there were eleven parents with a physical condition. Of these, ten had outwardly observable conditions and nine used mobility aids such as walking sticks or wheelchairs. Arguably, both the visibility of the actual condition and the presence of mobility aids acted as cues to the presence and nature of these physical conditions.

However, in relation to non-physical conditions, outward or observable cues were not apparent, and thus, as expressed by a number of participants, the parental condition (and by implication, the young caring role) remained hidden to a greater extent:

> Physical's obviously a lot more, people walking down the street can see it, you can't hide it the same (Caroline, 23, mother, problem alcohol use).

In addition, this suggested that the young person compared different conditions and disabilities to come to an understanding of her own circumstances.

Whilst explicit cues were apparent in relation to physical conditions, the participants caring for parents with substance misuse or mental health problems identified a range of 'behavioural cues'. These were indicative of both the presence of the condition, as well as deteriorations in the parent's wellbeing. As outlined in Table 4.8, the most frequently reported 'cues' related to the parent staying in bed, crying or exhibiting some form of unpredictable behaviour (such as laughing violently and inappropriately), as well as subjecting the young carer or another family member to abuse or neglect. All of the participants caring for parents with substance misuse or mental health problems identified that their parent presented multiple behavioural cues. However, these cues were often fleeting or hidden by the parent in a manner that a physical condition could not be and were also open to misinterpretation by others outside of the immediate family.

Table 4. 8 - Cues to the Parental Condition

SPECIFIC 'CUE'	EXAMPLE OF SUPPORTING STATEMENT
Unstable/ 'Bad Moods'	Oh, she's always goes in moods and that...she was always in bad moods for days, and I just knew (Pamela, 14, mother, problem drug use)
'Crying'	Sometimes she's just like on a downer and she just cries to herself (Kayleigh, 15, mother, mental health problem)
Stays in bed/ bed as solace	Most of the time she stays in her bed because she...she just gets bored, she prefers her bed, she's in her bed every day...and you hardly get to talk to her when she's in her bed, she's not sleeping but she's just in her bed constantly with her hot water bottle...well that's her safety, she said that's her safe place so she just stays there all day (Kayleigh, 15, mother, mental health problem)
Angry/ Mad	I've sort of learnt and I could tell like if he's going to get angry, what to say to calm him down (James, 18, mother, physical disability; father, physical disability and mental health problem)
Self-Harm	And her mental illness as well causes her sometimes to self-harm...she's taken 2 overdoses when she was really stressed...my mum's last overdose was her worst because she had an allergy to the tablets...she tied herself to the bath too and I was really scared (Susan, 13, mother, mental health problem)
Abuse (Emotional / Physical)	...but it was the nasty that I didn't like...the nasty she'd hit, she'd lash out, she was just nasty, abusive (Rose, 18, mother, problem alcohol use)
Neglect (Emotional and Physical Neglect)	I was basically put in my room for a year, just over a year and I had to eat in my room, I just used to come home from school and that was it and at 15, 16...that's not what a kid wants to do....it was games, mental games of alcohol and I missed out on a lot (Caroline, 23, mother, problem alcohol use)
Environmental Cues	When she gets depressed, the house gets untidy (Tina, 14, mother, mental health problem)
Vocal Changes	'Cause I could tell by her voice if she'd took anything (Pamela, 14, mother, problem drug use)
Bodily Changes/ Changes in Appearance	It's their eyes, their neck size...and their hands as well, my mum's hands used to swell up (Caroline, 23, mother, problem alcohol use) And like, she lost weight (Rose, 18, mother, problem alcohol use)
Unpredictable Behaviour	She used to tell us lies about things, she told us things we didn't need to know, she locked one of my sisters out of the house, she's driven whilst drunk, we had to phone the police on her...living with it for two years you live with the unpredictability of it (Caroline, 23, mother, problem alcohol use) I mean if she's in a happy mood and she know she embarrasses me, if we're in the town, she's like dancing and singing and everything and I'm like 'Mum, be quiet' (Kayleigh, 15, mother, mental health problem)

As already highlighted, the cues were indicative of the parent's state of health and in many cases, these enabled the young carer to observe deteriorations in their parent's mental health or allowed them to gauge whether the parent had been drinking or had taken drugs.

Perhaps the most obvious 'cue' that suggested a decline in the parent's state of health related to hospital admissions. This was discussed by the majority of the participants across the caring contexts. The reasons for hospital admissions and the impacts of these on the young carers, differed according to the nature of the parental condition. With physical disability, hospital admissions were largely described as routine *'check-ups'* planned in advance. In contrast, with substance misuse and mental health problems, admissions to hospital or alternatively, rehabilitation clinics were instigated by various crises. These were described as having a disruptive or negative impact on the young carers:

> She's been in like [psychiatric] hospital, like a few times, 'cause she's went a bit mad, but it does get scary when she goes like that 'cause you don't know what to do (Kayleigh, 15, mother, mental health problem).

Summary of Key Points from Section 4.4

As described, the 'type' and nature of the parental condition had an affect on the young carer's experience. For instance, there was an evident link between the nature of the parental condition and the types of roles and tasks assumed by the young carers. More importantly, the outward visibility of physical conditions compared to the invisibility of non-physical conditions was a defining factor in terms of the experiences of the young carers. Generally, invisible conditions were unpredictable, misunderstood, misinterpreted and could be ignored or overlooked by others. In turn, this detrimentally affected the level of support offered to the family, and thus, increased the role and responsibilities of the young carer.

4.5 Definitional Issues, Self-Identification and Disclosure

Self-Identity as Young Carer

Whilst there was some level of awareness of the definition of 'young carer' amongst the participants, there was a very limited recognition of the term as equating to one's own caring role at home. Instead, the participants largely associated the term with various other factors, including being a member of a young carer's group; paid caring; caring for persons with a physical disability or undertaking practical and quantifiable roles and tasks. Moreover, the process of identification was largely facilitated through contact with specific professionals, particularly young carers' workers. Approximately one-third of the participants had never had such contact, which had obvious implications in terms of self-identification. Each of these elements will now be considered in turn.

Definition Based on the Caring Role at Home

Participants were invited to explain their understanding of the term 'young carer' and in response to this, 18 offered a definition. The majority of these were broad and pertained to the undertaking of a caring or supportive role in respect to another person. Where expansion of this basic definition was offered, key issues highlighted related to the relationship between the care recipient and young carer (described as a parent or family member) and the age of the young carer (quantified as 'someone young' or a person aged under 16 or 18). However, unlike official definitions and those offered by the young carers approach, neither the amount of time spent caring, nor the impacts of caring explicitly featured in the definitions offered. For example, typical definitions offered included the following:

> A young person looking-after an adult or a brother or sister that's got an illness of some sort (Tina, 14, mother, mental health problem);

> It's just someone quite young, like under the age of 16 or whatever, just looking-after a member of their family if they are disabled or something like that (Donald, 14, mother, mental health problem).

For two older young carers (both aged 25), the age distinction was pertinent in terms of their understanding and personal application of the term to their own situations:

> ...from the young adult side of it, I'd still class myself as a young carer. If you look at a person who's over what, say in their forties, then they're a carer, but not a young carer (Mark, 25, mother, physical disability);

> Well right now, I always think it's someone sort of younger than 25. You always imagine it as like maybe kids, around 11-12 kind of mark (Grace, 25, mother, physical disability).

Young Caring Role Defined by Professionals

In all cases, where there was an evident familiarity with the term 'young carer', this resulted exclusively from contact with professionals, mainly young carers workers. Indeed, 19 of the participants discussed how they had never encountered the term or had not been referred to as a young carer prior to professional contact, as illustrated in the comments below:

> It's just part of my daily life for me but being a young carer wasn't something I thought of 'til [contact with] TD [young carers' worker] and the group (Jenny, 17, mother, physical disability and mental health problem);

> Yeah, until GH [young carers' worker] said I was a carer, I wouldn't have thought about it (Rose, 18, mother, problem alcohol use).

This perhaps highlighted that in the absence of key terminology, it was not possible for the young carers to define themselves according to their caring role and responsibilities, which in turn, compounded their invisibility, as indicated in the quotation below:

> I wouldn't have even thought it 'cause I'd never heard of it (Emily, 16, father, problem alcohol use)

The Meaning of Young Carer and Alternative Understandings

Association of the Term 'Young Carer' with Group Membership

Rather than associating the term 'young carer' with the caring role at home, there was an implicit recognition that the label referred to being a member of, or having some connection to, a young carers support service. This association was asserted exclusively by seven individuals in contact with a young carers group. For instance, in response to an interview question about the positive and negative aspects of being a 'young carer' (which was in reference to their caring responsibilities), several individuals instead discussed the positive and negative aspects of belonging to a young carers group. The statement below illustrates this:

> The good thing [about being a young carer] would definitely be like...where you go on all the outings and the activities (Jane, 14, mother, physical disability)

Association of 'Young Carer' with Paid Carers

One participant associated the term 'young carer' with young *paid* carers working in residential care settings:

> I wouldn't actually specifically put it [to mean] in the household or in the home, I would take it to mean working in care homes and that (Caroline, 23, mother, problem alcohol use).

The context in which this young carer was placed may be of interest. For instance, she had never been formally identified as a young carer and had not previously considered her role according to this label. Thus, she lacked a fundamental awareness of what the term indicated.

Young Caring Associated with Physical Tasks and Physical Disability

There was a clear association of the young caring role with the undertaking of physical, practical and quantifiable tasks, which implied caring for persons with a physical disability. Thus, being regarded as a 'young carer' was almost justifiable in contexts involving parents with a physical disability, where a suitable amount and type of work was undertaken. Interestingly, this association was made by 14

young carers, all of whom were supporting parents with non-physical conditions. This perhaps implied that they viewed their own identities as young carers as less permissible than those caring for parents with a physical disability, as illustrated in the following statements:

> I mean I see a lot of things and see a lot of people who have to do a hell of a lot more than what I would consider that I do...and there's people who are a lot more in-depth with it who are constantly caring, whereas mine is just sort of...just the general crap really, not a deep one, 'cause he is able to do things, he just sometimes doesn't want to do them (William, 16, father, mental health problem);

> For me its [young caring] always been more associated with people who are actually physically disabled and only for severe mental handicap, but sometimes you do end up feeling a bit like a young carer for somebody like dad (Rachel, 15, father, mental health problem).

The Validity of Emotional Support as a Type of Care

Definitional Issues Around Emotional Support

In summary, as the young caring role was largely associated with physical caring tasks and parents with a physical disability, this posed questions about the recognition of those caring for parents with substance misuse or mental health problems. Indeed, emotional support (largely undertaken in non-physical caring contexts) was not readily recognised as a viable form of assistance. In illustration of this, when asked about the types of care they provided at home, all of the young carers initially discussed visible, quantifiable tasks, which were practical in nature – none highlighted emotional support without some prompting from the researcher. Following an explanation of what was meant by emotional support, 11 simply indicated that they provided this, yet offered no elaboration as to what this involved, as indicated in the following statement:

> Emotional support...a lot of that (James, 18, mother, physical disability; father, physical disability and mental health problem).

Even after the term was used by the researcher, only two of the young people explicitly referred to 'emotional support' and when discussing this, described only the most recognisable forms of this, such as 'talking' and 'listening':

> She needs to sit and talk...for like hours (Katrina, 16, mother, problem alcohol use).

However, in addition to the explicit forms of emotional support, other more implicit forms were arguably described, but not recognised as emotional support, by a further 11 participants. As indicated in Table 4.9, these included cheering up and 'cuddling' the parent; offering reassurance and perceiving and responding to the state of the parent's health; as well as showing empathy.

Table 4. 9 - Manifestations of Emotional Support

REASONS OFFERED	EXAMPLE OF SUPPORTING STATEMENT
Talking and listening	Yeah and sometimes during the night I'd hear it [crying]and I'd know it was fake and I'd know she'd been drinking, so, it was hard, because she'd shout me in the middle of the night to go through to listen to what she had to say, that was the worst bit (Rose, 18, mother, problem alcohol use)
'Cheering Up'	I'd just try to talk to them a lot and be patient with them and try to cheer them up. You know just trying to cheer him up is one of the best things you can do (Cameron, 22, father, mental health problem)
'Cuddling'	Most of the time she just needs a hug (Donald, 14, mother, mental health problem)
Reassuring	I would try to calm her down (Kayleigh, 15, mother, mental health problem)
Perception and Empathy	You're having to be mentally quite agile to realise, Ok you've really got to back off and it's just the little things you've got to be aware of (Rachel, 15, father, mental health problem)

Thus, a total of 22 young carers identified that they were either providing emotional support or alternatively, described forms of care that could be considered as emotional support. Incidentally, this was in excess of the normal affective bonds between parents and children expected in family relationships, as dictated by 'social norms' from an intuitive viewpoint and also sociological and psychological theory concerning conventions around family life. Whilst unwritten, such conventions have dictated a degree of expectation about the levels of support and engagement between different family members. These

expectations were exceeded in the case of the participants. For instance, they missed school because they worried about their parent in their absence and forfeited romantic relationships and friendships because of their caring responsibilities.

These 22 participants included all of those caring for parents with mental health problems, nine in the context of parental substance misuse and three in relation to physical disability. In terms of the latter context, two of the three young carers, Jenny and James, cared for parents with both physical and mental health problems. Therefore, the impacts that they reported may have related to their parents mental health problems.

Providing Emotional Support as Problematic

Whilst the contribution of emotional support was largely overlooked, it was this form of support that the young carers (of parents with substance misuse or mental health problems) found most difficult to provide. Eight of the 22 indicated that they found this type of care highly challenging or that it was inappropriate for them to provide, as highlighted in the statements below:

> She needs somebody to listen to her, but I'm the wrong person, cause I'm only 17, I can't deal with all the stuff that she's got in her head...I've got my own stuff in my head to worry about, rather than someone else's (Jenny, 17, mother, physical disability and mental health problem);

> I mean we do speak and we do like to communicate and we do talk about things emotionally, but I find it challenging to deal with such in-depth things (William, 16, father, mental health problem);

> Also I'd say the mental work is more demanding than the physical work (Donald, 14, mother, mental health problem).

Interestingly, such difficulties were not expressed in relation to providing practical or physical assistance.

Overlooking the Caring Role and the Resulting Impacts - *'Used to it'*

Arguably, being accustomed to or *'used to'* one's caring situation contributed to a lack of recognition over the young caring identity. This notion was expressed through the young carer's perceptions of their caring role and home life as average or normal and a lack of recognition of the impacts and restrictions imposed by caring. Being or becoming *'used to it'* was discussed by thirteen young carers across the three caring contexts, most frequently by those caring for a parent with a physical disability, as illustrated in the comments below:

> ...when you're mum's been disabled from the second you were born, then you get used to it and you like, don't know any other way of living really, than your mum being in the wheelchair (Peter, 14, mother, physical disability);

> To me now, stress is normal, having the amount of stress I have is normal, I've got used to it (April, 16, mother, problem alcohol use).

Disclosure 'versus' Concealing the Caring Role and Identity

Only one young person explicitly stated that they objected to being labelled a 'young carer, as illustrated below:

> I've helped my mum since my sister was born...doing some things for her and like my social worker said that I'm a young carer and I was like 'No' (Katrina, 16, mother, problem alcohol use).

Nevertheless, the label was not wholeheartedly accepted by the other participants. Indeed, 24 of the 30 young carers described a preference for others not to know and hid their identity as young carers from teachers and classmates at school in particular, as highlighted below:

> Well, there's not a lot of folk at school that know I'm a young carer...cause it's not exactly something I go about bragging (Chloe, 13, mother, physical disability).

This lack of disclosure and hidden-ness of the caring role was also apparent in terms of the non-disclosure of classmates about their own status as young carers. Indeed as illustrated below, several of the participants highlighted that it was only through their attendance at young carers' group meetings that they became aware that others at school were carers:

> There's quite a few people in my class, but I don't think anybody knows, 'cause I only know because I go to the group, the parties and that, that's why I know who people are (Tina, 14, mother, mental health problem).

The active concealment of the caring identity was most frequently practised by those caring for parents with substance misuse or mental health problems. Accordingly, of the 24 young carers who concealed their caring roles, ten were caring for parents with a mental health problem, eight, for parents with substance misuse problems and six for parents with a physical disability. Of the six, two were caring for parents with dual diagnoses of physical disability and mental health problems. This lack of disclosure was perhaps due to 'courtesy stigma' as well as a strong desire to 'fit in' with peers or not 'stand out' as being different.

Furthermore, where the young carers had disclosed their caring identity or details of their caring role to others, this was described as being a highly selective process. Those most likely to be confided in were *'select'*, trusted others. This notion of 'select' had both 'quantitative' and 'qualitative' elements, and thus, referred to a select number (one, two or a few people) and select characteristics. Such individuals were perceived to possess particular traits such as trustworthiness, understanding and empathy (very often other young carers), usually within the context of an established relationship. These were mainly close friends or partners, and in one case, a young carer's worker. Interestingly, it was exclusively individuals caring for parents with substance misuse or mental health problems that discussed the process of selective disclosure. The quotations below illustrate this notion of selective disclosure:

> I've only told one person...and she's got the same problem as what I've got (Abbie, 13, mother, problem alcohol use);

I mean I didn't tell David about my mum for a couple of months, so I didn't have to tell him 'til I knew my feelings were really, really strong (Rose, 18, mother, problem alcohol use);

Actually, I'm quite lucky 'cause my friends, they have had difficulties, so we're all on similar levels, so we both know what it's like to have really difficult parents every so often, so I don't really have that problem, 'cause I've got quite supportive friends (Rachel, 15, father, mental health problem).

Furthermore, nine participants discussed how they had been required to inform a guidance teacher at school about their caring responsibilities. This had been necessary due to their difficulties with attendance or workload. In each case, there was an evident degree of resistance over the sharing of this with other pastoral staff:

My guidance teacher is well-informed on it, but my other teachers don't really know about it...I'd sort of say if they don't need to know, why tell them (Rachel, 15, father, mental health problem);

However, in contrast, not all of the young carers demonstrated concern about others discovering details of their home situation or their caring identity. Indeed, in one case, the young carer agreed to be interviewed about her caring role for a 'Champion Young Carers' article in a national newspaper, as described below:

They said 'we're doing an article on young carers and we're wondering if we could write a bit about you, 'cause we've like heard about you before' and I'm like 'Ok, Yeah, Ok', cause I like being in the paper being famous, it's fun. So, they interviewed me about that and I told them what I do and everything and the next day, the photographer came round and took some pictures of me and the next day, I was in the paper... (Jane, 14, mother, physical disability).

Interestingly, whilst this young person was deemed a 'young carer' and was in contact with a young carers' group, her levels of responsibility at home were relatively minimal. Whilst she lived in a family context involving two parents both with a physical disability and a sibling with learning difficulties, her parents largely addressed each other's care needs, as well as those of her autistic brother. Therefore, perhaps those young carers with less caring responsibilities and fewer impacts were more inclined to share details of their caring role and responsibilities with others outside their family.

The Presentation of 'Two Sides' in Private and Public

Hiding the caring identity and role and identity often required the young carer to present two 'distinct sides' - a 'public side' and a 'private side'. These were demonstrated interchangeably according to the situation and context. This notion was highlighted by five individuals caring for parents with substance misuse or mental health problems. Whist in the company of individuals aware of their caring role, the young people felt at liberty to 'be themselves'. With others such as classmates, however, they actively concealed their caring identity through 'putting on a brave face', as illustrated in the following statements:

> There are two different sides...yeah, like you do have a different character (William, 16, father, mental health problem);

> I put on this front that I'm all fine and I'm all happy and cheery, but no, not really (April, 16, mother, problem alcohol use).

Perhaps this further illustrated a need to 'fit in', common to all adolescents, or at least, not 'stand out' as being different from one's peers. Also, this may have been underpinned by fears about negative treatment or 'courtesy stigma'. It also reflected the process of developing a social identity and particularly Mead's notion of self (i.e. the dawning awareness of 'who I am') (Mead, 1932).

Reasons for Non-Disclosure and Selectivity

These reasons for choosing not to disclose, selectivity over disclosure, 'courtesy stigma' and a need to fit in with one's peers, will now each be considered in turn.

Fitting In/ Not Standing Out

Whilst a failure or resistance to disclose was perhaps due to a need to fit in or not stand out, it must be stated that 'fitting in' and not 'standing out' were not necessarily dichotomous terms. The former related to a desire to be accepted within the peer group and the latter described a withdrawal from social situations. Again, this linked to Mead's notion of the 'self' (i.e. reflexive, emergent) (Mead, 1932). The idea of 'fitting in' is evident in the first statement below and not 'standing out' in the second:

> I think young kids, they just want to fit in, they won't always come forward and ask for extra time to do their homework, cause then it means they'll be handing in theirs and everyone else has handed in, cause you just want to be like everyone else so you don't want to single yourself out for special treatment (Grace, 25, mother, physical disability);

> I keep myself to myself when in school, just do my own thing and avoid the others (Kayleigh, 15, mother, mental health problem).

Courtesy Stigma

The participants discussed both their experiences and fears of 'courtesy stigma':

> And some of my friends think my mum's like weird because when she takes her tablets she gets quite hyper, so she comes up and cuddles everyone, so they all think she's strange...then they sort of take it as a grudge on me so (April, 16, mother, problem alcohol use).

Whilst 'courtesy stigma' was discussed by young carers across each of the caring contexts, the actual nature of this was context-specific. With physical disability, others drew attention to this by teasing or bullying the young carer, as highlighted in the following quotation:

> It's difficult because when you're going out with them [the parent], you have to cope with people staring and maybe, kids pointing at her and you and things like that and then that affects their confidence and then you in

turn, your confidence gets taken down as well (Grace, 25, mother, physical disability).

In relation to substance misuse, others 'tip-toed' around the issue with the young carer, yet openly discussed their situation with others. This caused a sense of unease, as highlighted below:

> I mean they wouldn't say anything to me, but I know what they're saying about me behind my back...it's horrible (Katrina, 16, mother, problem alcohol use).

Risks Associated with Disclosure

Undoubtedly, deciding whether and with whom to share details of the caring role, were decisions which carried considerable risks. Informing others had not always translated into understanding and helpful practices. A total of 19 young carers had experienced a lack of understanding from others such as teachers, partners, friends or colleagues, as highlighted in the following quotations:

> ...and a lot of people like teachers and things don't understand quite what it involves either...how much involved you are with that person and how much you have to do for them. They just think its maybe 'oh, you have to get them out of bed' or something. They don't realise it's something that you are never away from (Grace, 25, mother, physical disability)

> 'cause very few people understand it and that can be quite hard when they meet him or you try and tell people what your dad's condition is and they automatically go on sort of the movies interpretation of it (Rachel, 15, father, mental health problem)

> He [boyfriend] didn't see it that way...it's hard 'cause he sees my mum ill and he doesn't really sort of understand (April, 16, mother, problem alcohol use)

The participants also discussed their experiences of explicitly punitive or collusive practices which again, were perhaps underpinned by a lack of understanding by others. Punitive practices included being issued with detentions at school for caring-related problems such as lateness, absences or difficulties with assigned work, as well as being subjected to bullying or mockery by peers. As highlighted in Table 4.10, this further demonstrated the ignorance and discrimination endured by the young carers. Collusive practices involved 'turning a blind eye' or 'tiptoeing' around the young carer. Interestingly, the risks associated with disclosure were discussed most often by the female participants – 16 female participants and three males – which suggested that this issue had a gender-related dimension. Perhaps females were more perceptive to the collusive or punitive practices directed toward them, or found these more troublesome or alternatively, discussed these more readily than their male counterparts.

Table 4. 10 - Risks Associated with Disclosure

TREATMENT	AREA AFFECTED	EXAMPLE OF SUPPORTING STATEMENT
Collusive Treatment	School	And in a way I think she lets me off with a bit more because I think Mr P's [teacher] actually said on the sly, she has problems at home. He's probably not said that I'm not at home, but I think she does let me off with a bit more because there was one time I couldn't do an essay or something,...told her and due to other things, I got really upset about it probably because of stress and she says '...do what you can and I'll probably forget about it' and I was like 'Oh right Ok' (Rose, 18, mother, problem alcohol use)
	Social Life	They [friends] will be like all worried about asking me things and sometimes it's like they're going behind my back and that... (Raymond, 11, father, physical disability)
Punitive Treatment	School	They bullied me a lot. If I didn't take in homework...and if I'd lose a bit of homework they'd come down on me like a ton of bricks...I had an after-school detention every day...for not putting in homework (April, 16, mother, problem alcohol use) My guidance teacher does [know] but she always gets on at me if I'm off school, 'cause I don't think she understands the full story of what happened (Katrina, 16, mother, problem alcohol use)
	Work	I just got a letter from her [manager] saying bye-bye and that was it... from the time she came to speak to me, it wasn't even two weeks...was supposed to get two weeks notice and it wasn't even that when they fired me. I wasn't even aware that they'd got rid of me I had to phone her up...they see you more as a liability rather than anything else. If I couldn't get time off I had to phone in sick and of course they just see it as you being off and they just want rid of you (Grace, 25, mother, physical disability)
	Professional	She [social worker] just sort of assumed that I was ok about doing all that, so I just have to get on with it (April, 16, mother, problem alcohol use)

Positive Impacts Resulting from Disclosure

Nevertheless, in some cases (as evident across the caring contexts), the young people described the positive effects of disclosure such as the understanding and empathetic responses and treatment from others, particularly teachers. This included the acknowledgement of and appropriate response to problems such as poor attendance at school and difficulties with homework. This involved teachers adopting a 'firm but fair' approach to such problems or making referrals to appropriate support services, such as dedicated young carers' projects. The following were examples of helpful practices demonstrated by teachers:

I normally get quite high marks on things apart from maths, when my marks kind of dropped she always asks what's wrong when I'm not concentrating...yeah, when I don't get my homework done for a week at a time, she always gives me enough time to do it in school 'cause she knows (Nicole, 11, mother, mental health problem);

My guidance teacher has always been there to help me get through it and just have a break if things get too much...they could be asking for an 800 word essay to be done in a week and I'm like 'I can't do that', and they will say 'Ok, it has to handed in by the end of next week, that's the final date you'll get' (Fiona, 15, mother, mental health problem).

Summary of Key Points from Section 4.5

As highlighted, various ambiguities surrounded the definition of 'young carer' and the self-comprehensions of the term. In broad terms this related to differences between the established definitions and the understandings of the participants within this study. Most significantly, the role and contribution of young carers was related to the assumption of practical roles and tasks in the context of physical disability. In effect, this served to exacerbate the invisibility of some young carers, particularly those caring for parents with non-physical conditions. This was particularly problematic considering that they were most likely to assume roles and tasks (particularly in terms of emotional support) which were identified as being the most difficult to provide.

4.6 Problematic Issues Resulting From Caring

In relation to the effects and impacts of young caring, relatively few positive issues were highlighted by the participants. In contrast, they reported a range of problems and difficulties in relation to their education, social life, health, work, relationships and moves to independent living. Thus, within this section, firstly problems pertaining to each domain will be described, followed by a brief description of the positive impacts highlighted. Differences according to the caring contexts will be outlined in relation to each area.

Educational Impacts

In terms of education, the issues raised included: difficulties completing homework and assigned classroom tasks; absences and lateness; concentration problems; tiredness; problems balancing further education with home

responsibilities; and 'dropping out' of further or higher education. Indeed, as demonstrated in Table 4.11 below, the vast majority of the participants (24 out of 30) identified that their caring role and responsibilities had created one or more of these problematic issues and 17 reported more than one problem. The remaining six young carers with no such difficulties lived (or had lived whilst at school) in two-parent families, where the second parent was available to care. This allowed the young carer to concentrate on their educational needs. Each of these issues will now be considered in greater detail.

Table 4. 11 - Educational Problems and Issues Reported

	Participants	EDUCATIONAL ISSUES IDENTIFIED				
		Homework	Frequent absences	Lateness	Concentration Problems	Dropping Out
Physical disabilitys	James	✓	✓	✓	✓	
	Peter	✓	✓	✓	✓	
	Lewis					✓
	Mark					
	Raymond					
	Chloe	✓		✓		
	Jane					
	Charlotte	✓		✓		
	Grace	✓			✓	
	Jenny	✓	✓	✓		✓
Substance misuse	Pamela		✓			
	Rose	✓	✓			
	Caroline					
	April		✓			
	Katrina		✓	✓	✓	
	Janice	✓			✓	
	Julie		✓			
	Grant				✓	
	Emily		✓			
	Abbie		✓		✓	
Mental Health	Kayleigh		✓		✓	
	Cameron					
	William		✓		✓	
	Rachel					
	Donald		✓		✓	
	Douglas	✓				
	Susan		✓		✓	
	Nicole	✓		✓		
	Tina	✓	✓	✓		
	Fiona	✓			✓	

Difficulties Completing Homework Tasks

12 young carers indicated that they had often experienced difficulties completing homework tasks. Interestingly, those that were caring for parents with a physical

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disability reported the greatest difficulties, largely because of a need to carry-out specific caring tasks (particularly domestic tasks) after school, which meant that they had little time or energy to undertake homework:

> I was just really tired and I didn't really have enough time to do it (Grace, 25, mother, physical disability).

However, the reasons that underpinned homework difficulties differed according to the caring context. For those that were caring for parents with a substance misuse or mental health problem, such difficulties were largely attributed to their disruptive and chaotic home life, as illustrated below:

> Homework...sort of had time to do it, but there was like distractions always going on as well (James, 18, mother, physical disability; father, physical disability and mental health problem).

Some of those young people that attended young carers' support groups highlighted that they benefited from the 'time and space' away from their parent, as well as the adult help and supervision with homework, offered at the group meetings. This was deemed as being particularly helpful and viewed as a measure which prevented the development of significant homework difficulties.

Absences

Very few of the participants indicated that they had *never* been required to take time off school to care. However, absences varied in terms of frequency, from being very regular, to very occasional during periods when the parent was particularly unwell. A total of 15 young carers reported that they had to take time off school to care on a frequent basis. This mainly involved those caring for parents with substance misuse or mental health problems - seven and five respectively. As indicated in the statements below, reasons given for these caring-related absences included a need to be at home in order to carry out particular tasks, or to keep an eye on the parent. In relation to the latter, some young people indicated that being at home allayed their fears about their parent's wellbeing, a concern which was heightened whilst away from the parent during school hours.

...I missed lots of school...cause my mum...helping out really with stuff around the house, doing shopping and stuff like that (James, 18, mother, physical disability; father, physical disability and mental health problem);

Well, I tend to worry more 'cause I'm away from her, so that's why it affected it my absences...In first and second year definitely, I was only there for about half the time (Tina, 14, mother, mental health problem).

In other cases, there was a sense of parental collusion over absences, as the parent allowed the child to stay off school to 'keep them company':

She [mother] said 'Oh, please don't go to school today'...she wanted someone around to talk to and stuff (Rose, 18, mother, problem alcohol use).

Lateness

Eight participants mainly caring for parents with a physical disability reported that they often experienced difficulties getting to school on time. Again, arriving at school late was evident on a scale which ranged from persistently late to never late. Most young carers reported occasional lateness, as highlighted below:

Sometimes I'm about 15 minutes, but that's the most I've ever been I think (Nicole, 11, mother, mental health problem).

Concentration Problems

12 young carers across the three caring contexts experienced concentration problems at school due to caring-related factors such as tiredness, worrying about the parent and thinking about their after-school tasks. Illustrative examples of each of these are stated below:

So you get quite tired and you get more tired at school and can't concentrate (Donald, 14, mother, mental health problem);

Like if my mums been upset the night before and I've got like school the next day I'm like all upset and sometimes I burst into tears and I won't tell

my friends why, I'll just stop crying and I'll sit in class and I'll hardly do any work, I'll write like one letter 'cause I'm worried about my mum... (Susan, 13, mother, mental health problem);

'Cause even if you are at school and things, it's always at the back of your mind that you have to go home and do this or that (Grace, 25, mother, physical disability).

Moreover, the effects of poor concentration were discussed by several participants and generally related to overall performance problems at school, as illustrated below:

I failed half of my prelims because I was too busy worrying about my mum (Fiona, 15, mother, mental health problem).

Notwithstanding this, it must be questioned whether some of the young carers used their caring responsibilities as a scapegoat to justify difficulties at school and other domains.

'Dropping Out'

The majority of the participants were too young to be involved in further or higher education. However, of the older participants, two reported that they had been required to withdraw from their college course or degree programme, due to difficulties balancing their studies with their caring responsibilities. Such difficulties resulted from worrying about the welfare of the parent in situations where the young person was studying away from home, as illustrated below:

Basically when I had my year at university I could sense things weren't right, I was really worried then and came back up from uni (Caroline, 23, mother, problem alcohol use).

Furthermore, their caring responsibilities also precluded some of the participants from pursuing further or higher education. As highlighted in the following statement, one participant discussed how she had made a conscious decision not

to follow a career in speech therapy as the training programme was based in Edinburgh, a two hour drive from the parent:

> You had to go down to Edinburgh and that to do it and I think because of being away from the family and things I wouldn't have really wanted to do that (Grace, 25, mother, physical disability);

Impact of the Caring Context on Educational Problems

The nature of the caring context was important in terms of the number and types of educational difficulties reported. Firstly, educational difficulties were reported most frequently by those caring for parents with substance misuse or mental health problems. However, problems of a more extensive nature were reported most frequently by those caring for parents with a physical disability. Secondly, the actual types of difficulties that were reported also varied. Whilst those caring for parents with a physical disability experienced a range of difficulties, those caring for a parent with substance misuse or mental health problems were most likely to report frequent absences. Perhaps this reflected the chaotic and unpredictable situations within which they lived and cared.

Impact on Social Life

In terms of social functioning, a number of difficulties were reported by the young carers, which included a lack of their own space or time; difficulties inviting friends home or getting out; being subjected to bullying, as well as various curfews and restrictions. Collectively, these resulted in experiences of social isolation. As is indicated in Table 4.12 below, 25 of the 30 participants reported social difficulties and 19 described multiple problems or concerns. Of the five that reported no such problems, four occupied 'secondary' caring roles and thus, were able to pursue their own social lives. The remaining one young carer stated that she preferred to stay at home and partake in solitary activities such as watching television and thus, did not actively seek to socialise with peers. Each of these particular issues will now be considered.

Table 4. 12 – Reported Social Life Difficulties

	Participants	SOCIAL ISSUES IDENTIFIED				
		Lack of Time and Space	Friends not invited home	Difficulties getting out	Bullying	Curfews and Restrictions
Physical disability	James	✓		✓		✓
	Peter					
	Lewis	✓				
	Mark	✓				✓
	Raymond					
	Chloe			✓		✓
	Jane			✓		
	Charlotte	✓		✓	✓	✓
	Grace			✓		✓
	Jenny	✓	✓	✓		
Substance misuse	Pamela	✓		✓		✓
	Rose	✓	✓			✓
	Caroline	✓	✓	✓	✓	
	April			✓	✓	✓
	Katrina					
	Janice					
	Julie			✓		✓
	Grant	✓			✓(unrelated to caring)	
	Emily				✓(unrelated to caring)	
	Abbie	✓		✓		✓
Mental Health	Kayleigh	✓	✓	✓		✓
	Cameron					
	William		✓	✓		
	Rachel	✓	✓	✓		
	Donald			✓		✓
	Douglas	✓				
	Susan				✓	✓
	Nicole			✓		
	Tina				✓	
	Fiona	✓		✓		

Lack of own Time and Space

A total of 14 young carers across the caring contexts expressed a wish for their own time and space away from the parent and caring, yet had difficulties attaining this, as described below:

> It does get like you need time out from looking-after people...sometimes at home, you feel trapped, you've got to stay in every time, got to look after your mum (Kayleigh, 15, mother, mental health problem).

Nevertheless, during physical absences from the home, telephone contact with the parent was maintained. Indeed, five of the participants expressed that such contact during short-term absences acted as reassurance and allowed the young carer to monitor the parent from a distance, as illustrated in the following statement:

Yeah, I used to phone her all the time and if she didn't answer I'd end up going home straightaway....so if she didn't answer the phone I'd be home straightaway in a taxi (Pamela, 14, mother, problem drug use).

Friends Not Invited Home

Six participants stated that they had never brought friends home. Of these, five were caring for parents with non-physical conditions, as well as Jenny who cared for her mother with both a physical disability and a mental health problem. Indeed Jenny revealed that her disinclination to invite friends home related to her potential embarrassment caused by her mother's unpredictable behaviour, rather than her physical disability, as highlighted in the statement below:

> I never ever brought anyone back to the house ever, well you never knew how she'd be with them [friends] (Jenny, 17, mother, physical disability and mental health problem).

Similarly, the reasons underpinning such disinclination discussed by all six of the participants related largely to fears of 'courtesy stigma', specifically in terms of friends finding out about the parental condition or the young caring role, as well as concerns about the parent embarrassing them and friends *'going off'* them as a result. All of these issues were more evident in relation to parents with substance misuse or mental health problems, due to the stigma, misperceptions and misunderstandings associated with these.

Difficulties Getting Out

17 of the participants across the three caring contexts described difficulties either *'getting out'* socially or spending time with friends outside of the home, either due to their caring responsibilities or worrying about the parent, as illustrated in the statements below:

> You've got to stay in every time, got to look after your mum (Kayleigh, 15, mother, mental health problem);

Even on those days even if she's alright I still wouldn't go out, mostly I
don't have a social life (Fiona, 15, mother, mental health problem).

On a similar note, whilst a further three participants stated that their caring
responsibilities did not affect their ability to get out, this was only due to the
availability of another family member at home to care for the parent, as described
below:

I get out when I can if there's somebody with her (Lewis, 21, mother,
physical disability).

Bullying

In relation to negative treatment, seven individuals highlighted that they had been
subjected to bullying, although two attributed this to reasons unrelated to their
caring role. Where bullying was attributed to caring, in all cases across the three
caring contexts this was underpinned by 'courtesy stigma', as illustrated in the
following statement:

Well just like my mate, she found out my ma was disabled and she started
slagging her off...and all that...cause her ma wasn't disabled...started
slagging me off cause of it, saying 'At least my ma's not disabled'...she
used to batter me all the time (Charlotte, 15, mother, physical disability).

Curfews and Restrictions

A further difficulty reported by 13 of the participants across the three caring
contexts, resulted from various curfews and restrictions, which prevented or
restricted them from socialising outside the home. In seven cases, these were self-
imposed by the young carer and in the other six cases, imposed or enforced by the
parent, as described in the following statements:

'Cause I always want to stay in with my mum... (Abbie, 13, mother,
problem alcohol use);

I'm always trying to be home about twelve-ish, cause I know that she wants
to go to her bed and things like that and don't really want to keep her

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up…there's an extra dimension to anything you're planning to do…but it's difficult to know how much of it is down to yourself if you're maybe limiting yourself (Grace, 25, mother, physical disability).

The restrictions and limitations imposed by parents were evident in both explicit terms and implicit forms. On the one hand, explicit forms included prohibiting the young carer from going out:

> With my mum being ill, she sometimes doesn't like us going out just in case something happens to her…cause she doesn't like me staying with my chums just in case something happens to her again (Chloe, 13, mother, physical disability).

On the other hand, in terms of implicit restrictions, circumstances stemming from the parent's behaviour prevented some young carers from socialising outside of the home. For instance, two young carers living in rural settings reported that their mothers had lost their driving licences due to 'drink-driving'. As a result, the young carers no longer had the means to get out socially with friends, as highlighted below:

> She lost her license 'cause she was drink-driving as well…it was worse when I went to secondary school 'cause I was always wanting to go out and be with them [friends]…and I couldn't get (Julie, 15, mother, problem alcohol use).

The Impact of the Caring Context on Social Difficulties

Social difficulties were described consistently by the vast majority of the participants regardless of the nature of their parent's condition. Indeed socialising outside the family unit is a common adolescent concern. However, failing to invite friends home was an issue associated exclusively with parental substance misuse and mental health problems and was underpinned by embarrassment, stigma and a perceived lack of understanding of peers.

Health Impacts

A total of 27 young carers reported that they experienced health complaints or symptoms relating to their physical and/ or mental wellbeing, which they attributed to caring. As demonstrated in Table 4.13 below, 12 of the 27 young carers experienced multiple health problems. Each identified issue will now be considered.

Table 4. 13 – Health Problems and Issues Reported

	Participants	Stress	Anger and Upset	Depression	Self-Harm	Tiredness	Musculoskeletal Pain
Physical disability	James		✓		✓	✓	✓
	Peter	✓	✓			✓	
	Lewis	✓					
	Mark						
	Raymond						
	Chloe						✓
	Jane					✓	
	Charlotte						✓
	Grace	✓					✓
	Jenny	✓			✓	✓	
Substance misuse	Pamela		✓				
	Rose	✓	✓			✓	
	Caroline	✓		✓	✓		
	April	✓		✓		✓	
	Katrina		✓				
	Janice			✓			
	Julie	✓					
	Grant						
	Emily	✓					
	Abbie	✓					
Mental Health	Kayleigh					✓	
	Cameron	✓					
	William	✓		✓		✓	
	Rachel	✓					
	Donald		✓			✓	
	Douglas			✓			
	Susan	✓	✓		✓	✓	
	Nicole	✓	✓			✓	
	Tina					✓	
	Fiona	✓	✓	✓		✓	

Impacts on Young Carers Mental Wellbeing

The young carers self-reported a range of mental health impacts which included stress, anger, upset, self-harm and depression. In addition, a self-esteem measure,

The Rosenberg Scale (Rosenberg, 1965), was administered to the young carers to gauge their feelings of self-esteem and self-worth. Each will now be examined.

Stress

16 young carers stated that they experienced stress, an issue that was mainly associated with caring in the context of parental substance misuse or mental health problems. Of the 16, six were caring for parents with a mental health problem, six, for parents with substance misuse problems and four for parents with a physical disability. This included Jenny whose mother had a dual diagnosis of both physical and mental health problems. Nevertheless, whilst stress was a common occurrence, few of the participants elaborated on the specific cause of this, or the symptoms experienced when 'stressed'. Where discussed in greater detail, this was largely attributed to difficulties coping with caring in addition to other commitments such as school or work, as illustrated below:

> Like the pressure of being at home and the pressure of being at work just sort of...had a negative effect on my health so in January I got signed off then...it is a lot of stress (Grace, 25, mother, physical disability).

> 'Cause it does get quite stressful. Coping with home and school and stuff like that (Peter, 14, mother, physical disability);

In terms of the manifestations of stress, one young carer stated that she experienced physical symptoms:

> Sometimes I don't feel well because of the stress, 'cause my mum puts a lot of stress on me, I get a bad gut (Abbie, 13, mother, problem alcohol use).

Anger, Upset and Worry

Feeling angry or upset with the parent or about the caring responsibilities was discussed by nine participants, again mainly those caring for parents with substance misuse or mental health problems (four, mental health problems; three, substance misuse; and two, physical disability). This included one participant who was caring for his father who had both a physical condition and mental health

problems). Additionally, exhibiting concern or 'worrying' about the parent was a common experience, as discussed in the following section on 'parent-child role reversals'. Feelings of anger and upset were largely underpinned by frustration regarding the demands of the caring role or the problematic behaviour displayed by the parent, as evident in the statements below:

> Yeah, I get agitated quite easily...'cause the way mum gets my attention is you know to open the door...she buzzes like a couple of times and it just gets me really angry actually (Peter, 14, mother, physical disability);

> We used to argue all the time, you know, it'd be over her and the drugs and that and I used to just get annoyed with it (Pamela, 14, mother, problem drug use).

Depression

Six individuals caring exclusively for parents with non-physical conditions (three mental health problem and three substance misuse), expressed 'feeling down' or 'depressed' (although this had not been clinically diagnosed in any of the cases) due to their caring responsibilities. However, they did not elaborate on either the frequency or symptoms experienced, as illustrated below:

> And then I'm depressed for weeks, I'm never really happy (April, 16, mother, problem alcohol use);

> I think I'd get really down in the dumps (Fiona, 15, mother, mental health problem).

Self-Harm

Four young carers indicated that they had 'self-harmed' or considered self-harming in the past, in a bid to escape from their worries and problems. This included self-mutilation, suicidal thoughts and suicide attempts, as described below:

> There was just some days it got too much, just sort of...well put it this way I saved up some tablets that I found and I was going to take all them...cause

I'd had enough of it 'cause things, they were getting so bad...he was just so terrible to me...I was just tired of it, just couldn't hack it any longer (James, 18, mother, physical disability; father, physical disability and mental health problem);
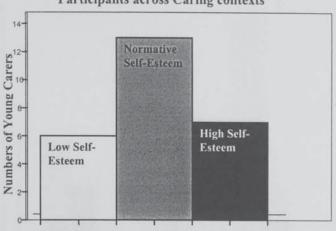
And I did cut myself, just a little wee bit, but not much, that was just another escape (Caroline, 23, mother, problem alcohol use);

I have self-harmed, I've...said that I was going to kill myself (Susan, 13, mother, mental health problem).

This was associated with caring for parents with non-physical conditions. Whilst two of the four young people were caring for parents with both a physical disability and a mental health problem, their self-harming behaviour was linked to the demands placed on them due to their parent's mental health problems.

Self-Esteem
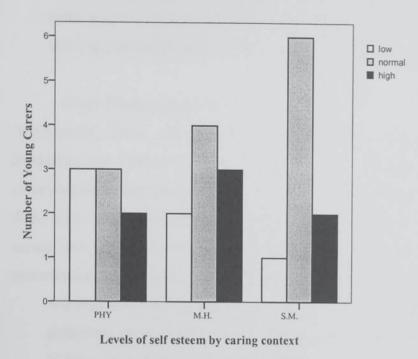
In terms of The Rosenberg Scale (Rosenberg, 1965), scoring guidelines suggested that from a potential of thirty, the average score for all age groups is twenty-two, and scores between fifteen and twenty-three indicates normative levels of self-esteem (Heatherton and Wyland, 2003). In the current study, a total of twenty-six young carers completed The Rosenberg Scale, and of these, approximately one-quarter or six of the participants demonstrated low self-esteem, one-quarter or seven high self-esteem, and the remaining half or 13 demonstrated levels within the expected range (see Graph 4.1 below). Collectively, these scores represented the normal 'spread' expected within any population.

Graph 4.1. - Combined Scores of Rosenberg Scale of all Participants across Caring contexts

Levels of Self-Esteem of all participants

Moreover, as demonstrated in Graph 4.2 below, there were no marked differences in levels of self-esteem according to the different caring contexts. Notwithstanding this, whilst a similar pattern was evident in relation to young people caring for parents with substance misuse or mental health problems, a slightly different pattern was apparent in terms of those caring for parents with a physical disability. With parental mental health problems and substance misuse, the majority of the participants exhibited normative levels of self-esteem, followed by high levels and thereafter, low levels. However, in terms of parental physical disability, equal numbers of young carers exhibited low and normative levels. Thus, a higher proportion of the young carers that were caring for parents with a physical disability experienced low levels of self-esteem. Nevertheless, these findings were suggestive rather than conclusive, because the small sample size prevented more detailed statistical analysis of the findings according to the different caring contexts. Furthermore, no particular differences were apparent in relation to the age or gender of the young carers.

Graph 4. 2. Levels of self-esteem by caring contexts

Levels of self esteem by caring context

Impacts on Young Carers Physical Health

In terms of the young carers concerns about their own physical health, particular problems noted included tiredness, headaches and musculoskeletal pain.

Tiredness

Tiredness was a commonly described complaint, with a total of 13 young carers attributing this to their caring responsibilities, specifically *'sleepless nights'*, due to either worrying about the parent or having disturbed sleep because of a need to assist the parent during the night. In order to cope or deal with tiredness, the participants discussed how they went to bed during their 'spare time' or 'slept in' in the mornings. This resulted in difficulties getting to school on time or alternatively, some described falling asleep during class. The majority - seven - of those that experienced such fatigue were caring for parents with a mental health problem. The following statement was illustrative of one young carer's experience of disrupted sleep and their fatigue:

Yeah, all night long, if there's something the matter she'll shout on me, 'cause I'm sleeping downstairs... I don't get to sleep at all...but at weekends if I'm staying over at my friend's house I just want to sleep, I just don't get out of my bed at all (April, 16, mother, problem alcohol use).

Other Physical Symptoms

Additionally, three young carers stated that they regularly suffered from headaches and a further one had a stomach ulcer. Whilst none of these young carers explicitly attributed this to caring, each can be a manifestation of stress and thus, there may have been some association. Furthermore, four participants, caring for parents with a physical disability, stated that they experienced musculoskeletal pain due to lifting and other physical caring tasks:

But it does sometimes hurt cause with her being really heavy it takes ages to push her...an hour later we're still like two inches up, she's really heavy (Chloe, 13, mother, physical disability).

The Impact of the Caring Context on Health Difficulties

There were some key variations in terms of the health problems reported in relation to the differing caring contexts. For instance, due to the nature of their role involving heavy lifting tasks, all of those young carers affected by musculoskeletal pain were caring for parents with a physical disability. In contrast, experiences stress, anger, depression, and self-harming were discussed mainly by those caring for parents with non-physical conditions. For example, of the 21 that reported such concerns, five were caring for parents with a physical disability (which included two participants whose parents had physical conditions and mental health problems), nine in relation to parental substance misuse and seven in relation to mental health problems.

Career and Employment Impacts

Due to the wide age range of the participants involved in the study, only those in the older age group had direct experience of work-related issues. In relation to this, the main issue reported concerned difficulties balancing work and caring.

However, two further issues were also evident, namely a lack of planning over one's future career and an association between caring and career aspirations. The latter two issues were also highlighted by some of the younger participants. Each issue will now be discussed in turn.

Balancing Work with Caring

Six older young carers reported difficulties balancing paid work in addition to managing ongoing caring responsibilities. This either prevented them from seeking work outside the home or where they were employed, they had been required to reduce their working hours or take time off to care, as illustrated in the statements below:

> Well, she [home carer] didn't come down yesterday and I had to phone up and say, 'I'm having to change plans' and say 'Right, I'm not going to come in today' (Mark, 25, mother, physical disability);

> Last year I was working full-time but I had to cut down to part-time 'cause I could see that she wasn't really coping that well (Grace, 25, mother, physical disability).

All six occupied a primary caring role and were living in the absence of a second parent at home, yet all received some formal assistance. This adds further credence to the assertion that formal care sources do not protect young carers from the negative consequences of caring to the same extent as the availability and support of a second parent.

Lack of Planning

Whilst all of the participants across the three caring contexts described their career aspirations, six of the older young carers commented upon difficulties fulfilling these due to their caring responsibilities or alternatively, they demonstrated a lack of planning in realising their ambitions, as highlighted below:

> I just take each day as it comes really...don't really plan for my job. (Jenny, 17, mother, physical disability and mental health problem).

Nevertheless, a lack of planning for the future is not unusual during adolescence and thus, this issue is not necessarily unique to young carers.

Career Aspirations Linked to Caring

The young caring role appeared to have had some influence over future career aspirations. The participants expressed an interest in pursuing careers in a range of caring professions such as social work, social care, nursing and childcare (in terms of becoming a teacher or nursery nurse), as illustrated in the following quotations:

> I've applied to college for an access to care course...maybe work in a nursing home after that (Charlotte, 15, mother, physical disability)

> At one point I wanted to be a primary school teacher (Jane, 14, mother, physical disability);

> 'Cause I know so much about people on drugs and that I'd like to be a drugs counsellor...'cause everyone that comes to my house says you would be a good drugs counsellor 'cause you know what it's like (Pamela, 14, mother, problem drug use).

In addition to these obvious caring-related professions and vocations, perhaps a more implicit link existed between young caring and other career choices. Similar to the recognised caring professions and vocations, other career choices (such as acting and drama; the armed forces or police force; catering and animal care) commonly discussed by the young people, were perhaps borne out of caring-related experiences. In terms of this, firstly acting and other forms of self-expression such as art and writing offers a means of 'escape' for the young carers, or offered an opportunity to 'try out' a range of new and exciting roles. Secondly, careers in the armed forces or police provide a structured and regimented lifestyle, similar to caring perhaps. Additionally, such careers require high levels of organisation, control and self-discipline, traits perhaps acquired through caring.

Thirdly, an interest in animal care was perhaps an alternative means of expressing care for another living being as illustrated below:

> I want to work in all different kinds of yards and get experience with all different types of horses whether it's driving horses, endurance horses, show-jumping...I either want to work in or own and run a horse sanctuary for horses that have been traumatised or harmed or abused (Emily, 16, father, problem alcohol use).

Lastly, catering requires the use of the key life skills learnt through caring or was perhaps indicative of nurturing tendencies, as indicated in the following statement:

> Because I do it at home, that's why I do H.E. in school...get into catering maybe (Peter, 14, mother, physical disability).

Although an interesting point, there is no actual evidence that such an interest in acting or the armed services is greater than that of other young people of similar social backgrounds, but without caring responsibilities. Therefore, in the absence of such comparative information, it is difficult to establish a firm link.

Impact of Caring on Spatial Transitions

In terms of spatial transitions, two contrasting patterns were evident, namely 'premature' and 'delayed' moves to spatial independence. Where young carers had moved or planned to move away from their parental home, this was largely conditional and rarely equated to an absolute cessation of their caring responsibilities. Each of these issues will now be discussed.

Moves to Spatial Independence

Firstly, a total of 17 young carers were either living independently or had hoped to move away from their parental home as soon as practicably possible. Of these, six were living apart from their parent - four lived independently and the other two, in foster care. Of the six, one moved following her mother's death and the other five moved because of conflicts and tensions between themselves and their

parent. This was due to abusive treatment or the chaotic behaviour of the parent relating to their substance misuse or mental health problem. The following comments illustrated the young carers' decisions to move:

But it was a relief to get my own space...peace and quiet and where I can sleep properly as well (James, 18, mother, physical disability; father, physical disability and mental health problem);

I was glad to get out of there, 'cause things were getting quite bad, she used to be drinking quite a lot, be drunk when we came home from school (Julie, 15, mother, problem alcohol use).

The remaining 11 young carers planned to move away from their parent's home as soon as possible, often quoting age 16 as the point at which they envisaged leaving. Eight of the 11 young people who asserted a desire to move in the future attributed this to difficulties living with their parent, as illustrated in the comments below:

When I'm older, well, yeah 'cause I want to move out 'cause she's doing my head in now...she's up all night up all the time...she just does my head in now (Pamela, 14, mother, problem drug use);

I'm quite fiercely independent, unlike my brother...he's relatively happy sort of here, where I like being away from it all... (Rachel, 15, father, mental health problem).

Conditional Factors Facilitating or Preventing Moves to Spatial
Independence

A move to spatial independence was perceived by the participants as being most easily facilitated, or indeed only practicable in the context of various conditional factors, namely the availability of alternative support for the parent in the absence of the young carer. Indeed seven of the 11 young carers who stated that they wished to move away, asserted that they would action this plan only if their parent

was well enough, or if someone else would be available to care in their absence, as illustrated in the comments below:

> As soon as I am 16 I want to get out of school and get away from all this...my mum should be stronger, if she's not I'll probably move beside her (Abbie, 13, mother, problem alcohol use);

> I think I'd be more happy if she had more support like maybe a home help or someone coming in during the day, I'd feel more comfortable about doing it then, but at the moment not really (Grace, 25, mother, physical disability);

> I realise that when I do move, if I'm somewhere far away, then my mum does have friends who know, so they could always come and go (Donald, 14, mother, mental health problem).

Sense of Continuing Responsibility Preventing Moves

Moreover, in 11 of the 17 cases where the young carer was living separately from the parent or planned to do so in the future, there was still a strong sense of continuing responsibility for the parent. As illustrated in the statements below, this was expressed in terms of worrying about, or feeling responsible for the parent's wellbeing. Tactics for addressing such concerns included making regular visits home and maintaining regular telephone contact with the parent.

> Yeah...still got a sort of responsibility feeling of looking-after my dad... yeah, so still feel responsible for what he's doing, how's he feeling and stuff (James, 18, mother, physical disability; father, physical disability and mental health problem);

> But, I'd come home once every second day to come and help out, so she's not left completely (Susan, 13, mother, mental health problem);

> I'd look to live there and come back in the weekend and trust that the care here is what I need and I'm only a phone call away (William, 16, father, mental health problem).

A Desire to Stay at Home

In contrast to those who had moved away or wished to move in the future, nine of the young carers stated that they could not envisage themselves moving away from their parental home. This was expressed in terms of a strong reluctance to move away, or a need to remain in close physical proximity to the parent. This was largely underpinned by a need to continue to care for the parent. Despite this, there were clear variations in terms of the interpretations of geographical 'closeness', ranging from the same house to the same town to the same country, as illustrated in the following statements:

> Now I really wouldn't want to go anywhere or study anything that would take me away outside Aberdeen. Cause I know even if I was doing a course and it was full-time as long as I'm sort of in the area then I'm always at hand or maybe like in an emergency or something... (Grace, 25, mother, physical disability);

> I'm going to get a granny flat for him. I think that will probably be the case (William, 16, father, mental health problem).

The Impact of the Caring Contexts on Spatial Transitions

Of the 17 young people that sought spatial independence, three were caring for parents with a physical disability (including two caring for parents with both a physical disability and a mental health problem); seven for parents with mental health problems and the remaining seven, for parents with substance misuse problems. This suggested that the young carers were most likely to initiate early moves to spatial independence to escape the chaotic and unpredictable home situations, commonly associated with mental health problems and substance misuse. Also, to add credence to this, the majority of those that indicated a firm desire to stay at home were caring for parents with a physical disability. Accordingly, of the nine young carers who planned to remain at home, five were caring for parents with a physical disability, two for parents with a mental health problem and two for parents with substance misuse problems.

<u>Impact on Relationships</u>

A further issue identified by the young carers related to tensions and problems in their family relationships with their parent(s) and/ or their sibling(s), as indicated in Table 4.14 below. Nevertheless, this issue was not fully discussed by all of the participants. Indeed, some simply stated that caring had little or no recognised effects in terms of their relationships. Others reported normative tensions which were apparently unrelated to caring:

> Sometimes it can be good, but sometimes we just have our arguments like all families have (Chloe, 13, mother, physical disability).

The effects of caring on the differing types of relationship will now be examined.

Table 4. 14 - Difficulties Reported within Family Relationships

	Participants	DIFFICULTIES WITH FAMILY RELATIONSHIPS	
		Difficulties with siblings	Difficulties with parent
Physical disability	James		✓
	Peter		
	Lewis		
	Mark	✓	
	Raymond		
	Chloe	✓	
	Jane		
	Charlotte		
	Grace		
	Jenny	✓	
Substance misuse	Pamela		✓
	Rose		✓
	Caroline	✓	✓
	April	✓	
	Katrina		
	Janice		
	Julie		
	Grant		
	Emily	✓	✓
	Abbie	✓	✓
Mental Health	Kayleigh		
	Cameron		✓
	William		
	Rachel		
	Donald		
	Douglas		
	Susan	✓	✓
	Nicole	✓	
	Tina		
	Fiona		✓

Relationships with Siblings

Nine of the 30 young carers reported that there were tensions and resentments in the relationships that they shared with their siblings which resulted from, or were related to caring. Such problems were largely underpinned by resentments about the disproportionate allocation of the caring responsibilities, as indicated below:

I hate her, but she's my sister so I love her, but I don't like her...I was always the one that would stay in and help she was away 'gallivanting' and stuff (Jenny, 17, mother, physical disability and mental health problem);

Half the time I just hate him 'cause I have to do everything and he just doesn't really do anything, he just lolls about the house and stuff, but we're sort of getting on better even though I do resent him, we get on better 'cause we have to (April, 16, mother, problem alcohol use).

In contrast, only one young carer explicitly stated that whilst she undertook the majority of the caring tasks, she felt no resentment toward her brother for his lesser contribution. This was justified on the basis of gender differences:

Yeah…If I'm not there…maybe if I've got to be somewhere or like when I was working he'll do what he can but obviously with him being at school and at university and things…it's difficult for him to get the time. Yeah…and with being a boy as well…there's certain things…especially if it's a woman you're caring for…'cause at his age as well you'd feel embarrassed... It's not something that automatically he thinks about like a woman would (Grace, 25, mother, physical disability).

The nature of the parental condition was irrelevant in terms of the presence of sibling tensions, although family composition and the availability of additional support were perhaps significant factors, particularly the presence and availability of a second parent. Whilst all nine of the participants that reported such problems were living in the context of formal assistance and most (eight of the nine) received some informal help from outside the immediate family, it was perhaps support in the family that was most significant in terms of sibling tensions. Although all identified that their siblings assisted to some extent, none had the support of a second parent. Arguably, this increased the types and amount of caring work that the young carer and siblings were expected to undertake. In turn, this perhaps exacerbated tensions.

Nevertheless, some positive impacts on sibling relationships were also reported. These resulted from the physical closeness facilitated by caring, which enabled a greater level of emotional closeness, as illustrated in the following statements:

It's closer because we're spending more time together singularly, ourselves (Rose, 18, mother, problem alcohol use);

Me and my sister are easy come, easy go, like deciding who goes out and stuff like that and I think that we've actually got closer with my mum being ill, like we're depending on each other to do certain jobs around the house, help each other out and stuff. Like if I didn't have my sister there it would just be me and if she didn't have me, it would just be her, so we're kind of glad that we have each other and take turn, and to talk to and that (Fiona, 15, mother, mental health problem);

Again, the positive impacts that caring had on sibling relationships were discussed by participants across the caring contexts. Thus, the nature of the parental condition appeared to have no bearing on this.

Parental-Child Relationships

Similarly, both tensions and positive effects were reported in terms of parental–child relationships, although the extent to which caring underpinned tensions must be queried. Indeed, rather than resentments about undertaking caring tasks, nine young carers reported that tensions resulted from the nature of the parental condition. This pertained to personality changes, as well as aggressive and violent behaviour in the contexts of parental mental health problems and substance misuse, as highlighted in the statements below:

My dad really didn't appreciate it and it's quite a long story like, but he took his aggression out on me all the time really, all the time (James, 18, mother, physical disability; father, physical disability and mental health problem);

In a way I think she blamed me and then she blamed my step-dad and she was just feeling sorry for herself and she was drinking more and she was being more violent to me…it got a bit much (Rose, 18, mother, problem alcohol use).

Conversely, the positive impacts reported in relation to the parental-child relationship could be directly attributed to caring. The notion of 'closeness' was again reported. Similarly, this resulted from the enforced physical and emotional proximity between parent and child, as illustrated in the statements below:

> The good things, you've probably got more contact with the person than you usually would, I reckon (Peter, 14, mother, physical disability);

> Yeah, it's made it stronger, you know 'cause we're a team. There's nothing that we do that we don't know what each other's doing and we always talk about what we're going to do and how we're going to tackle things, so it has brought us stronger together in that way (William, 16, father, mental health problem).

In one case, the notion of 'closeness' was discussed in terms of the blurred generational boundary that existed between one young carer and her mother:

> And me and my mum are more like best friends than mother and daughter (Katrina, 16, mother, problem alcohol use).

Romantic Relationships

Moreover, seven participants discussed how caring had prevented them from either pursuing or considering a romantic relationship either at that particular stage or in the future. This was discussed by both older and younger participants. Firstly, some of the older young carers who had previous experience of personal relationships discussed how these had been detrimentally affected by their caring responsibilities:

> Yeah, I split up with my boyfriend because of it...we'd been going out a year and 4 months and 'cause my mum got really bad, I got stressed out because of it and we ended up splitting up because of it (April, 16, mother, problem alcohol use).

Secondly, some of the younger participants indicated that they could not envisage having a relationship in the future if they were still caring, as their parent was their ultimate priority:

> A lot of the time, I just don't really think about the future, you just get on with each day as it comes, you don't really think that much about what's going on in the future and things. So when there's a third person in the equation you're maybe pulled in two directions...you've got conflicting demands (Grace, 25, mother, physical disability).

Thirdly, it was perceived by both the younger and older participants that any future relationships would be detrimentally affected due to their ongoing caring responsibilities:

> They'd have to understand 'cause if something happened and you had to go and stay with your mum and she was like really, really bad, they would have to understand that you couldn't be there all the time. Like most husbands would go out working and they come home and their dinners on the table...they'd have to understand that you wouldn't always be there when they get home from work (Susan, 13, mother, mental health problem).

<u>Summary of Key Points from Section 4.6</u>

Thus, as indicated by the participants, the impacts of young caring spanned a number of key domains, which included their education, social life, health, spatial transitions and relationships. They described their experiences in relation to these in largely negative rather than positive terms. Significantly, those that experienced the most extreme effects were caring for parents with either substance misuse or mental health problems.

4.7 Parental-Child Role Reversals

In terms of parental-child relationships, the notion of role-reversals was also apparent. Whilst only a small minority of the participants explicitly stated that they were undertaking a parental role at home, it was questionable whether this

actually applied to a greater number of young carers. Indeed the nature and type of the tasks undertaken by many of the young carers could have been deemed 'parental'. Also there was some suggestion that parents abdicated from their parenting role, which perhaps necessitated the adoption of a parental role by young carers in such situations. These issues will now be discussed further.

Four participants explicitly acknowledged the existence of role reversals between their parent and themselves, as indicated in the following statements:

> I think a lot of the time you actually become more like a parent rather than the child...it's kinda like a role reversal sometimes, it's difficult to sort of have a definite sort of boundary between you...'cause you're doing what you'd expect a parent to do for you and you're doing it for your own parent (Grace, 25, mother, physical disability);

> I just saw him as the child and me as the parent...he was like a 'big bairn' (Emily, 16, father, problem alcohol use).

Whilst the remaining 26 young carers did not *explicitly* acknowledge a reversal of roles, there was some evidence which suggested that role reversals were perhaps experienced. In terms of this, firstly, seven participants caring for parents with substance misuse or mental health problems identified that their parent abdicated from the parental role during relapses or exacerbations in their condition. Such 'abdications' were described in terms of parental absences, either from the home or within the home (in situations where the parent spent much of their time in bed away from the family). This resulted in the young carers looking-after themselves, and in some cases, their siblings too, as well as enduring extreme worry about their parent's wellbeing, as illustrated below:

> I think that at times when she was least drunk or more in control, that was when she was more of a parent, but when she was ill-er or drunker she wouldn't, but then she didn't know what she was doing...it was certainly a relief when mum did something, if she put out the washing or something it

was a relief...it was all up to me then...to do the stuff she was meant to (Caroline, 23, mother, problem alcohol use).

Although this was not overtly described as resulting in role-reversals, arguably in the parent's 'absence', the young carer was required to undertake the role of 'parent' in the home. Secondly, the majority of the participants discussed how they undertook a range of roles and tasks which they conceptualised as adult tasks, but arguably could have been categorised as parental tasks. The actual roles and tasks undertaken will now be considered in detail.

The Parental Roles Undertaken by Young Carers

The Parental Role and Parental-Type Tasks

Firstly, there was agreement amongst the participants over the defining characteristics of the parental role. Indeed all associated this with particular domestic tasks, such as cooking and shopping, as illustrated below:

> She doesn't really seem like my mum anymore, she's just always there really, she doesn't do motherly things, she doesn't go out shopping with me, doesn't really do anything (April, 16, mother, problem alcohol use);

> Well at work I share a room with a 19 year old that can't cook, can't clean and takes her washing home to her mum to do...I do all of that stuff and get called the mother of the group at my work.. (Emily, 16, father, problem alcohol use).

Thus, as the majority of the young carers were undertaking such domestic chores, arguably they were to some degree undertaking a parental-type role. In addition, the participants described their involvement in a range of other tasks and roles normatively associated with the parental role. These included: ensuring the safety and welfare of the parent; setting boundaries for the parent; organising the parent's daily routine; cooking meals, feeding and monitoring their parent's nutrition; and dealing with the family finances.

Ensuring Parental Safety and Welfare

Arguably, an overarching parental role or responsibility may involve promoting the welfare of the child. However, in the current study, the participants showed a heightened concern about their parent's welfare, arguably to an extent over and above that expected within families. The young carers essentially promoted the physical and mental wellbeing of the parent, through a range of practical tasks.

In terms of parental welfare, worrying about the parent was discussed by 19 young carers across the three caring contexts. Whilst this was a common experience, 'worrying' was evident in differing guises and to varying degrees. Firstly, ten participants who were mainly caring for parents with substance misuse or mental health problems described this as an extreme and constant feature within their lives. Worrying even persisted during periods of relative stability in their parent's condition. In such cases, even brief separations from the parent (whilst at school or out socialising) exacerbated the worry and concern experienced, as highlighted below:

> Well, I tend to worry more 'cause I'm away from her, so that's why it affected it my absences... (Tina, 14, mother, mental health problem);

> It's always on my mind...cause like I mean it's during school as well, it's still on your mind (Kayleigh, 15, mother, mental health problem).

Secondly, a total of six young carers reported that they normally worried only when confronted with a particularly stressful situation, such as when the parent suffered a relapse or was admitted to hospital, as described below:

> Like, if she's to go into hospital, I'll still worry quite a lot. It's not that I just don't care anymore (Peter, 14, mother, physical disability).

Of these six participants, three were caring for parents with a physical disability; two for parents with a mental health problem and one in the context of parental substance misuse. This suggested that those most likely to worry on a transient basis were caring for parents with a physical disability.

Thirdly, a further three young carers supporting parents with non-physical conditions stated that being separated from their parent actually alleviated their worry. Basically, this allowed them to forget about their parent's problems or their home situation, as highlighted in the following statements:

When I was at school I just used to forget it, but when school finished and I got to the end of my lane, I was hoping that she wouldn't be drunk and there were some days he [brother] used to come up the days and meet me and say 'oh, mum's drunk' and we used to walk home slow (Julie, 15, mother, problem alcohol use);

When I was at school, I forgot about it, I forgot about every problem (Rose, 18, mother, problem alcohol use).

Moreover, various tactics were employed in order to alleviate the worry experienced and to promote the welfare of the parent. All of these involved 'checking up' on the parent, taking time off school to be at home with the parent, maintaining regular telephone contact with them, and taking basic safety precautions such as locking doors or switching off lights at night. However, in the context of substance misuse, this also involved undertaking extraordinary measures, such as monitoring the parent's alcohol intake or removing or hiding alcohol or other substances:

Mum used to hide bottles under the sink, so I used to go and search the house when she wasn't in, take them away and stuff (April, 16, mother, problem alcohol use).

In addition, this involved watching over parents' who were threatening to self-harm:

I've always stayed inside just in case my mum does something stupid, 'cause she's just jumped out the balcony before (Abbie, 13, mother, problem alcohol use).

Lastly, this meant watching over parents after they injected or ingested drugs:

> Sometimes, I'd wake up in the middle of the night, she used to sit up in her bedroom and she used to inject it, but then she went onto the smoking it the other way, but when she injected it I'd go to my bed and if she was sitting there, I used to get worried in case she stopped breathing and that and I'd wake up in the middle of the night and check, just to check up on her (Pamela, 14, mother, problem drug use).

Setting Boundaries and Organisation

Additionally, a further role outlined by eleven of the participants (caring mainly for parents with non-physical conditions) involved setting boundaries for the parent and organising the parent's day-to-day life. This was described by one young carer in terms of setting boundaries around and the parents' alcohol use, as indicated below:

> I used to say 'Mum, I'll tell you what, we'll have wine with our meal, we can have a bottle of wine in the evening' and she agreed to that obviously...but if you take the drink away, they go out looking for more. The illness says, 'I want drink, I need drink now', so that's when she maybe got in the car drunk. Then there was the local shop that was two minutes down the road and she used to go down there and buy and I remember asking the shopkeeper, 'Will you please not sell mum drink', but legally they can't do that (Caroline, 23, mother, problem alcohol use).

This was described by another participant in terms of organising his father's daily schedule:

> What I have in the house is a notepad, because part of his illness is, or part of his medication is, he sleeps late and obviously I'm up early, so what I tend to do, is write him a 'to do' list, so that what I want done and what I expect done in the day, I'd write it down. You know I wouldn't put 'I expect', I'd put 'How about...' 'Let's do...' or 'Could you...' and that's what I tend to do when I want things done and I phone him and just say 'Are you up yet' (William, 16, father, mental health problem).

Parental Nourishment

In terms of parental nourishment, 15 young carers highlighted that they cooked for their parent, or in one case, assisted to feed their parent through a gastric tube. In addition, several of those that were caring for parents with substance misuse problems, had to encourage their parents to eat. As indicated in the statement below, parents would forget to eat or would forsake food whilst intoxicated:

> 'Cause my mum puts a lot of stress on me, like she doesn't listen to me, when I say about the eating she just ignores me and tells me to shut up and all that and to get out of her face (Abbie, 13, mother, problem alcohol use);

> No she'd never eat, she was down to like 5 stone and that then...so, she never ate...'cause I used to try to get her to eat all the time, I used to when I'd make myself something to eat, I'd make her as well, but she'd never eat it, it just got given to the dog (Pamela, 14, mother, problem drug use).

Family Finances

One role that the young carers appeared to have minimal involvement in concerned organising the family finances. In only two cases was it evident that the young carer was financially supporting the parent, or involved in planning the family's finances:

> I'll maybe help him out with a bit of money as well if I can, but if I do that, that lowers me (James, 18, mother, physical disability; father, physical disability and mental health problem);

> I've got a mandate...I can access details on his account, 'cause that's one of his main things and one of the things that we were scared of when he broke down last time was that we didn't have enough money... I've taken out financial things with the company...I've taken out shares within the company, so if I can make that extra on top of my hours, it's better that way (William, 16, father, mental health problem).

The other participants appeared to have minimal knowledge about the family's financial situation or expressed that the parent supported them financially:

> Well, my mum's partner Charlie, he helps out a bit, but he just deals with the financial side and the bills and stuff like that. 'Cause I'm not allowed to do it 'cause I'm not 16 yet (April, 16, mother, problem alcohol use);

> She always gave me the money back...sober or unsober I think she'd remember and say 'Oh, here's for your tea what you bought last night', I mean she always did that. And she says, 'Oh can you go down the shop and get some bread, do you want money'...she'd make me take it from her purse, she wouldn't make me pay for her cigarettes 'cause I don't smoke (Rose, 18, mother, problem alcohol use).

In relation to this, it must be regarded that many of the participants were perhaps too young to successfully manage money or the family's budget.

Parenting Oneself, Siblings and Others

In addition to undertaking parental roles in relation to the parent, the young carers were also required to parent themselves, their siblings and in some cases, also others outside the family. A total of 17 young carers described roles and tasks which pertained to this. The majority of these young people were caring for parents with non-physical conditions (two physical disability; five mental health problems and ten substance misuse). Perhaps this suggested that parents with substance misuse or mental health problems abdicated from their parental roles to a greater extent than parents with a physical disability. In such contexts this increased the need for the young carers to adopt the role of 'parent'. Moreover, only one of the 17 young people had a second parent at home, which indicated that the parental role was likely to fall on the young carer where there was no second parent available to take it on.

Firstly, the participants expressed this notion of looking-after (or parenting) themselves in terms of undertaking practical, domestic and self-care tasks, as indicated below:

> I had to do much more for myself, like cook my supper and tidy up and everything really (Grant, 16, mother, problem alcohol use).

Secondly, where the participants described 'parenting' their siblings, in all cases this related to those younger than the carer. As illustrated below, the tasks undertaken were those normally carried-out by a parent, such as assisting with homework, cooking meals and getting siblings ready for school:

> My brother was like round about 10, so I had to look after him, make sure he had everything ready for school and stuff like that, she would do that as well, but I would like, make sure...well, it's like you're helping out with your family, in my case I was a young carer because I was looking-after my brother, his tea and homework and that, when I shouldn't have been, it should have been my mum, but like I was always there for him and just make sure everything is ok (Julie, 15, mother, problem alcohol use).

Conversely, two young carers with older siblings discussed how they themselves had been 'parented' by their older siblings, as indicated below:

> When she [sister] was living at home, I wasn't really doing much cooking 'cause she'd do the cooking 'cause she was older, she kind of took on the role of being 'mum', so I didn't actually do that much it was just tidying and that. And [sister] practically took on the whole mum (Tina, 14, mother, mental health problem).

Furthermore, two individuals discussed how they also carried-out parenting roles in respect to others outside the family context, as highlighted in the following statement:

> I get called the mother of the group at my work...there's these really old cookers at work and nobody could work it apart from me, they're learning now, but I was the first one to (Emily, 16. father, problem alcohol use).

Again, this highlighted how the young carers associated 'parenting' with domestic tasks.

Others Undertaking Parental Tasks

In addition, seven young carers described how other people fulfilled specific parental roles and tasks, such as practical tasks (cooking and shopping), as well as emotional support:

> She's [sister] got two carers when she's here...when they're here, they usually cook me food (Peter, 14, mother, physical disability);

> I've been told that I've got the support of my best friend's mum whose been really good over this past couple of months...so even if I don't have my mum's support, I've got her support, she's made that quite clear (Rose, 18, mother, problem alcohol use).

Recognition of the Parental Identity

15 young carers clearly viewed their parent as the parent, even though they themselves had assumed a range of parental-type roles and tasks. This parental identity was associated with advisory and disciplinary functions, as indicated in the following statement:

> I mean, if mum says, don't bother going I won't go...if I want to do things, I'll do it, you can't stop me. The only person likely to stop me is mum (Mark, 25, mother, physical disability).

Additionally, there was some evidence that the parents themselves strived to maintain their parental identity, as indicated in the statement below:

> I think that sometimes it can get quite confusing...'cause sometimes I'll say to my mum oh you can't do that and she'll sometimes say, 'Oh who's the parent here'...it puts you in your place (Grace, 25, mother, physical disability).

However, as the parental role was also associated with practical and domestic tasks, the division between parental roles and the parental identity was not clear-cut.

Dependence and Interdependence in the Family

There was some discussion around the notion of parental dependence, although this was mainly evident in implicit terms as the parent *'relying on'* or *'leaning on'* the young carer. Interestingly, only one participant stated that he viewed the relationship he shared with his father as one of *interdependence*:

'Cause we're a team, there's nothing that we do that we don't know what each other's doing and we always talk about what we're going to do and how we're going to tackle things, so it has brought us stronger together in that way (William, 16, father, mental health problem).

Adult Roles and Maturity

Rather than viewing themselves as 'parents', however, 16 participants caring mainly for parents with non-physical conditions, indicated that they were mature for their age or 'more adult' than their peers, as indicated in the statement below:

Probably when my mum went into hospital and I was looking-after my dad that's probably when I felt different, 'cause I had to grow-up sort of quicker. Think on a lot of stuff to do and everything, yeah, I felt like I had to grow-up quicker. Probably when he was depressed I'd be taking on more of an adult role... (James, 18, mother, physical disability; father, physical disability and mental health problem).

Interestingly, maturity was again viewed as task-orientated, and was measured by comparing the type and amount of practical tasks carried-out (in terms of what one *does*) with those undertaken by peers:

I feel a bit older 'cause children my age don't really do anything at all (Nicole, 11, mother, mental health problem).

In addition, maturity was discussed in terms of *'bypassing childhood'*, or as a consequence of particular family circumstances, particularly living in a lone-parent family:

> I'd say I'm a little bit more mature than the people I hang around with, the one's that haven't had that, the one's that have had two-parent families, they're a little bit more immature (Tina, 14, mother, mental health problem).

In more implicit terms, maturity was related to having an adult mindset or making adult choices, particularly in terms of forfeiting adolescent experimentation:

> I think that it's helped me develop and mature much more quicker and I'm able to do much more things maybe other people wouldn't. And I haven't fallen into the traps, like drugs and alcohol, which I've actually lost a lot of friends through. And obviously I had to move away 'cause I felt that that was rather dodgy to go down that road as it were of doing that because of basically having the life of having social services on your door, but just generally, the general fact that you've got to be there for him (William, 16, father, mental health problem).

Nevertheless, early maturity' was not universally described by the participants. Indeed several of the participants felt no older than their chronological ages and a further two with older siblings, felt younger. In one case, the participant justified 'feeling her age' on the basis of the tasks that she undertook:

> ...because at 14 years old, we should be starting to cook and tidy and stuff... (Tina, 14, mother, mental health problem).

Summary of Key Points from Section 4.7

Whilst several of the young carers described their parent's dependency, this did not necessarily imply that they viewed their relationship with their parent in terms of role reversals. Indeed this concept was referred to in direct terms by only a very small number. Instead, the majority referred to the roles and tasks that they had assumed as 'adult tasks'.

However, perhaps a greater proportion of the participants undertook 'parental' roles than acknowledged. In support of this assertion, firstly, the majority of the young people had assumed responsibility for a range of practical, domestic and welfare tasks self-defined as 'parental'. Secondly, the levels and types of worry described and discussed by the participants appeared to be beyond 'normal', rather than indicative of healthy levels of interdependence. This was particularly evident in relation to those caring for parents with substance misuse or mental health problems. Finally, the parents periodic 'abdications' from their parenting responsibilities, often resulted in the participants fulfilling the parenting role in respect to themselves and their siblings.

Despite this evidence, there was still a firm sense that the parent maintained their parental identity. This indicated that the parental role and parental identity were viewed as distinct elements and thus, parental 'functions' were separate from parental 'status'. However, ambiguities existed here as 'parenting' was clearly associated with domestic, practical and control functions, which in many cases, were fulfilled by the child rather than the parent. Thus, the elements of parental identity and parental role appeared to be closely bound and interdependent.

A Commentary on the Findings According to the Age of the Respondents

As there was only seven young adults (aged 18-25) involved in the study, the sample was not wide enough to fully differentiate according to age. Moreover, in line with the research questions it was not sought to differentiate the findings according to age. The older participants were included in order to provide an insight into the effects of young caring into early adulthood. For instance, the older participants could reflect on their actual experiences of work and spatial transitions, whereas the younger participants had no personal familiarity in relation to these areas.

However, in many ways the children and young people were on a par. Indeed, the younger participants exhibited levels of maturity beyond their chronological age, a finding highlighted elsewhere (Tatum and Tucker, 1998; Dearden and Becker,

2000; Banks et al, 2002b; Aldridge and Becker, 2003; Thomas et al, 2003). They discussed and described similar issues and concerns including difficulties with personal and family relationships and the adoption of adult roles and tasks. Thus, the differences between the younger and older participants were not as significant as age alone may have suggested. Notwithstanding this, the very young participants had increased difficulties in expressing themselves clearly and their linguistic abilities were more limited than the older participants and thus, they required much more prompting from the researcher.

4.8 Conclusion of the Main Points from the Findings Chapter

In conclusion, the current study set-out to explore firstly, the understanding of young carers around definitional issues and secondly, how and the extent to which the nature of the caring context affected young carers' experiences, which included parental-child role reversals. These issues were examined with a mixed group of 30 young carers across three different caring contexts. The key findings will now be summarised.

Firstly, in terms of definitional issues, there was a somewhat limited recognition of the term 'young carer' as equating to one's own caring role at home. Instead, there was an evident association between the term and alternative comprehensions such as being a member of a young carer's group, paid caring and caring for persons with a physical disability or in contexts where the main tasks undertaken were practical and measurable in nature. The latter association was arguably the most significant as those caring for parents with substance misuse or mental health problems were generally not recognised because of their unquantifiable - yet highly challenging - roles. Essentially, this lack of recognition, as well as the young carers' own failure to disclose their caring status, served to exacerbate the invisibility of those young carers perhaps most in need of support.

Secondly, the 'impacts' of young caring were considered in relation to a range of key domains. These included education, social life, health, work, relationships and spatial transitions. The impacts were reported mainly in negative terms and were construed as 'problems', with few positive effects mentioned. In addition, key differences in the problems and experiences reported were evident according to the different caring contexts. Generally, those most adversely affected were caring for parents with substance misuse or mental health problems. This perhaps reflected the chaotic and unpredictable lifestyles of those living in such contexts, because of the nature and demands of, and the behaviour associated with the parental condition. Such young carers were 'doubly disadvantaged' due to both the extent of their difficulties, combined with their increased invisibility. In addition to the caring context, the 'impacts' reported were perhaps partly attributable to factors other than, or in addition to, caring. Of particular significance was the presence and availability of a second parent at home to care, which appeared to act as a protective factor against some of the potential impacts experienced. Also the study involved a wide age range of young carers. Whilst there were some differences according to age and developmental stage, it was neither practicable nor necessary to fully differentiate the findings according to this due to the limited sample size and the scope of the research questions. The older participants provided an insight into the effects of young caring into young adulthood, although in many ways the younger participants were on a par with their older counterparts in terms of maturity. Some further commentary in terms of age will be provided in the discussion chapter.

Lastly, in terms of role reversals, the majority of the young carers acknowledged that they had assumed adult roles and tasks, although very few explicitly recognised role reversals between themselves and their parent. However, perhaps a greater number actually undertook 'parental' roles than was acknowledged. Indeed, the majority had assumed roles and tasks that were associated with or had been self-defined as being parental roles, namely practical and domestic tasks and welfare roles. Moreover, whilst the parents were generally viewed as the parent, a blurring between the parental role and parental identity was evident. Indeed the

practical roles directly associated with parenting were very often undertaken by the young carers, rather than the parents. Whilst this was evident in relation to the young carers across the three caring contexts, two key differences relating to this were evident. Firstly, periodic abdications from the parental role by parents with substance misuse or mental health problems increased the level and type of caring responsibilities undertaken. Secondly, the levels of worry and concern experienced by young carers of parents with substance misuse and mental health problems were heightened.

Chapter 5 – A Discussion of the Key Findings

5.1 Introduction to the Discussion Chapter

Of fundamental interest within the current study was the impact that differing 'types' of parental conditions had on the resultant issues and impacts experienced by young carers. This constituted a somewhat neglected area in the existing body of young carers' literature. Where previous studies on young caring have reflected on the impact of the parental condition, they tended to consider either physical disability or mental health problems, or alternatively, a specific diagnosis. Thus, genererally these studies have not compared young carers experiences across a range of caring contexts. Other studies have been more generic and have involved young carers across a range of caring contexts. For instance, those caring for parents and other family members with some form of physical disability, mental health problem or substance misuse. However, within such studies, there has been little attempt to differentiate the experiences of caring for parents with different 'types' of conditions. Arguably, this oversight has been problematic as young carers experiences have been generalised as applying to young carers in a universal sense. Thus, the distinct experiences and issues faced by young carers in particular caring contexts have been overlooked.

Within the clinical and social literature (and latterly, within the young carers literature), the experiences of children and young people living with disability or illness in the family have been considered. However, these studies generally related to one type of condition or a specific diagnosis and thus, lacked a comparative element across a range of contexts. The findings of various clinical and social studies were compared in order to highlight issues in particular contexts. Whilst differences in children's experiences were noted, these could

have been partly due to methodological inconsistencies across the various studies, rather than differences according to the caring contexts. Also, the clinical and social research did not relate specifically to young carers. Instead, this was concerned with children affected by illness or disability in the family. Thus, it was not clear whether caring within particular contexts created additional or special issues for young carers.

Accordingly, the current study set-out to address this identified gap by comparing and contrasting the experiences of young carers within various caring contexts. The specific contexts considered were parental physical disability, mental health problems and substance misuse. Within the constructive-interpretive framework adopted, the aim was to understand how young carers understood and defined their worlds. Whilst the researcher was the principal tool within this process, she relied on a range of other tools to access this understanding. This included some novel methods of data-collection (with respect to research on young carers) such as a diary method and a self-esteem measure. Analogous to previous studies, however, semi-structured interviews were used as the principal means of data-collection. Fundamentally, these allowed access to the rich data that was required.

The original design had also encompassed young caring in the context of parental learning difficulties. However, it was not possible to identify such individuals and thus, this focus was abandoned. Whilst relevant professionals were used to gain an insight into the specific issues and problems in this caring context, it was not appropriate to compare these insights with the young carers' accounts, because as stated, the focus was on the young carers' own understandings of their situations. However, the professionals did provide a useful insight into some of the special issues in this caring context (a summary of which can be found in Appendix 9).

This chapter will systematically discuss the findings according to each of the research questions initially posed, to highlight the contribution that the current study has made to knowledge within the young caring field. Thus, firstly

definitional issues will be considered particularly in terms of the meanings attached to the term and the significance of this to the identification of young carers. Following this, the experiences of young carers in relation to a range of key domains, such as education, social life, employment, health, spatial transitions and relationships will be critically discussed. Key differences that were evident according to the different caring contexts will be highlighted. A range of other factors which perhaps underpinned the issues and problems identified, will be considered. Finally, reference will be made to the key category, hidden-ness. This concept related to the multi-level, non-identification of young carers.

5.2 Young Carers Definitional Understanding

Research Questions One and Two - Definition and Comprehension

What do young carers comprehend by the term 'young caring' and to what extent do these understandings concur with previously proposed definitions? And

What is the significance of 'definitional ambiguity' in terms of the various understandings of young caring?

Definitional Understanding, Ambiguity and the Invisibility of Young Carers

The notion of 'young caring' is a concept of increasing familiarity within contemporary western society. Within the UK, a growing body of research has offered an insight into the lives and experiences of young carers. Essentially, this has shaped public policy in relation to these children and their families (O'Neill, 1988; Bilsborrow, 1992; Aldridge and Becker, 1993a; Frank, 1995; Newton and Becker, 1996; Thomas et al, 2003). Nevertheless, as has been discussed, the lack of a universally accepted definition of 'young caring' has created ambiguity and confusion (Aldridge and Becker, 1993a; Fox, 1995; Banks et al, 2002a).

This has complicated the recognition and identification of young carers by professionals and family members and has contributed to the lack of self-identification by young carers. This has also underpinned the problem of hidden-ness. Within the literature, hidden-ness has been attributed to definitional issues, mainly in terms of the difficulties that definitional ambiguity has created for professionals. Specifically, this has related to the narrow definitions which govern professional practice, as these exclude particular young carers. Further discussion has focused on professional confusion caused by the lack of a universally accepted definition and the failure to identify young carers (Aldridge and Becker, 1993a; Fox, 1995; Frank, 1995; Tatum and Tucker, 1998; Banks et al, 2002a).

Indeed, young carers are principally identified and 'labelled' through their contact with professionals (Keith and Morris, 1995; Morris, 1995), particularly social workers and young carers' workers. Thus, definitional ambiguity undoubtedly complicates the process of recognition and identification, as well as service-provision and support. Also, such ambiguities around the definition perhaps manifest in the inconsistent identification of young carers, as particular agencies and professions utilise different definitions.

However, arguably the issue of hidden-ness also derives from a lack of self-recognition and self-identification of the caring role by young carers themselves. Whilst professionals may be responsible for the identification of young carers, an element of self-recognition can facilitate this. In the current milieu of definitional ambiguity, the extent to which young carers understand the definitions, or conceptualise themselves according to these is fundamental. This, however, was an element which had not been investigated prior to the current study.

In terms of this, it was necessary to firstly consider the two main established definitions, proposed by official sources and the young carers approach (Department of Health, 1996; Carers National Association, 1998). Whilst the main emphases with each of these differ, a degree of parity now exists between

them as each acknowledges the fundamental elements presented within the other. Official sources principally conceptualise young caring in quantitative terms according to the amount and level of caring undertaken (Department of Health, 1996). The young carers approach has, however, migrated toward an understanding based on the impacts of caring (Carers National Association, 1998). Whilst each offers a differing level of understanding, each also presents unique difficulties. For instance, quantifying the young caring role serves to exclude those young carers who provide less quantifiable forms of care such as emotional support. Thus, the caring role of many young people who provide emotional support as the main form of care is likely to be overlooked. This may apply most commonly in relation to young carers of parents with substance misuse or mental health problems. The failure to identify such young people may be particularly problematic considering that providing emotional support has been most associated with negative outcomes for young carers, in terms of their own health and wellbeing (Elliott, 1992; Frank et al, 1999; Aldridge and Becker, 2003; Bancroft et al, 2004). Nevertheless, impacts-based definitions are also potentially problematic, because of their extensiveness. Firstly, because these definitions are likely to be applicable to such a vast number of young people, services such as social work may be unable to cope with the resulting mass demand. Secondly, these encompass young people with wide-ranging needs - from those that experience very minimal impacts to those that endure a range of problematic effects.

Moreover, the findings of the current study suggest that young carers do not explicitly understand the term according to either the amount of care undertaken or the impacts experienced. When asked to discuss their understanding of the term, the majority of the participants offered definitions. However, these were presented in very basic terms. Whilst most made reference to the role in terms of providing care for a family member, they did not acknowledge the amount of care undertaken or the impacts of caring. This suggested that neither element was recognised or acknowledged by the participants.

Although not in direct reference to questions about their understanding of the term, there was a very apparent association between young caring and measurable, visible tasks and persons with a physical disability. This suggested that young carers did at some level, associate the term with a quantifiable basis. Nevertheless, conceptualisation of 'young carer' in terms of the impacts of young caring was not indicated. The general message conveyed by the young carers was that helpful support equated active and quantifiable support. This perhaps explained why those undertaking quantifiable tasks for parents with a physical disability recognised themselves or were recognised by others as 'genuine' young carers. This notion was not evident in relation to unquantifiable care or support provided to parents with substance misuse or mental health problems.

In addition, the young carers offered further insight into their understanding of the term. This concerned an association between 'young caring' and being a member of a young carers' group, rather than their caring roles at home. This narrow conception has important implications in terms of the self-identification and self-recognition of young carers. Thus, those not in contact with young carers' services are perhaps less likely to recognise themselves as young carers. Thus, the two key issues resulting from the lack of a single, universally-accepted definition are, firstly, a lack of uniformity over professional recognition and identification of young carers, which may manifest in the lack of service provision; and secondly, young carers failure to identify their caring roles or their status as carers.

Potential Solutions to the Problem of Definitional Ambiguity

Various strategies have been proposed to address this definitional ambiguity. Firstly, it has been suggested that the label 'young carer' should be abandoned completely. After all, there has been widespread confusion over the terminology as well as queries regarding the appropriateness of labelling young carers (Parker and Olsen, 1995; Nolan, et al, 1996). However, such a 'solution' may be both undesirable and unnecessary. Surely, defining and labelling young carers according to their caring role promotes an awareness and recognition of their

distinct needs and serves to delimit professional responsibility in addressing the needs of young carers. Also, as indicated in the current study yet contrary to the findings of previous studies (Banks et al, 2002a), the label is generally not rejected by individual young carers. This suggests that concerns about labelling may be based on professional judgments, rather than young carers' objections.

Secondly, it has been queried whether an alternative label or labels could be used which better reflect the situation of young carers within different contexts such as 'children with home responsibilities' (Rose and Kennedy, 1995; Edwards, 1997). Taking this notion one step further, it may be useful to introduce multiple labels which refer not only to the level of responsibility, but also the level of impact. For instance, perhaps those with minimal caring responsibilities or those who experience few impacts could be regarded as 'children/ young people with some home responsibilities' and the term 'young carer' could be reserved for those with heavier caring responsibilities. These labels could be used to highlight an increase or decrease in the young carers' responsibilities and the impacts.

Nevertheless, whilst substitute labels may offer a clearer indication of the roles and responsibilities undertaken by young carers and/ or the impacts experienced, undoubtedly any change in the terminology would confuse young carers, families and professionals, at least initially. Also alternative terminology would not address the fundamental concerns around 'labelling'. Moreover, perhaps this would not tackle the real issue, which arguably is not which label or labels are utilised, but rather the meanings attached to these.

A New Working Definition of Young Caring

Perhaps the most helpful solution would involve the use of a single, collective working definition of 'young carer'. Whilst this study did not explicitly set out to establish a definition of 'young carer', the findings led to some conclusions about what a definition should encompass. As already discussed, it has been argued that a good definition should incorporate three main elements: the amount of caring; the significance of the care work to the family, and the impact of the care work

(Banks et al, 2002b). As such, arguably the most holistic, comprehensive definition should consist of a consolidation of the main emphases within the established definitions offered by the young carers approach and official sources, as well as young carers own self-comprehensions. Considering that the two definitions now implicitly acknowledge the areas of emphasis within the other (Department of Health, 1999; Becker, 2000), the definitions are less bi-polar than generally assumed. Whilst this forms an ideal starting place, the areas of similarity require to be made explicit and formalised in the form of a collective definition. Based on the established definitions and some of the key findings of the current study, it was possible to construct a 'working definition', as follows:

A young carer is a person normally under the age of 18 who *either*:

i. **undertakes a regular, substantial or significant caring role in terms of the time spent caring, or the amount of care work undertaken, or the benefit to the cared-for person; and/ or**

ii. **experiences a range of impacts in relation to one or more of the following areas: their education, social life, physical and/or mental health or relationships, due to caring for another person.**

The cared-for person may be a parent, a sibling (brother/sister) or someone else, normally a family member. The cared-for person requires support because of some illness or disability (which may be a physical disability, a physical condition, a mental health problem, problem alcohol use or drug use, or learning difficulties). Roles and tasks undertaken by young carers may include practical or 'hands-on' assistance and/ or emotional support for the cared-for person. Where emotional support is undertaken, this may include 'talking to' and 'listening to' the cared-for person; or reassuring them).

The key finding which underpins the above definition relates to the invisibility of certain young carers and the resulting necessity of making the definition as explicit as possible. The findings also revealed that those young carers who were least likely to be recognised as young carers or indeed acknowledge their own

caring roles were largely undertaking invisible or unquantifiable caring tasks for parents with non-physical conditions. Thus, it is important to make clear that young caring includes visible and invisible roles and that emotional support encompasses both obvious as well as more implicit forms of care. In addition, the domains affected by caring and the full range of caring contexts included must be made explicit within this new definition.

As has been highlighted elsewhere, the definition should contain both qualitative and quantitative elements. Whilst none of the participants in the current study explicitly recognised their role according to an impacts-based understanding, all discussed the impacts that they experienced. However, as discussed, those young carers that provided unquantifiable forms of care could not be conceptualised as young carers according to the amount of care undertaken. Therefore, the new definition should explicate that young carers could be considered so on the merit of satisfying one or the other element.

Nevertheless, to be useful a definition must be meaningful to those that are defined. However, it is questionable whether this definition would necessarily be wholly meaningful to all of the young people involved in the study. Indeed, some understood the term according to a range of alternative meanings such as their membership in a young carers' group or paid caring. However, incorporating these notions into a definition would merely serve to confuse the issue and thus, these are not embraced within the working definition. Arguably, this issue may be addressed through appropriate awareness-raising as a key part of primary and secondary education. Additionally, further development work involving young carers requires to be undertaken to explore issues such as their understanding of ambiguous terms such as 'regular', 'substantial' and 'significant', to enable the definition to be reworked or expanded on according to their understanding. This could also enable the development of a common application of these terms.

Potential Objections to the New Definition

Objections to the definition are likely to be raised by policy-makers on the basis of its wide remit. Potentially, this inclusive definition would result in the identification of a greater number of young carers which could create concerns in the current situation of limited agency resources. However, if we consider what research has taught us over the past 15 years about young carers' needs, such resource implications may be minimised. Essentially, young carers want their role to be acknowledged, they want someone to talk to and be listened to and they want others to demonstrate understanding. Arguably, these are not necessarily costly in financial terms. Where there is a financial burden, perhaps there is a natural assumption that social work would have the principal responsibility to bear this. However, other professionals and services may be better placed in terms of offering support in relation to particular issues. For instance, teachers may be best placed to deal with educational issues, such as difficulties with homework, or absences. Indeed, inter-agency working and responsibility is embraced within the recent Care 21 proposals (recommendation 2) (Scottish Executive, 2006) relating to young carers. Within this document, it is stated that the main principles within the policy document guiding children's services *'Getting it Right for Every Child'* (Creegan, Henderson and King, (2006), should be upheld. This relates to shared assessments and inter-disciplinary joint working in particular.

Implications of the Upper Age Limit in the Definition

As indicated, the proposed new definition includes only those young carers aged 18 and under. This reflects the upper age of young carers as proposed within definitions in the UK and the views of the young adult carers involved in the study. Those carers aged 18 and over are currently included in the definition of adult carer. Nevertheless, perhaps this is not wholly appropriate as young people have some unique needs as young adults, such as moving away from the parental home, establishing a career and developing partnerships. Whilst other adult carers may encounter these issues, typically these are associated with early adulthood.

However, including young adult carers within the definition of young carer would not be practicable either. Firstly, this would serve to blur the unique status of those carers under the age of 18. On the merit of being children, those under 18 have very specific needs relating to their schooling and social development. In the same thread and as evidenced in the current study, those aged 18-25[11] also have different needs mainly relating to difficulties with spatial transitions and gaining suitable employment. Additionally, incorporating those aged 18-25 into a definition of young carer would undoubtedly put additional pressure on services to recognise and address the needs of thousands more young people.

Thus, perhaps the most suitable resolution would be to develop a separate definition of 'young adult carer' and apply it to 18-25 year olds. This is important in terms of the recognition and identification of young adult carers and the appropriate response to their unique needs. This would also serve to delimit agency responsibility in relation to this particular group. The current study did not set out to consider the definition of young adult carer and thus, it would be inappropriate to attempt to offer a working definition. However, in this study there were some obvious commonalities between young carers and young adult carers both in the contexts in which they were caring and the consequences of this. Therefore, perhaps the two definitions would have obvious similarities.

Also, as evident in the current study, the older participants also failed to recognise caring for parents with non-physical, invisible conditions, or non-quantifiable roles and tasks. Therefore, such a definition should again explicate the wide range of caring contexts included within the definition. This definition represents a starting point, which requires to be explored with concerned groups and individuals including young carers, their families, relevant professionals and agencies as well as policy makers.

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[11] As indicted, 18 is the accepted upper age limit of young carers according to UK definitions and the eldest participant in the current study was 25. This group of young carers aged 18-25, often referred to as 'young adult carers', have a range of distinct needs as recognised in the current study and elsewhere.

Addressing the Lack of Private Recognition and Public Acknowledgement

Nevertheless, from a young person's perspective, it may be argued that an awareness or understanding of the term 'young carer' does not necessarily imply application of this label to one's personal situation, nor the willingness to disclose one's identity as a young carer to others. Within this study an understanding of the term appeared to be distinct from either the 'private recognition' or 'public acknowledgement' of one's status as a young carer. Thus, whilst young carers may have an understanding of the definition, they may not necessarily apply this to their own situation. Even if they do recognise themselves as young carers, they may not disclose this to others. This may further compound their invisibility as young carers. It is thus instructive to consider the reasons why this may be the case.

Private Recognition

In terms of 'private recognition', firstly, it may be asserted that lack of recognition of one's status as a 'young carer' derives in part from being or becoming 'used to' caring. Thus the role may be viewed as normative rather than exceptional. Nevertheless, even where one recognises that they have exceptional responsibilities at home, this does not automatically mean that they will recognise their identity as a young carer. Identification and assignment of the label 'young carer' is instigated largely through professional contact, usually with a young carers' worker. Where no such contact occurs, it is unlikely that young carers will conceptualise themselves in such terms. This echoes the notion of secondary deviance, which is created through contact with relevant and powerful authority figures (Becker, 1981). It was found in the current study, that prior to professional contact, the young carers were either unfamiliar with the term, or alternatively, had encountered this, yet lacked an understanding of its meaning and therefore, had failed to identify their own role accordingly. Based on the findings of both the current and previous studies around secrecy and non-recognition, it was perhaps unsurprising that this term had not been previously encountered (Wiener et al, 1993; Aldridge and Becker, 1994; Keith and Morris,

1996; Fiedler, 1996; Tatum and Tucker, 1998; Barnett and Parker, 1998; Frank et al, 1999; Banks et al, 2002b; Aldridge and Becker, 2003).

Secondly, as already intimated, the general perception amongst the young carers was that caring related to the undertaking of physical, visible and measurable tasks, principally in relation to persons with a physical disability. As a consequence, this may negate the validity of young caring on the basis of providing invisible and immeasurable care such as emotional support, mainly for parents with substance misuse and mental health problems.

Public Acknowledgement

In terms of 'public acknowledgement', the young carers within the current study operated a system of 'selective disclosure' in terms of when, why and with whom they shared knowledge of their caring role. In terms of this, the participants discussed how they had either not shared details of their role with others such as their wider peer network, or had confided in and discussed their situation with 'select' individuals only.

Firstly, in relation to others such as the wider peer group and some professionals such as general teachers, there was a strong sense of concealment. The young carers - in Goffman's dramaturgical terms (Goffman, 1959) - presented a different side to their audience to hide their home situation. Indeed, this was also discussed with reference to 'putting on a brave face', which arguably parallels with dramaturgical notions such as 'wearing a mask' or presenting a facade in public. Interestingly, this was discussed only by those caring for parents with substance misuse or mental health problems, although 'courtesy stigma' was experienced by young carers across the three caring contexts.

A failure to discuss the caring role with others was largely underpinned by various concerns and fears such as standing out or not fitting in with one's peers or punitive treatment. Arguably, actively concealing one's caring identity or home situation may involve isolating oneself and may result in social isolation.

Nevertheless, confiding in others may also result in stigmatising or negative treatment which can culminate in social isolation. Within other studies (Aldridge and Becker, 1994; Banks, et al, 2002a), parental resistance has also been highlighted as a further reason for secrecy around the caring role. This was not however, evident within the current study.

Moreover, it was found that 'disclosure' was selective on the basis of who and when to tell. Important factors in relation to this included the level of familiarity and length of relationship shared with the confidant, as well as the trustworthiness and perceived understanding of this individual. Thus, those confided in were typically 'best friends', with similar experiences, or other young carers. Additionally, professionals such as guidance teachers or young carers' workers were also informed. It was also intimated that guidance teachers were informed on a 'need-to-know' basis, due to problems experienced at school. Similar to other studies (Dearden and Becker, 1998), it was found that young carers very often chose to share more intimate details about their caring roles with young carers' workers. This was based again on the young carers' perceptions regarding the trustworthiness and understanding of young carers' workers. This perhaps demonstrates a further key difference in the system of disclosure utilised by young carers, particularly between 'mandatory' disclosure in relation to school personnel and 'voluntary' disclosure with trusted professionals and friends.

In terms of other professionals, whilst social work was the most commonly received service, none of the young carers had talked openly to their social worker about their caring role and responsibilities. As highlighted in other studies, this may have been due to concerns about how the young caring role would be perceived and addressed by professionals (Rose and Kennedy, 1995; SSI, 1996; Aldridge and Becker, 2003). Thus, in relation to systems of disclosure, young carers present different personas or fronts to different 'audiences'. With classmates, teachers and particular professionals, they may strive to conceal their carer identity and only present their true selves in the context of 'safe' relationships, with friends or specific professionals.

Also, the nature of the caring context appeared to be particularly significant as concealing the caring role was most associated with those caring for parents with substance misuse or mental health problems. Perhaps this was due to a combination of 'courtesy stigma', as well as the invisible nature of the parental condition. Within other studies, the degree of family stability has been regarded as an influential factor in relation to the willingness of young carers to disclose, with those living in unstable and chaotic family situations least likely to disclose (O'Neill and Platt, 1992). This perhaps implies those living with parental substance misuse or mental health problems.

Thus, whilst the new definition could partly address the issue of hidden-ness, it would not in itself facilitate the private recognition or public acknowledgement of the young caring role. In addition to active discussion around the new definition, those professionals likely to have contact with young carers need to be aware of the factors which may prevent recognition and disclosure. Young carers need to be active partners within this process and eventually, an increased awareness and understanding may result in some level of cultural change, where the stigmas surrounding caring and disability would be diminished. In turn, this could remove some of the identified barriers to disclosure. This will be discussed in further detail in terms of the 'recommendations' presented in the conclusion of this thesis.

5.3 The General and Specific Experiences of Young Carers in Different Caring Contexts

> **Research Questions Three and Four - 'Impacts' of Young Caring**
>
> **How and to what extent does undertaking a young caring role impact upon the developmental tasks that young people undertake in relation to education, social life, health, spatial transitions and relationships?**
>
> **And**
>
> **How and to what extent does the nature of the parental condition affect the experiences of being a young carer?**

As highlighted in the young carers' literature and reflected in the findings of the current study, young carers have commonly reported a range of 'impacts' resulting from their caring roles. These relate to various key domains such as their education, career, spatial transitions, social life, health and relationships (Aldridge and Becker, 1993a; Fox, 1995; Marsden and Lund, 1995; Dearden and Becker, 1998; Tatum and Tucker, 1998; Frank et al, 1999; SCDR and CCS, 1999; Shah and Hatton, 1999; Dearden and Becker, 2000; Aldridge and Becker, 2003; Thomas et al, 2003). However, in the literature these have been considered as applicable to young carers in a general sense. Where differences according to the caring context have been highlighted, this has been somewhat superficial.

Nevertheless, arguably young carers' experiences differ according to the nature of their parent's condition. Thus, whilst young carers and their experiences cannot be neatly 'categorised' according to this, it must be acknowledged that particular issues may be more prevalent in certain contexts. Being aware of this may initiate more sensitive and apposite professional intervention with young carers. Prior to considering the context-specific experiences, the common experiences identified by young carers within the current study will be described. These common issues are similar to the findings of previous studies conducted by proponents of the

young carers approach (Aldridge and Becker, 1993a; Dearden and Becker, 1995; Dearden and Becker, 1998; Frank et al, 1999; Dearden and Becker, 2000; Aldridge and Becker, 2002; Aldridge and Becker, 2003). Undoubtedly this increases the validity of the findings of both the current and previous studies.

The General Experiences across a Range of Domains

Education

Arguably, the various issues relating to educational performance have attracted the greatest attention within the literature. The issues and difficulties highlighted by young carers within previous studies were similar to those reported by participants in the current study. These include absences, difficulties with punctuality, homework and workload, poor concentration, collusive practices or lack of understanding of teachers, as well as difficulties balancing caring with further education (Aldridge and Becker, 1993a; Dearden and Becker, 1995; Fox, 1995; Marsden and Lund, 1995; Dearden and Becker, 1998; Crabtree and Warner, 1999; Frank et al, 1999; Watson, 1999; Dearden and Becker, 2000; Aldridge and Becker, 2002; Aldridge and Becker, 2003). Significantly, these issues when experienced in childhood can be linked to a range of problems in late adolescence and early adulthood, such as a failure to attain formal qualifications and poor employment opportunities (Frank et al, 1999; Dearden and Becker, 2000).

Social Life

As has been discussed, peer group interactions are pertinent within adolescence for healthy development. However, as indicated in a range of other studies, young carers can face a range of disadvantages in terms of their social functioning. This has been evident both in terms of primary impacts and secondary consequences. Primary impacts include difficulties socialising and sustaining friendships due to the caring role. Secondary consequences relate to the resulting social isolation experienced. Issues within the literature relating to social functioning include a reluctance or inability to invite friends home or partake in social activities, as well as other restrictions and curfews (Page, 1988; Bilsborrow,1992; Aldridge and Becker, 1993a; Frank, 1995, Marsden and Lund, 1995; Dearden and Becker,

1998; Gates and Lackey, 1998; Broadbent, 1999; Crabtree and Warner, 1999; SCDR and CCS, 1999; Banks et al, 2001; Cree, 2003; Thomas et al, 2003; Currie, 2004). In terms of the current study, the issues and impacts reported were similar to those highlighted in previous studies.

Health

Within the literature on both adult and young carers, a range of impacts have been identified in relation to health and wellbeing. Nevertheless, by virtue of their age and status as children, young carers may experience particular difficulties in terms of their physical, mental and emotional wellbeing. In both the body of young carers' literature and the current investigation, the issues identified were broadly similar and related to both physical and mental health. These included musculoskeletal injury, tiredness, stress and anxiety and stress-related symptoms, such as headaches and stomach ulcers, as well as self-harm (Elliott, 1992; Landells and Pritlove, 1992; Aldridge and Becker, 1993a; Dearden and Becker, 1995; Imrie and Coombes, 1995; Dearden and Becker, 1998; Broadbent, 1999; Frank et al, 1999; Hill, 1999; SCDR and CCS, 1999; Dearden and Becker, 2000; Aldridge and Becker, 2002; Becker and Aldridge, 2003; Cree, 2003; Thomas et al, 2003).

Career and Employment

Finding suitable employment is a principal means of escaping poverty and social exclusion (Dearden and Becker, 2000; Kroger, 2000). This is pertinent considering that young carers may be at an increased risk of experiencing both. However, despite the obvious need to address these, the difficulties in attaining the means to do so – through employment – are well-documented in the literature (Dearden and Becker, 2000). These difficulties were also evident in the current study. Common issues were outlined in both the current and previous studies which related firstly, to difficulties finding suitable employment (Dearden and Becker, 2000). Whilst few of the participants were old enough to seek full-time employement, the principal concern of those that were related to their difficulties in balancing work and caring. The second issue concerned the participants'

caring-related career aspirations (Fallon, 1990; Aldridge and Becker, 1993a; Dearden and Becker, 1995; Frank et al, 1999; Dearden and Becker, 2000; Lackey and Gates, 2001). Whilst some had perhaps limited themselves to caring-related vocations, others had found that these aspirations were unrealistic due to a lack of qualifications and that they were largely restricted to low-paid caring jobs.

Spatial Transitions

Achieving spatial independence is fundamental in terms of attaining adult status (Coles, 1995; Jones, 1995), yet again often problematic for young carers. Indeed, the current and previous studies highlighted two basic patterns in terms of spatial transitions - early and traumatic moves or late and protracted moves (Aldridge and Becker, 1994; Dearden and Becker, 2000). In the current study, early and traumatic spatial transitions were discussed both in terms of moves to independent accommodation, as well as removal from the parental home due to care proceedings. Protracted moves were discussed in terms of the entrapment imposed by the caring role and their associated responsibilities. This was also paralleled by the avoidance of romantic relationships or the establishment of partnerships. Moreover, other studies have highlighted a factor, which may explain early transitions amongst young carers. This relates to early maturity and attainment of life skills required for independent living (Tatum and Tucker, 1998; Dearden and Becker, 2000; Banks et al, 2002b; Aldridge and Becker, 2003; Thomas et al, 2003). Nevertheless, this was not discussed by any of the participants within the current study and instead a need for one's own space and freedom were most often cited as the reason for moving away.

In the current study these core problems or issues presented were interpreted by the researcher as potential cues or indicators of caring or difficulties due to caring. Indeed, there is a need for professionals to appropriately and sensitively read and interpret such cues, to facilitate the identification and support of young carers. As cues may relate to educational performance, health complaints or social difficulties, arguably all professionals have a role in the identification and support of young carers. However, cues can be misinterpreted and thus, professionals

must be aware that not all problems presented are necessarily or wholly linked to caring.

The Specific Experiences of Young Carers According to Different Caring Contexts

Although not evident in the young carers' literature, the experiences of children and adolescents according to the nature of the parental condition have been highlighted in the medical and social literature. Whilst these studies failed to compare multiple contexts, it was possible to extrapolate the findings of various different studies, each of which considered different types of condition. This suggested that the experiences of children and adolescents are variable according to the caring context in which they are placed. Reflective of the findings within these bodies of literature, the results of the current study suggested that generally those young carers that were enduring the most adverse affects were caring for parents with a mental health problem or substance misuse. The specific impacts discussed by young carers in different caring contexts will now be discussed.

Education

It has been suggested that those caring for parents with substance misuse problems generally experience the most extensive educational difficulties (Dearden and Becker, 2004). This finding has been substantiated by various clinical and social studies (Bowen, 1974; Black, 1981; Dulfano, 1981; Cermak, 1986; Velleman et al, 1998; Velleman and Templeton, 2003). This perhaps further supports the general consensus that educational problems are experienced by a minority of young carers living in the most extreme circumstances. The findings of the current study both concurred and conflicted with this assertion. Both the number of educational difficulties and those reported most frequently differed according to the caring context. Educational difficulties were reported by fewer participants caring for parents with a physical disability. However, where these were reported, such young carers typically described the highest number of problems, which suggested that they were most acutely affected. Conversely, a higher proportion of those in the other two caring contexts had at least one

educational problem, although fewer had problems of an extensive kind. Perhaps the availability of a second parent at home was however, more significant than the nature of the parental condition. All of those that reported no educational problems (whilst in mandatory education) had a second parent at home who was available to share the care (this issue is explored within the literature on 'resilience', such as Velleman and Orford, 1993). The actual types of educational difficulties experienced varied according to the caring context. Those caring for parents with a physical disability reported difficulties across the core areas whilst those caring for parents with substance misuse or mental health problems reported major difficulties getting to school and concentrating whilst there.

Social Life

Differences in social problems according to different caring contexts have not been fully explored within the young carers literature. In the current study, difficulties were widespread across the caring contexts, which perhaps suggested that the actual caring context was insignificant. Perhaps this reiterates that maintaining an active social life is a common adolescent issue. Particular issues however, such as failing to invite friends home or being subjected to bullying by peers were strongly associated with young caring in the contexts of parental mental health problems or substance misuse. Indeed, this reflected findings of other social studies which suggested that those with the greatest social difficulties were living in the context of parental substance misuse (Dore et al, 1996; Barnard, 2003; Velleman, and Templeton, 2003). Moreover, the quality and experience of 'courtesy stigma' differed according to the type and nature of the parental condition. In relation to all three caring contexts - physical disability, mental health problems and substance misuse - stigma originated from a breach of society's notions of normality and acceptability, due to the outward appearance or behaviour of the parent. With physical disability, the young carers' experiences of stigma derived from the outward appearance of the parent and manifested in openly discriminatory practices, such as others drawing attention to the conditon or mocking the young carer. In terms of parental substance misuse and mental health problems, stigma was linked to the parental behaviour evident in terms of

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both explicitly stigmatising treatments, as well 'tip-toeing' around the young carer. The latter involved discussing the parent with other people 'behind the young carer's back', an action which was perhaps underpinned by a lack of understanding of the nature of mental health problems and substance misuse.

Health

Within the young carers literature there has been some interpretation of the specific health impacts experienced by young carers in different contexts. For instance, physical injury such as back pain has been associated with physical disability and attributed to heavy lifting (Aldridge and Becker, 1993a; Hill, 1999). This association was also evident within the current study. Additionally, it has been found that the consequences of providing emotional support for parents may be more harmful to young carers own mental and emotional health, than carrying-out other forms of care (Rutter, 1966; Elliott, 1992; Frank et al, 1999; Weissman et al, 1999; Dogra et al, 2002; Aldridge and Becker, 2003; Bancroft et al, 2004). This form of support was most required in the contexts of parental substance misuse and mental health problems. Thus, it can be surmised that young carers in these caring contexts may experience the greatest difficulties with their own mental health. Indeed those who demonstrated the most difficulties with their own mental or emotional health (such as stress, anger, depression and self-harm) were mainly caring for a parent with substance misuse or mental health problems. Indeed the factors which may precipitate or increase the risk of developing health problems, such as living with violence and neglect, have been most frequently associated with children of parents with substance misuse (Powell, 1995, cited in Tunnard, 2002a; Forrester, 2000; ACMD, 2003; Bancroft et al, 2004), a finding which was also apparent in the current study.

Moreover, there has been limited reference to young carers' self-esteem within the literature. Where this has been considered, however, it has been concluded that young carers generally experience lower levels of self-esteem (Frank et al, 1999; SCDR and CCS, 1999). In terms of the current study, the young carers' scores on The Rosenberg Scale were not compared to a matched group of non-caring

children. However the majority scored within the expected range, which indicated normal self-esteem. Thus, the sample of young people in the current study differed from other young carers insofar as they enjoyed higher self-esteem. Also, as a collective group, they produced scores within the range expected of any population (approximately one-quarter high, one-quarter low and the remaining half, normative) and no marked differences were evident according to the different caring contexts. Significantly, there were no apparent differences in the self-esteem scores between those that indicated possible signs of mental or emotional health issues (such as stress, anger, depression and self-harming) and those that did not. Alternatively, perhaps this suggested that the participants were either unwilling or unable to declare negative feelings about themselves using this medium.

Spatial Transitions

Lastly, within the young carers and social literature, there has been a degree of consensus about the influence of the caring context over decisions about leaving home. Indeed, it has been suggested that children subjected to harsh living conditions are most likely to make premature spatial transitions, which implies those living with parental substance misuse or mental health problems (Dearden and Becker, 2000; Velleman and Templeton, 2003). This finding was largely reaffirmed within the current study. Also some of the young carers suggested that they had delayed moving away from home. This was most often associated with young caring in the context of physical disability and underpinned by an evident need to remain in close proximity to the parent.

The Extent and 'Root' Cause of 'the Impacts' of Young Caring

In offering a comprehensive discussion of the 'impacts' of young caring both in relation to the common and specific experiences reported, it is important to consider two key issues. Firstly, within previous studies, problems experienced by young carers have been reported by a minority of participants. Also, the levels reported within different studies have varied considerably. Therefore, the extent to which the impacts described reflect young carers' experiences must be queried.

Secondly, a range of factors additional to the caring role may underpin the experiences or 'impacts' (Dearden and Becker, 2001). Thus, it is important to question whether some of the apparent 'impacts' of young caring are at least partly due to alternative or inter-related factors. Each will now be considered.

Extent

Arguably, the majority of studies undertaken by proponents of the young carers approach have discussed the problems reported as being reflective of the general experience of young carers. However, it may be argued that on the basis of the statistical information presented within these studies, it has usually been the minority of young carers who have actually reported such difficulties. This has been particularly evident in relation to education, social life and health. For instance, education has been depicted as the most detrimentally affected area, however according to the most recent national survey, only 22% of young carers reported difficulties (Dearden and Becker, 2004). Conversely within the current study, the majority of young carers did report educational difficulties, although the extent of such difficulties varied greatly. In part, the differing degrees of problems reported within various studies, perhaps reflected the different definitions of 'young carer' utilised. For instance, in the current study 'educational problems' referred to problems with homework, attendance, punctuality, concentration issues and 'dropping out'. In comparison, the most recent survey considered only absences and 'educational difficulties'. As this was so non-specific the young carers involved perhaps overlooked the particular problems that they experienced.

Also, as evident within both the current and previous studies, where problems are reported, these can vary in terms of their severity or frequency. For instance, absences due to caring may be regular, enduring and problematic or relatively infrequent and non-problematic. In relation to this, it must be questioned whether such difficulties and the levels reported differ either qualitatively or quantitatively from those experienced by other children, particularly those enduring other forms of disadvantage, such as poverty (Parker and Olsen, 1995).

Lastly, it is unclear the extent to which problems experienced by young carers in childhood, impact upon adult functioning. For instance in relation to mental health, whilst some evidence has indicated that psychological difficulties can persist into adulthood (Frank et al, 1999), other studies have disputed this (Shifren, 2001; UNICEF, 2001). Nevertheless, a correlation has been established between better educational attainment and stable employment (Frank et al, 1999; SCDR and CCS, 1999; Dearden and Becker, 2000; Aldridge, 2003).

Thus, it may be surmised that perhaps only a minority of young carers endure severe difficulties in relation to the areas discussed. This may lead to queries about whether these problems are actually experienced by young carers to a greater severity than other disadvantaged children and also whether these difficulties are enduring or transient in nature. However, two inter-related points may in part negate these suppositions. Firstly, if particular young carers fail to fully recognise their role or status, it is perhaps unlikely that they will fully recognise the impacts of caring. Indeed they may attribute problems to alternative causes, which could bias their reporting of such difficulties within a research context. Secondly, this highlights the key difference between those impacts reported and those actually experienced. Young carers may be reluctant to report such difficulties, due to fears about the consequences of doing so. They may be unsure of the researcher's jurisdiction to report these to official sources and the potential consequences of this. Also the findings of studies which have utilised retrospective samples may be somewhat dubious. Indeed recall difficulties may have prevented the participant's accurate portrayal of problems experienced during childhood.

Alternative 'Root' Causes

Based both on the findings of the current study and critical evaluation of previous studies, it may be argued that the actual caring role is only partially responsible for the disadvantages and problems discussed. Indeed, in the young carers literature it has been acknowledged that various factors (such as poverty, family

structures, stress and social exclusion) may underpin the detrimental experiences reported and also may initiate young caring in the first place (Dearden and Becker, 2001).

In addition, other factors have been proposed which may affect the experience and outcome for young carers in certain key areas. Thus, firstly in relation to educational problems, low IQ, as well as a lack of parental interest and stimulation may also affect young carers' experiences (Dearden and Becker, 2001). Similarly, in the current study, the findings suggested that in some instances, the educational difficulties encountered were attributed to the caring role and responsibilities. However, perhaps alternative reasons - such as a lack of interest in school – existed. Thus, in a sense, the caring role may be a scapegoat for all problems experienced.

Secondly, problems relating to social functioning were partly underpinned by the restrictions imposed by the care receiver, as well as prioritisation of the young carers' education over their social needs by parents. Moreover, in both the current and previous studies, it was unclear whether specific issues such as bullying, were directly attributable to the caring role, or due to other, normative adolescent concerns, such as being overweight or having acne. Further, these concerns may be age or gender-specific.

Thirdly, in relation to health issues, young carers face an increased risk of living in poverty due to the presence of illness or disability in the family. This in turn heightens their own risk of ill-health, regardless of their caring status (UNICEF, 2000). In addition, violence, abuse or neglect (particularly evident in relation to parental mental health problems and substance misuse) pose further risks in terms of the young carers' physical and mental health (Powell, 1995, cited in Tunnard, 2002a; Forrester, 2000; ACMD, 2003; Bancroft et al, 2004). In terms of the current investigation, whilst the majority of the young carers indicated that they experienced problems with their own physical or mental health which they attributed to caring. It must be noted however, that the links between caring and

some of the problems outlined - such as stomach ulcers - were tenuous. Thus, such claims should be observed with caution. Lastly, the extent to which premature or prolonged transitions are due to the caring role again must be questioned. It may be argued that other factors such as the threat of violence or abandonment are likely to contribute to decisions regarding moves to spatial independence. In the current study, these issues were evident mainly in contexts that involved parental mental health problems or substance misuse, perhaps due to parental frustration or chemically-induced violent tendencies.

As already highlighted, the experiences and apparent 'impacts' discussed within the young carers literature were identical to those raised within the clinical and social literature, relating to children living with illness or disability in their families, but not necessarily caring for the ill or disabled member. This raises questions about whether these problems and 'impacts' actually result from young caring, or conversely, are merely the result of living with illness or disability and the restrictions that this may impose.

Nevertheless, in response to this, two points may be raised. Firstly, as highlighted, there are specific issues faced by young carers that can be directly attributed to caring, such as caring-related absences. These may be truly considered as 'impacts', although other factors may serve to exacerbate these, such as the lack of appropriate services. However, the links between young caring and other issues which have been referred to as 'impacts' (such as stress or bullying) are arguably tenuous. Thus, referring to the latter as 'impacts of young caring' is perhaps misleading and ultimately, serves to conceal or negate the 'special' issues directly attributable to caring, experienced specifically by young carers. However, it is also possible that the social and clinical research overlooked the fact that at least some of the children studied were indeed 'young carers'. Thus, their experiences were perhaps due to caring, rather than simply living with illness or disability in the family.

'Parental Needs as Priority' as a Root Cause

The root cause of the difficulties presented by young carers can also be considered in a further original way. This relates to the young carers' prioritisation of their parents needs over their own. According to Parsons, the relationship shared between parents and children is the ultimate priority of the child during their early life and adolescence (Parsons, 1943; 1971). However, this viewpoint perhaps does not represent normal adolescent functioning within contemporary, western society. During this life stage, peer relationships are highly significant and parental authority is challenged and redefined. However, Parsons theory may have some mileage in relation to the young caring family, as the parent is often cast in a position of priority over peers and other external relationships (Youniss and Ketterlinus, 1987; Clark-Lempers et al, 1991). Moreover, on the merit of their condition, the parent has the right to expect to be cared-for and the right to be excused from their parental responsibilities (Parsons, 1971). Arguably, this may further require the child to care for the parent and ultimately, prioritise the parent's needs. As a result, the young carer's needs may be sacrificed or placed in a position of secondary importance. These personal sacrifices may manifest in terms of the various difficulties described, in relation to education, social life, health, work and career, spatial transitions and relationships. Additionally, prioritisation also relates to the 'pecking order' of the key areas within the young carers' life. In the young carers literature, it has been indicated that parents maintain this system of priority, by placing the child's educational needs higher in the pecking order than other needs (Aldridge and Becker, 1993a; 1994; Becker, 1995; Tucker and Liddiard, 1998). In the current study, however, this 'scale of importance' was also supported by the young carers themselves.

In the current study, there was a great deal of evidence which suggested that the young carers key concern was their parents needs. In terms of explicit instances of this, firstly, the young carers appeared to sacrifice their own social and educational needs in order to care, through mechanisms such as setting self-imposed curfews and restrictions. Secondly, all of the older young carers had sacrificed their careers in order to care. Whilst they discussed their career

aspirations, there were no concrete plans to accomplish these. Thirdly, protracted moves to spatial independence were discussed in terms of the entrapment imposed by the caring role. Again, this suggested that the parental needs had been accorded priority position over the young carer's needs for spatial independence and romantic relationships. Additionally, it was highlighted by the majority of those respondents who asserted a need for their own space and freedom, that moving away would be attainable only on the condition that their parent's needs were satisfied by an alternative source. This again suggested that ultimately, the parental needs were given priority position.

As well as the young carers, it was found that this 'system of priority' was also maintained by parents and professionals. Within the literature, it has been highlighted that parents consider their own needs above their children's (Aldridge and Becker, 1994; Cree, 2003). This finding was reflected within the current study and particularly apparent in relation to the young carers' social lives and to a lesser extent, their education. This was managed through various restrictions and curfews. Nevertheless, this was not apparent in relation to other areas, such as the young carer's health. Additionally, social work and health professionals assigned priority position to the needs of parents, with the young carers' needs often overlooked. Professionals may be unaware of the caring status of a child or choose to visit the parent when the child is at school. Also, the parents' needs were arguably still prioritised over the young carers, even though in some cases the young carers reported few problems with their education or social functioning. In such cases, the parents needs were addressed by alternative sources (such as a professional or a family member), or caring tasks were undertaken by the young carer at times during the day, which created minimal interference with their own education, employment or social life. This allowed the young carers to 'balance' or 'integrate' their caring responsibilities with other areas of their lives.

In summary, consideration of these factors raises several important questions. Fundamentally, it must be queried whether some of the apparent 'impacts' of caring are partly due to other factors. This includes living in poverty, the presence

of illness or disability in the family and social exclusion. In addition, other factors such as the prioritisation of the parents' needs or even normative adolescent concerns may be responsible. Thus, perhaps viewing all of the difficulties identified by young carers as 'impacts' is somewhat misleading and serves to 'scapegoat' the caring role.

The Impact of Other Factors in Relation to the Findings

The current study was interested in the experience of young caring according to the nature of the parental condition, rather than other factors such as the age or gender of the young carer, family structures or experiences of living in poverty or social exclusion. However, as stated, factors such as family structures, poverty and social exclusion may underpin some of the issues and difficulties experienced by young carers and therefore, it is appropriate to acknowledge these within the current study. Moreover, it is appropriate to consider the impact of other variables on the findings, such as the age and gender of the young carers.

Age and the Differences between the Younger and Older Participants

The current study set out to consider young caring from the perspectives of both young carers up to the age of 18 and young adult carers aged between 18 and 25. The purpose of involving the older age group was to get an insight into the effects of young caring into early adulthood. Indeed they were in the unique position of being able to consider the resulting impacts of the problems that were commonly described – for instance the effects of educational and social problems in terms of later unemployment and social isolation. Therefore, on the one hand, those under the age of 18 reflected on the impacts of caring and speculated on how this could affect their lives in the future. On the other hand, the young adult carers reflected on their current and previous experiences of young caring and evidenced the impacts of this on their lives and development.

In particular, the unique experiences discussed by the young adults included 'dropping out' of further and higher education; difficulties accessing suitable carer-friendly employment and balancing work with ongoing caring

responsibilities; unfulfilled career aspirations; as well as the impact of caring on establishing and maintaining personal relationships. They also rereiterated that there was a dearth of appropriate carers' services for young people aged 18 and over. This was expressed in terms of there being *'nothing for us'* because they were no longer under in the remit of young carers' services and felt that adult carers' services catered for those older than them. Thus, perhaps consideration of the experiences and needs of young adult carers could inform the direction of future research.

Gender

Traditionally, caring has been viewed as a female-related domain (Carers UK, 2002) due to commonly-held perceptions about gender-appropriate roles. However, research findings have shown that caring has become more equally-balanced according to gender, particularly in relation to young caring. Within the current study there was no attempt made to recruit a representative sample and thus, the sample contained 20 females and 10 males. The sample was not large enough to fully differentiate according to this characteristic and thus, inferences made were suggestive, rather than conclusive. However, only one of the issues discussed appeared to have a gender bias. This related to the risks associated with disclosure of the caring status, which was discussed much more frequently by the female participants. As suggested, this may have been due to an enhanced awareness of or concern about the negative consequences of disclosure.

There were no apparent gender differences in terms of the tasks performed by the young carers. Instead, this was dictated by the needs of the parent. Thus, it appeared that they were not merely categorised into gender-typical roles. There was, however, one exception to this, as a female participant raised the issue of difficulties in performing intimate care tasks for a parent of a different sex to them. This may be a significant issue worthy of future exploration.

Moreover, gender had no obvious impact on how and when the caring role started. Equal proportions of the male and female participants were socialised and elected

into the caring roles, for some at an early age. Rather than gender, the family circumstances and their birth order amongst siblings appeared to be much more significant. Regardless of gender, both the males and females were expected to take on a caring role in the absence of other forms of support, particularly where they were an only child or the eldest sibling.

Family Structures

The young caring family has challenged the functionalist notion of the universal nuclear family (Murdock, 1960). For instance, in the current study over half of the young carer families were headed by a lone parent[12], who could neither independently sustain their family financially, nor received any financial assistance from the absent parent. Nevertheless, within a minority of the lone-parent families, the young carers parent had split up from the other parent following the diagnosis or progression of their condition. Thus, in such cases, perhaps the family could have been considered as a breakdown of the nuclear family. The small minority that were living with two parents, either in a nuclear or reconstituted family, generally reported fewer or less severe difficulties than the other participants, particularly in relation to their education and family relationships. Moreover, those living within a nuclear family rarely reported that they had been required to take on a parental role. Instead, the second parent in such a set up had presumably fulfilled this function.

Poverty and Social Exclusion

As indicated, the majority were living in lone-parent households and/ or with parents who were unemployed and in receipt of state benefits[13]. On this very basis, the young carers and their families were likely to be income poor (Flaherty,

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[12] This was contrary to wider changes in the structure and composition of households. For instance, approximately 24% of families in the UK are headed by lone parents (Economic and Social Research Council (ESRC), 2006).
[13] So-called 'safety net' benefits (such as income support) are paid at levels below the 'poverty line' (Flaherty et al, 2004)

Veit-Wilson and Dorman, 2004) and living in poverty according to the notion of relative deprivation (Townsend, 1979).

Indeed, some of the difficulties experienced by the young carers could well have been due to or exacerbated by living in poverty, such as poor educational attainment or a lack of participation in social activities. For instance, one study indicated that in England in 2004, pupils in receipt of free school meals achieved significantly fewer GCSEs than other children (Department for Education and Skills, 2004). Also, whilst not explicitly mentioned by the participants, a lack of income may have created a further barrier to their participation in some social activities.

As well as living in poverty, the young carers were at an increased risk of social exclusion due to experiencing a number of other inter-related factors, such as disability in the family, unemployment, poor health, poor housing, social isolation, discrimination and family breakdown. This was particularly problematic considering that the effects of social exclusion can be life-long, difficult to escape and has a detrimental effect on one's life chances. It has been found that young people aged 16-25 are one of the groups at particular risk of experiencing these factors which underpin social exclusion and in turn, its negative consequences such as poor health, depression and drug use (Cabinet Office, 2005). Whilst various strategies to address social exclusion have been put in place and the specific needs of particular young people recognised, this has not explicitly acknowledged 'young carers' as a high risk group. For instance, the government's 'social exclusion action plan' (Cabinet Office, 2006) has concentrated on the most excluded groups which in relation to young people, includes children in care, teenage parents and those with low educational attainment. Arguably, this is an oversight which requires to be addressed. Thus, as the majority of the families were arguably experiencing poverty and social exclusion, this may well have underpinned some of the problematic issues discussed.

5.4 Parental-Child Relationships and Issues in Particular Caring Contexts

Research Question Five - Parental-Child Relationships

Within a young caring context, to what extent is 'parentification' or parental-child role reversals evident and how does the nature of the parental condition impact upon the experience of parental-child role reversals?

Whilst the effect of young caring on family relationships has been considered within the literature, experiences across differing caring contexts have not been compared, hence the interest in this area within the current study. However, such an awareness of the specific needs and issues which may arise in particular caring contexts is fundamental as this can inform professional practice. The impact of caring on family relationships has been variously described within the literature. Of particular interest in the present study was the nature of parental-child relationships and specifically, the extent to which role reversals were an evident feature of such relationships within the young caring context. Across the bodies of literature, the presence of parental illness or disability has been principally described in detrimental terms with references to ineffective parenting, as well as guilt and resentment in the parental-child relationship (Arnaud, 1959; Castro de la Mata, 1960; Anthony, 1970; Power, 1977; Aldridge and Becker, 1994; Broadbent, 1999). In the current study, resentments toward parents were raised particularly by those caring for parents with substance misuse or mental health problems. However, some of the young carers enjoyed a more intimate relationship with their parent, a finding also noted in the literature. It has been stated elsewhere that this may be particularly evident where children are given choice over their caring role and offered support. (Aldridge and Becker, 1993a; Beach, 1997; Heron, 1998; Shah and Hatton, 1999; SCDR and CCS, 1999; Dearden and Becker, 2000; Banks et al, 2001; Aldridge and Becker, 2003; Becker, 2005).

Nevertheless, it must be questioned whether these positive or negative effects actually derive from the caring role per se. On the basis of the findings of this study, the positive effects did appear to be related directly to caring. For instance, the very nature of caring dictated physical proximity between parent and child which further facilitated closeness on an emotional level. However, actual difficulties could not be attributed to caring in the same way. Instead, these were due to the parent's unacceptable or unpredictable behaviour which included aggression and violence against the young carer. Incidentally this was evident only in relation to those parents with substance misuse or mental health problems. This suggested that the nature of the parental condition rather than the young caring role was perhaps responsible for relationship problems.

Parentification within the Context of Young Caring

In terms of parental-child relationships, the notion of 'parentification' or the premature assumption of adult and parental roles by children is a further factor which may affect the quality and nature of relationships. Within the literature, various 'types' of parentified children have been described, including young carers. However, parallels can be drawn between the roles, responsibilities and outcomes typically experienced by young carers and other 'types' of parentified children, such as those who have experienced sexual abuse or parental divorce. It is noteworthy, however, that such categories of parentified children would not be regarded as young carers according to any of the proposed definitions, unless they are also caring for a family member.

In terms of these parallels, parentified children have been described as being responsible for a range of roles and tasks including domestic and caring tasks, childcare, emotional support, companionship and decision-making (Broszormenyi-Nagy and Spark, 1973; Minuchin, 1974; Walsh, 1979; Sroufe and Ward, 1980; Stein and Riedel, 1999; Ward, 2003). This may result in a range of detrimental impacts to their health, education and relationships. These roles and outcomes are almost identical to those that young carers experience. This similarity between the impacts described in relation to parentified children and

young carers adds further credence to the assertion that factors of disadvantage - such as living in a situation of poverty, family structures, stress or social exclusion – defines the roles that children assume and underpins at least some of the issues and problems they experience.

Arguably, young carers can be viewed as parentified children on the basis of their assumption of adult roles before they are developmentally, psychologically or emotionally ready (Broszormenyi-Nagy and Spark, 1973; Bekir et al, 1993; Valleau et al, 1995). Within the young carers literature, there have been various references made to parentification (Aldridge and Becker, 1993a; Frank, 1995; Tatum and Tucker, 1998). However, these have been heavily criticised particularly by the disability rights approach who have argued that interdependence within any family should be regarded as normal and expected and that the parental identity should not be viewed as wholly dependent on the tasks undertaken (Morris, 1995; Keith and Morris, 1996). However, these points have latterly been embraced by the young carers approach (Aldridge and Becker, 2002; Aldridge and Becker, 2003).

Nevertheless on the basis of the findings of the current study, these assertions may be challenged. Firstly, the participants undertook a range of practical and domestic tasks which they had defined in implicit terms as 'parental', yet referred to in direct terms as 'adult' tasks. Few conceptualised the relationships shared with their parents in terms of 'role reversals' and all of the participants ultimately recognised their parent as 'the parent'. However, this does not mean that parental tasks and the parental identity are separate entities. Instead, it may be asserted that as particular practical roles and tasks are closely bound up with the parental identity, the parental role and parental identity are perhaps best viewed as interdependent, rather than separate entities. However, role reversal does not equate to parental-child 'identity reversal'. Regardless of what the young carers' were doing in terms of the tasks undertaken, the parent still retained their identity and was given respect and status in accordance with this.

Secondly, there was some ambiguity around the young carers' interpretations of the reciprocity between themselves and their parents. On the one hand, only one young carer explicitly recognised such reciprocity within the relationship with their parent. Thus, perhaps reciprocity was perhaps compromised due to the priority status accorded to the parents needs. On the other hand, perhaps the young people simply failed to analyse or comprehend their relationships in such terms or were 'used to' the way their family functioned.

Parental-Child Role Reversals in Relation to Different Caring Contexts

The effect of different types of parental condition on role reversals has been discussed within the parentification literature, but has not been explored within the body of young carers literature. In relation to this, a degree of parity exists between the findings of the current study and the parentification literature, particularly in terms of the children affected most severely. Similar to the literature, the findings of the current study indicated that the greatest difficulties in the relationships shared with their parents were experienced by those caring in the context of parental mental health problems or substance misuse. Such difficulties described included worrying to acute levels, instances of periodic or temporary abdications from the parental role, as well as the assumption of the most extreme types of roles and tasks. These were certainly not illustrative of normal reciprocity within the family.

Within the parentification literature, it has been intimated that the actual condition is less influential in terms of the experiences and impacts for the parentified child, than the severity of the condition (Stein and Riedel, 1999). However, the findings of the current study challenged this assertion. Indeed, the manifestations of the actual condition (particularly unpredictable or chaotic behaviour displayed) influenced whether and the extent to which, the young carers adopted parental roles and tasks. Additionally, the impacts reported in relation to 'parentified' children within the parentification literature have been largely similar, regardless of the context - whether disability or illness, divorce or sexual abuse. Thus, these

impacts are perhaps due to a range of socio-economic factors such as poverty, stress or social exclusion rather than, or in addition to, the actual context.

5.5 The Factors Underpinning the Hidden-ness of Young Caring

Within the young carers literature, the notion of hidden-ness has been documented in both explicit and implicit terms. The invisibility of young caring has been maintained through various macro and micro systems, by policy-makers, professionals, families and young carers (Elliott, 1992; Aldridge and Becker, 1997; Tatum and Tucker, 1998; Frank et al, 1999; Dearden and Becker, 2001; Banks et al, 2002b). As already discussed, such hidden-ness is principally the product of definitional ambiguity (Aldridge and Becker, 1993a; Fox, 1995; Banks et al, 2002a). In turn, this creates 'professional ignorance', and a lack of awareness or recognition of young carers. Both the findings of the current and previous studies have provided an understanding of the role of each of these and potential ways to counter them.

Professional Ignorance and the Need for Awareness-Raising

Professional ignorance may be addressed through firstly, the use of a collective definition, adequate awareness-raising and the adoption of 'lateral thinking' to recognise young carers in various caring contexts or those not previously defined as young carers. In terms of children and families, parental guilt or a fear of the repercussions, may ultimately prevent the disclosure of the young caring role (Elliott, 1992; Aldridge and Becker, 1993a; Aldridge and Becker, 1994; Newton and Becker, 1996; Aldridge and Becker, 1999; Frank et al, 1999; SCDR and CCS, 1999; Shah and Hatton, 1999; Banks et al, 2002b). Additionally, young carers may have concerns about other negative consequences such as 'courtesy stigma', 'standing out' or 'not fitting in' with peers. Also, in cases where young carers are 'used to' caring and the restrictions that this imposes, they may fail to note the exceptionality of this. Arguably, these fears and concerns may be addressed by firstly, the use of a collective definition, in conjunction with a programme of

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awareness-raising. This programme should aim to address some of the common fears and misconceptions around disability, illness and caring.

Unquantifiable Roles

Firstly, as official definitions largely conceptualise young caring in terms of the amount of caring undertaken, there is an implicit assumption that young caring equates with quantifiable, visible care largely in the context of parental physical disability. This is problematic in terms of the identification or self-identification of those providing non-quantifiable support – particularly emotional support for parents with substance misuse and mental health problems.

Visibility of the Parental Condition

Additionally, the visibility of the parental condition may affect the visibility of the young carer. In the current study, the parents' physical conditions were all highly visible. On the basis of this, the parental needs were relatively obvious and the young caring role was almost justifiable. On the other hand, substance misuse and mental health problems were less visible and could be hidden or controlled by the parents to some extent. Where visual cues were presented, these were behavioural, such as erratic or anti-social behaviour, which were open to misinterpretation. Thus, the potential needs of the parent were less obvious and on the basis of these factors, the young caring role was less readily recognised by others. Thus, it is perhaps not incidental that within dedicated young carers support services, those young carers most often identified care for parents with a physical disability.

Others Overlooking or Ignoring the Parental Condition

Indeed within the current study, there was some suggestion that others (namely relatives, professionals and colleagues) 'turned a blind eye' in relation to parental substance misuse and mental health problems. This was perhaps compounded by two factors: firstly, a lack of actual diagnoses amongst the parents with a mental health problem; and secondly, a failure to recognise parental depression as a valid condition. Perhaps this reflects the general perceptions within society around

mental health problems, which generally attract less sympathy than physical disability.

5.6 Conclusion of the Discussion Chapter

Defining and classifying young carers is fundamental and necessary in terms of facilitating the recognition and identification of such individuals and their distinct needs. Indeed, the importance of this cannot be overstated, as the problem of hidden-ness originates largely from definitional ambiguity. In terms of this, there is still no universally accepted definition utilised by policy-makers, researchers, professionals, proponents of the young carers' and disability rights approaches and young carers themselves. This has resulted in a range of comprehensions and misconceptions, and ultimately, a lack of recognition of young carers in particular caring contexts.

Generally the two main contemporary definitions acknowledge the core areas of emphasis evident within the other, pertaining to the amount of care undertaken and the resultant impacts. However, this parity needs to be formally and explicitly acknowledged. The new working definition represents a comprehensive understanding of young caring as it takes into account how young carers conceptualise themselves. It also counters some of the main difficulties apparent in relation to each of the present definitions. Principally, young carers have largely identified with the quantifiable element of the definition, yet have failed to recognise their role in terms of the impacts experienced. However, this element is pertinent as it may be the only basis on which particular young carers can be recognised and identified. Indeed to facilitate the recognition of all young carers, the definition needs to be as explicit as possible with regards to the range of caring contexts and types of care encompassed. Objections to this broad definition are likely to come from service-providers over the cost of providing support to extra young carers. However, this may be addressed through joint working and the commitment toward a collective responsibility for the identification and support of young carers. Additionally, perhaps further

consideration of the needs of older young carers is required. A separate definition of 'older young carers' may be the most appropriate means of addressing their specific needs and the current lack of suitable services for them.

Although a collective definition is a good starting point, this will not fully address young carers lack of self-identification, or the problem of hidden-ness. As highlighted, being aware of and understanding the term 'young carer', does not necessarily equate to 'private recognition' or 'public acknowledgement' of the young caring role. Whilst 'young carer awareness' features within the curriculum of some schools (Harrison and O'Rooke, 2003) the effectiveness of these programmes may be queried (Morgan, 2006). Educational programmes must also address and the allay myths and fears around disability, illness and young caring in order to promote a climate of disclosure. In conjunction with such programmes involving children and young people, similar training should be provided for professionals, during their initial training programmes and as part of their Continuous Professional Development (CPD) requirements. After all, health, education and social work professionals occupy a pivotal role in terms of the recognition, identification and support of young carers.

In addition to definitional issues, a further area of ambiguity concerns the various issues, experiences and 'impacts' described. Previous research has largely overlooked the distinct experiences and outcomes for young carers in different caring contexts. In the current study, key differences were highlighted which have important practice implications. Whilst it is unwise to make sweeping assertions, in general terms those enduring the most adverse affects were involved in the 'sharp end of care', namely in the contexts of parental substance misuse and mental health problems. Such young carers were dually disadvantaged however, as they were also least likely to be recognised or identified as young carers. Thus, it is fundamental that professionals are aware of these issues so that they can better focus their intervention with young carers.

Also, it must be regarded that the issues and problems experienced by young carers may be at least partly due to overarching structural and socio-economic factors, such as poverty, family structures, parental unemployment, stress and social exclusion as well as systems of priority in the family. These had some significance to the findings of the current study, although this requires further investigation in the future. Moreover, the study did not set out to consider the effect of age and gender on the experience of young caring, yet the effects of these factors were considered to a limited extent. In terms of this, firstly, the young adults discussed their actual experiences around particular issues such as work, further education and personal relationships, whilst the younger participants could only speculate as to how these areas might be affected in the future. However, apart from concerns around disclosure of the caring status, neither the issues discussed nor the tasks performed had any obvious gender bias. Nevertheless, the sample was relatively small and consisted of an unequal proportion of male and female participants. Perhaps other differences would have been apparent within a larger sample.

The notion of hidden-ness has been documented in both explicit and implicit terms within the literature. This was a central theme within the current study. Hidden-ness can be maintained at various levels and arguably is the product of various inter-related factors including definitional ambiguity, professional ignorance and the 'silence' exhibited by young carers and/ or their families. As stated, again this may be addressed through definitional clarification and appropriate awareness-raising.

The originality of the current study relates to the area investigated and the findings uncovered. As stated, never before had a single study contrasted the experience of young carers according to a range of different caring contexts. Subsequent work, however, should further develop the knowledge established in relation to this. For instance, in the current study, the caring contexts were considered in a blanket sense and thus, failed to differentiate experiences according to specific diagnoses within each of the broad contexts. In terms of

physical conditions there must be experiential differences in caring for parents with multiple sclerosis and epilepsy, in terms of the chronicity and associated duties. Also, as noted, there were similarities in the experiences of young carers who were supporting parents with substance misuse and mental health problems. Differences between the two have been outlined in the social and clinical literature, yet require to be investigated further specifically in relation to young caring.

Moreover, due to the small sample size within the current study, substance misuse was considered as a single 'category'. However, it is vital to acknowledge that there are key differences between problem alcohol use and problem drug use. Indeed, this has been highlighted in the social and clinical literature particularly in terms of legality and the stigma attached to each. Future research should further delineate the two. Whilst it was not possible to fully consider young carers of parents with learning difficulties, this area and specifically, the distinct needs of such children again require further consideration.

Chapter 6 – A Conclusion of the Main Points from the Study

6.1 Introduction

The principal aim of the current study was to describe and understand the differential experiences reported by young carers, in respect to their caring contexts. Thus, following an initial exploration of the conceptual and definitional understanding of young carers, the impacts and issues experienced by young carers in three caring contexts (parental physical disability, mental health problems and substance misuse) were considered and compared. By way of conclusion, this final chapter will report firstly, on the major findings of the study in relation to each of these areas, leading to a brief summary of the limitations of the study. Following this, suggestions around the direction and scope of future research within this field will be offered. Finally, based on the findings of the study, some recommendations will made around the following areas: trying out the new 'working' definition; the education of social workers and health professionals; mainstream schooling; the practice of social work and community nursing; as well as the implications for health and social care policy implications.

6.2 Overview of the Major Findings

The major findings of the study will now be outlined firstly in relation to definitional issues; secondly in terms of the experiences of young carers according to differing caring contexts; and thirdly, with regards to parental-child role reversals. Lastly, the principal theme of hidden-ness will be discussed.

The lack of a universally accepted, understood and applied definition has created a milieu of ambiguity and confusion, which has ultimately served to maintain the invisibility of young carers. This was evidenced firstly, by the participants understanding of the term, which was associated with a range of alternative meanings, such as being a member of a young carers group. Secondly, in many cases, the young carers failed to recognise, acknowledge or disclose their role and status. This is highly significant as a lack of recognition and awareness is likely to result in a lack of support, feelings of isolation and being undervalued. Worryingly, those that were most likely to overlook their caring status or to be recognised by others were supporting parents with substance misuse or mental health problems. Also, due to the unpredictability and harsh conditions associated with these caring contexts, such young carers also experienced the most severe impacts.

Further to this point, three key findings were uncovered relating to the significance of the caring context on the impacts and experiences of young carers. These can be classified as common issues, specific issues and underpinning causes. Firstly, there were definite commonalities across the caring contexts in terms of the young carers' experiences in their education, social life, health, career, spatial transitions and relationships. Whilst several positive impacts were described (such as closer parental-child relationships, maturity and the early development of life skills), the issues were largely reported in negative terms and construed as 'problems'. In part, these problems were perhaps underpinned by the prioritisation of the parental needs over those of the young carers.

Secondly, in addition to the common issues reported by the participants, other issues and experiences described were specific to particular caring contexts. Those caring for parents with non-physical conditions were most severely or adversely affected on account of their caring roles. For instance, such young carers were more likely to be bullied by peers, endure abuse or neglect by their parent and experience poor mental health.

Lastly, it was found that at least some of the apparent 'impacts' of young caring were perhaps attributable to factors alternative or additional to caring. Whilst there were some very clear direct associations between young caring and particular impacts (such as caring-related absences or back pain due to lifting), the relationship between young caring and other apparent 'impacts' such as 'stress' or poor performance at school, were tenuous. Indeed, socio-economic factors such as living in a situation of poverty, familial stress, and a lack of formal or informal assistance perhaps underpinned at least some of the problems reported. Arguably, the significance of overplaying the association between caring and the experiences reported by young carers is two-fold. Firstly, there is a clear danger of all negative life experiences being attributed to young caring when alternative causes may underpin such problems. Relating all negative experiences and problems to young caring serves to give critics (in particular, the disability rights approach) further ammunition in undermining the root cause and severity of those impacts directly attributable to young caring.

Several key findings were apparent in terms of the effect of particular caring contexts around parentification. Firstly, the young carers undertook a range of practical, domestic and 'control' tasks and roles which were self-defined by the participants as 'parental'. Despite this, they did not explicitly recognise or acknowledge the existence of role reversals between themselves and their parents. Secondly, parental tasks and the parental identity appeared to be interlinked entities. However, 'role reversal' clearly did not equate to parental-child 'identity reversal'. Regardless of what the young carers did in terms of tasks undertaken, the parent retained their identity as parent. This notion was evident across the three caring contexts. Thirdly, the young carers that assumed the most extreme parental-type tasks were mainly caring in the contexts of parental substance misuse or mental health problems.

A particular theme which underpinned the findings of the current study pertained to the notion of 'hidden-ness'. Such hidden-ness generally related to the invisibility of the young caring role, due to a combination of factors on both

macro and micro levels, principally ambiguities surrounding the definition of 'young carer'. Of particular significance, those caring for parents with invisible conditions such as mental health problems or substance misuse, who undertook mainly invisible and unquantifiable forms of care, were more likely to be overlooked, compared to those caring for parents with visible physical conditions.

6.3 Limitations of the Study

Notwithstanding the extent to which the present research was able to capture the experience of young caring according to a range of caring contexts, the study nevertheless was circumscribed by difficulties in relation to sampling. Thus, recruiting young carers into the study was complicated by an apparent disinclination of professionals to identify their service users as potential research participants. This created difficulties attaining the sample originally sought. On the one hand, it is fully understood and appreciated that agencies occupy a fundamental role in terms of the protection of service-users. On the other hand, professionals must play a proactive role in facilitating users' voices in a research capacity, particularly as this may present one of the few opportunities where their voices are heard. This was particularly problematic in relation to the context of parental learning difficulties. As a result of difficulties in identifying and recruiting such young carers in this context, it was necessary to abandon this area of interest, which formed a principal limitation within the study. Various relevant professionals offered a useful insight into some of the issues that can affect children living with or caring for parents with learning difficulties. However, this study was grounded in a constructive-interpretive approach and thus, was interested in how the young carers understood and interpreted their worlds. Therefore, it was not appropriate or desirable to compare or contrast the professional insights with the young carers' accounts[14].

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[14] As a result, the professional accounts were not presented within the main body of the thesis and instead can be found in Appendix 9.

6.4 Possible Direction of Future Young Carers Research

Based both on the process of conducting the current study and the research findings, four key areas should inform the direction and design of future research. Firstly, because of time and resource constraints it was not practicable within the current study to offer a comparative element between the experiences of young carers and a matched group of non-caring children. Nevertheless, this could have offered further insight into the effects of the socio-economic and structural factors which may underpin the caring role and thus, should be considered in future studies. Secondly, the current study did not attempt to differentiate the young carers' experiences according to the specific parental diagnoses. However, differences must exist, and thus, future research could compare and contrast the different diagnoses within each of the broad caring contexts. For instance, in terms of substance misuse, both problem alcohol and drug use should be considered separately. Also, in relation to physical disabilities, conditions such as multiple sclerosis, stroke and heart disease could be differentiated. Alternatively, to consider experiences according to a range of caring contexts, individual cases from each of the broad 'categories', such as multiple sclerosis, schizophrenia, down's syndrome, and heroin use could be compared. Thirdly, it is likely that young carers of parents with learning difficulties will become more numerous and/ or more visible in the future, because of the changing social-political milieu and specifically, the deinstitutionalisation movement. Therefore, the specific issues relating to this context need to be investigated and again, this could inform the direction of future research. Lastly, the needs of young adult carers (aged 18-25) need to be investigated further, ultimately to inform the development of appropriate services for this group.

6.5 Recommendations Based on Insights from the Study

Trying out the Proposed Definition

To be useful, the term 'young carer' must be collectively understood and meaningful both to those to whom it applies and those that apply it, that is young carers, policy makers, as well as health and social care professionals. This would

serve to aid the identification of young people with caring responsibilities and their resultant needs and provide a means to delimit agency responsibility which would ultimately increase the visibility of young carers.

However, as the findings of the current research indicate, there is a current state of definitional ambiguity and confusion, which serves to increase the hidden-ness of young carers. Although there is a level of consensus between the definitions offered by the young carers approach and official sources, this is largely implicit, with each approach still upholding the main definitional emphasis that it originally subscribed to. Additionally, the definitions offered were developed by researchers and policy makers, rather than by young carers themselves. Cumulatively, this has created a milieu of definitional ambiguity and misunderstanding and served to complicate the recognition and identification of young carers. As has been argued, **the visibility of young carers could be increased by the introduction of an accepted and widely utilised definition of young caring**.

Accordingly, an alternative definition has been devised in response to these issues and is also based on the key insights gained through this study. Specifically, this definition is based on a combination of the main emphases within the already established definitions, as well as some of the key observations from both the current and previous studies around how young carers perceive themselves and conceptualise their own roles. Nevertheless, it must be stressed that this definition is embryonic and thus, requires further development. This could be achieved through consultation with the key players – young carers, policy-makers, health and social work professionals and researchers - as part of the dissemination of findings from the research.

In terms of trying out the definition, firstly it could be introduced by the researcher to all relevant parties including policy makers and professionals as well as young carers and their families. This could be undertaken initially at a local level involving young carers and relevant professionals from health, social work

and education, with discussion facilitated through focus group sessions. This could further assist the clarification of terminology such as 'regular' and 'substantial' and issues relating to the upper age limit and whether a separate definition of 'young adult carer' should be devised. Simultaneously, the definition could be introduced to a relevant local MSP for discussion and presented to the Scottish Youth Parliament[15]. This could also be piloted by professionals in the local North-East of Scotland area and reviewed after a specified time period to assess its workability, practicability and user-friendliness. Following this, the implications in terms of identification and service provision would be clearer. Concern about the lack of identification of some young carers has already been shown by one local MSP and the Scottish Youth Parliament and thus, there is demand for a new definition.

The Education of Social Workers and Health Professionals

As well as social workers and young carers' workers, a whole range of professionals across the fields of health, social care and education are likely to have some level of contact with young people undertaking caring roles and thus, have potential roles in the identification and support of young carers. Accordingly, findings from the present study indicate that a range of professionals may have contact with young carers and/ or their families and thus, have a potential role in identifying them. As such, it is vital that they are equipped to spot the signs which may indicate that a child is caring.

In relation to health, such professionals may include hospital doctors, general practitioners, nurses, community nurses and community psychiatric nurses, health visitors, consultants, psychologists and psychiatrists as well as school nurses, occupational therapists and physiotherapists in contact with the ill or disabled

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[15] The Scottish Youth Parliament consists of 200 elected young people aged 14 to 25. They aim to represent the interests of all young people in Scotland and meet on a regular basis to discuss issues which affect young people, which includes young caring, education, health and leisure (North Lanarkshire Council, 2006).

family member being cared for. Similarly, within the social care sector, home carers may be in a prime position to observe the caring roles undertaken by children within the family. Lastly, due to the mandatory nature of education, pastoral staff (classroom, guidance and support teachers) may be the first or only professionals in contact with young carers, thus placing them in a prime position to identify and support young carers.

To facilitate the recognition and support of young carers, it is fundamental that professionals across these sectors are suitably 'young carer aware' and can recognise and appropriately respond to the signs or cues very often presented by young carers. Arguably, **facilitating the recognition and identification of young carers and their needs, as well as devising appropriate support should constitute an elementary aspect of both initial professional training programmes as well as continuous professional development (CPD)**. Such training should cover the following aspects and issues to ensure that professionals have a comprehensive understanding of the issue: cues presented by young carers; the differing contexts in which young people care; the issues and needs of young carers across a range of domains such as education, health, social life and relationships; the socio-economic and structural factors which underpin young caring; the role of professionals in the identification and support of young carers; access to differing types of support; reasons preventing disclosure of the caring role; and exploration of the young caring role with young people and their families. Fundamentally, educational programmes should explicate that it is the concern and responsibility of all relevant professionals to identify and support young carers. In order to aid such recognition of young carers, the adoption of lateral thinking is critical. In relation to the latter point, where the primary remit of the professional is to support or address the needs of the parent or the family member, rather than the young carer, there should be constant consideration of the wider family system and in particular, the informal caring arrangements within the family.

In terms of the delivery of educational and CPD programmes and training, the remit and responsibilities of the different agencies and sources of support could be explored within inter-disciplinary and inter-agency sessions involving students or practitioners across a range of disciplines, namely social work, health and education. This may be a useful way of ensuring that professionals are aware of the remit of other services, services that young carers can access and the referral procedures. These sessions could be delivered by practitioners with relevant experience working with young carers, with input from young carers themselves on their experiences and insights of helpful and unhelpful support.

With initial training and degree programmes, input relating to the identification and support of young carers should be provided throughout the period of study. This should be provided on a tiered basis, with initial input around the introduction of the concept of young caring with a gradual progression to the more complex issues relating to the consequences of definitional ambiguity; young carers needs and problems commonly encountered; issues surrounding disclosure of the caring status; as well as helpful support and their role in providing this. This ongoing exploration of issues relating to young carers would also facilitate an awareness which would become ingrained into professional practice and thus, consideration of the caring arrangements within families would become routine.

As stated, in addition to initial training, young carer awareness should feature within CPD programmes. For instance, in relation to social work, all practitioners must be registered with the Scottish Social Services Council (SSSC). Whilst a condition of registration with the SSSC relates to undertaking CPD in a range of areas such as child protection, this could also include a mandatory young carer awareness element.

Mainstream Schooling

In terms of mainstream education, schools occupy three key functions. Firstly, due to their mandatory and ongoing contact with young people, schools occupy a

key role in the identification of young carers; secondly, mainstream education must promote young carer and disability awareness, facilitating both the recognition and self-recognition of young carers and young people's disclosure of their caring roles and related needs; and thirdly, schools have a key role in enabling young carers to achieve their academic potential.

As already highlighted schools may be the first or the sole professional contact that young carers have and therefore, **pastoral staff members occupy a fundamental role in the identification and support of young carers**. Schools are also in the unique position of have ongoing, daily contact with children and young people, which thus enables teachers to become familiar with young people and to pick up on uncharacteristic behaviour or difficulties exhibited such as behavioural problems, coursework or homework difficulties, concentration problems, frequent absences or health issues. Whilst such difficulties do not necessarily stem from young caring, they are indicative of some problem that requires exploration, which in some cases, may well relate to young caring. Therefore, **it is fundamental that teachers are aware of and recognise the possible cues presented**.

Additionally, **education must attempt to tackle some of the stereotypical notions surrounding disability and illness**. This is important in terms of fostering a milieu of understanding and to lessen the stigma associated with disability and caring, which may ultimately facilitate young people's disclosure of their caring roles. **This could be addressed through Personal and Social Education (PSE) and perhaps delivered by appointed staff members with specialist young carers' knowledge and experience, as well as young carers' workers and young carers themselves**. Whilst this does currently occur in some schools, this is mainly in the format of a one-off session. Instead this must be addressed in a progressive format. For instance, the notion of young caring should be introduced at an early stage and then built upon throughout the school years. As well as young caring, notions around stigma and disability must also be

explored as stigma and perceptions around lack of understanding essentially prevent disclosure.

Furthermore, where **young people have been identified as young carers, schools should offer flexibility and understanding in order to support young carers' educational needs and enable them to fulfil their academic potential.** This is fundamental considering the link between young caring and poor academic attainment, and thereafter, limited employment and further educational prospects. Punishing young carers for the difficulties that they experience – through detention for lateness to school or lack of completion of homework tasks – is unconstructive. Moreover, failing to act and ignoring or overlooking problems are forms of collusion and are equally unhelpful to young carers. Instead **exploring the difficulties that they experience, the support that they require and the strategies that could address these, may be more helpful.** Essential in terms of this is good communication, as prior to offering and exploring possible strategies with young carers, they must be aware of their caring role and enabled to explore any impacts experienced.

Such support may include: lunchtime or after-school clubs which provide either homework assistance or an opportunity to meet and socialise with other young carers; young carers informal peer support systems within schools to address issues of loneliness and isolation, personal and social skills; offering careers advice which explores young carers full range of options and takes account of both individual wishes and aspirations as well as caring responsibilities; permitting time-limited leave of absence from school if deemed appropriate and necessary (for instance, in crisis situations); flexible timetabling for those experiencing difficulties getting to school on time or requiring to leave early or return home during the day to tend to the needs of the cared-for person; allowing the young person to phone home during the school day if they are concerned or worried about the cared-for person; providing outreach education or tutoring at home for those experiencing prolonged absences from school. In addition, it may also be helpful to discuss the caring situation with parents, in terms of their

support systems, their entitlement to an assessment of their own needs as well as the needs of their child, the support offered by the school, as well as exploration of other sources of support such as dedicated young carers' projects and education welfare services. This may be most appropriately managed by **appointing a member of staff with responsibility for the supporting young carers in each school.** This individual would be responsible for liaison with other agencies, offering support to young carers and parents, supporting staff; imparting relevant up-to-date research evidence to other staff and delivering the young carers' education programmes provided through Personal and Social Education.

The Practice of Social Work and Community Nursing

In order for the wide-ranging and complex needs of young carers to be recognised and addressed, they and their **families require access to appropriate health and social care services.** As the findings of this and other studies have indicated, social work is the service most frequently accessed by young carers and their families. Thus, **because social workers play a key role in the identification and support of young carers, it is imperative that practitioners are fully equipped (through educational programmes and CPD) to undertake this role.** This includes having an awareness of young caring and the associated issues, problems and needs, as well as access to up-to-date and relevant information relating to young carers rights (including their right to an assessment of their own needs), and services available to meet identified needs.

Although caring may well be inappropriate and can negatively affect the health and wellbeing of young people, the mere presence of a young caring role should not raise child protection concerns. Therefore, **social workers (and other key professionals) should respect young carers' wishes to continue caring and provide appropriate support and advice to facilitate this, where this is deemed appropriate.** However, in some cases involving abuse or neglect, there are very evident child protection issues. Thus, professionals – particularly social workers – must be aware of and sensitive to this. Moreover, in every case,

regardless of whether there are concerns about the child's welfare, young carers should be made aware that they have a right to stop caring if they wish.

However, not all families with disability or illness have or wish social work contact and thus, other professionals working with families with disability or illness or children and young people - particularly health professionals working in the community, such as community nurses - also require a sound awareness and understanding of young caring to aid the recognition, identification and support of young carers. Additionally, **professionals need to be aware of the 'bigger picture', in terms of their own role as well as the remit of other agencies** (including specialist young carers support services) in the identification and support of young carers. This includes access to and the referral procedures for other agencies. Thus, **a collaborative approach between a range of agencies including social work, health and education may best ensure that young carers are identified and their needs are appropriately and promptly addressed.**

Even where the principal responsibility of the professional or agency is to support the parent or the disabled family member, there should be consideration of the caring arrangements within the family. Whilst young carers do not exist in every family with disability or illness, children are responsible for caring in some families and thus, professionals should routinely reflect on and ask about the caring responsibilities of children in the family. This may be facilitated through simple measures such as arranging home visits with patients or service users at times when children are at home, such as after school. The details of any young carers present should be recorded in joint community care plans for the cared-for person.

It is fundamental that professionals avoid making presumptions regarding the needs of young carers and their families and the best ways in which these can be addressed. Instead this should be explored with young carers and their families and the full range of options presented and explored. **To enable young people**

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and their families to make informed choices, information provided needs to be both age and culturally appropriate and also must be clear and easy to access. Critically, information provided to young carers should not require the interpretation of parents, particularly where there may be conflicts of interest if parents are reluctant to access help for their child.

Moreover, **service-provision should be based around a whole family approach, as support offered to young carers may only be successful if the needs of the cared-for person are taken into account.** It is not sufficient to simply offer the young carer a service they must also be enabled to access this. For instance, providing social opportunities through a young carers group may only be suitable if alternative care is available for the cared-for person. This could be explored through the young carers' assessment. Thus, taking account of the needs and resources of the wider family system is fundamental.

Dedicated Young Carers' Services

As indicated in the current study and by other research, dedicated young carers support projects are the service most frequently accessed by young carers and indeed, the service viewed as offering most support and understanding. However, these services largely rely on funding from voluntary agencies, which in many cases is unsustainable or offered at low levels. Therefore, **there is an absolute need for ring-fenced, mainstream funding. Adequate levels of funding may enable services to employ more staff to address the needs of young carers and adopt a much family-focused approach – as the majority mainly cater for the needs of young people.** These dedicated services are intrinsically important in terms of the support of young carers and their needs. They have been instrumental in facilitating access to peer support networks, providing social opportunities and offering educational support. However, as the research illustrated, young carers have both common as well as specific needs. Perhaps young carers' services have in general terms been most successful in meeting general needs commonly experienced by young carers regardless of their caring situation. However, **the unique needs presented by young carers may require**

more intensive or specialised support – e.g. from trained counsellors. Thus, increased resources - particularly in terms of funding - would be required to address these needs in the form of tailored support packages.

Health and Social Care Policy Implications

Whilst health and social care policy has been shaped by research findings pertaining to the rights and needs of young carers, policy still deals with the needs of young carers in a somewhat contradictory manner. Whilst policy relating specifically to young carers has become much more supportive toward young carers, tensions still exist within the wider legislative framework. This is due to the unique position of young carers both as children and as carers, with their dual and sometimes conflicting needs. As children, with needs for protection from inappropriate and potentially damaging responsibilities and as carers, with needs in relation to adequate and appropriate support of the caring role. These varying needs are evidenced within different policy responses in relation to children and to caring, but have not been easily consolidated. For instance, the emphasis is on protection within key policy such as 'The Children (Scotland) Act 1995' and 'The UN Convention on the Rights of the Child 1989'. Indeed the ethos of the latter is on the promotion of the basic human rights of children, in terms of their development and protection, including their social development, physical and mental health and their rights to education, all of which may be compromised by caring in childhood.

Moreover, this explicitly stipulates that children should not carry out work that may compromise their physical or mental health, which thus, may oppose rather than support young carers in their caring role – although caring can have rewarding aspects and positive outcomes too. On the other hand, differing policy responses have supported young carers to continue in their caring roles. For instance, the Community Care and Health (Scotland) Act 2002 enables young carers to request an assessment of their needs as carers, from their local authority. Whilst these tensions in the wider policy picture may not be easily resolved, the

recognition and support of young carers and their needs can be improved within carers and young carers' policy.

Ultimately, **health and social care policy should be framed around the need to identify and support young carers and should also address the dual needs of young carers as children and as carers.** Therefore, such policy should be underpinned by the following principles, values and good practice measures:

Policy Should Embrace a Whole Family Approach

Young carers' needs must be placed within the wider family context and thus, policy-makers must recognise the needs of the whole family and the often conflicting needs and interests of parents and children. There must also be recognition of the strengths and resources of families in supporting the young carer and in offering alternative support.

Moreover, as has been already stated, there should be greater emphasis on supporting the needs of the disabled parents through formal sources, which would reduce the need to rely on children to care. To achieve this, firstly services must shift toward a more person-centred approach determined by the needs of service users rather than financial constraints. Secondly, welfare provision must be sufficient to enable individuals to buy in alternative care. Nevertheless, as has been widely recognised, such provision is unlikely to address all of the needs of sick or disabled individuals, or completely remove the necessity of young people to care and thus, attention must be given to providing the most appropriate and adequate support to young carers.

Improved Recognition and Identification of Young Carers

Improved and more consistent identification is required and could be partly achieved through the adoption and application of a standardised definition. Arguably, this would create greater uniformity in term of both the identification and support of young carers. Also, earlier identification of children at risk of assuming a young caring role should be facilitated. This may be achieved through

increased 'young carer awareness' of social care and health workers liaising with disabled parents or working with young children affected by parental disability, for instance, through 'Home Start' schemes or local authority family support services. The needs of the parent and alternative support could then be explored to prevent the onset of young caring or the adoption of heavy caring responsibilities.

Co-ordinated and Meaningful Assessment of Young Carers Needs

To prevent duplication, social work should continue to take the lead role in conducting and co-ordinating young carers' assessments. However, other agencies and professionals - such as health workers, young carers' workers and teachers - should be actively involved in terms of offering relevant information and the provision of services to address identified needs. Young carers should be enabled to explore and identify their needs and wishes and should be fully informed about the full range of services available. Where needs are clearly identified, meaningful responses to these must be strived towards in terms of services offered. Additionally, it should be reiterated that the identification and support of young carers is most easily and appropriately managed where all key services play an active role.

Choice Over the Initiation or Continuation of Caring

Health and social policy and provision should support young carers in their caring role as far as possible, where this reflects the informed choice of individual young carers and their families. In order to ascertain the wishes and rights of young carers, the full range of options must be explored including their choice to stop caring and alternative support available. In terms of this, the protection and best interests of the child must also be taken into account. Nevertheless, whilst some caring roles may well be inappropriate and cause harm to the child, it must be acknowledged that this is not necessarily the case. Where the child wishes to

continue caring and it is deemed appropriate for them to do so, they should be offered suitable forms of support.

Recognition of the Impacts of Caring and Young Carers' Resulting Needs

The range of impacts and issues experienced by young carers must be recognised including the unique issues and needs pertaining to particular caring contexts. In response to this, services provided should be as individualised and person-centred as far as practicably possible. In addition, it must be recognised that young carers may face an increased risk of living in poverty and experiencing social exclusion. Thus, young carers should be explicitly recognised as an 'at risk' group alongside lone parents and children in care, and their needs resulting from this addressed within policy responses.

Flexible, Accessible, Responsive and 'Joint Up' Service Provision to Address needs

As well as providing direct support, service-providers should refer young carers onto other services as appropriate to their needs. Whilst this must not take the form of 'passing the buck', supporting young carers or providing for their needs should not become the sole responsibility of one particular agency. Thus, there is an absolute need for collaborative practice – professionals must work collaboratively in identifying and supporting young carers, being aware of their own role and the roles and responsibilities of other agencies. Indeed this is consistent with the proposals pertaining to young carers set out in 'Care 21' which have called for both shared assessments and joint working amongst health and social care professionals, based on evidence suggesting that such practice best meets the needs of young carers. In order to facilitate this, 'young carer awareness' in the education of health and social care professionals must become a higher priority to facilitate recognition and their support.

6.6 Overall Conclusion

In conclusion, the current study has sought to differentiate the experiences of young carers relating to their specific caring contexts. Broadly, it has been found that as well as common experiences relevant to all young carers, other issues and concerns pertain to particular caring context. The extent however, to which these can be attributed to the young caring role, rather than or in addition to, other factors such as socio-economic factors is undetermined. Also, of the caring contexts considered, those young carers that were most severely or adversely affected in relation to a range of key domains (including education, social life, health and relationships as well as parental-child role reversals) were caring in the contexts of parental mental health problems and substance misuse. Ironically, despite enduring the most severe impacts, due to a combination of factors (such as stigma, as well as the unquantifiable and hidden nature of roles and tasks and ambiguous or narrow definitions), these young people were least likely to be recognised or identified as young carers. As a first step in tackling this invisibility, the resolution of conceptual ambiguity must be regarded as a priority in terms of the future development of policy and practice with young carers. Arguably this may be managed through the adoption of a collective and universally accepted, understood and applied definition of young carer.

Such a definition was devised and presented within this thesis. This is a first step and now this needs to be presented to relevant individuals and groups for consultation and development. As well as the definition, it is important that young carer awareness is promoted in mainstream education, as well as the training and development of a wide range of health and social care professionals. Professionals should also be trained to recognise and offer the most appropriate and co-ordinated support for young carers and their families. This improved recognition and support of young carers and their diverse needs, through co-ordinated, flexible and sensitive collaboration across disciplines, should be at the heart of future policy developments.

To further develop the findings highlighted within the current study, future research should address the following issues: the extent to which structural and socio-economic factors additional to caring, affect the experiences commonly reported by young carers; the experiences of young caring according to specific parental diagnoses; the experiences of those young carers within the context of parental learning difficulties; as well as the specific needs of older young carers aged 18-25.

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Understanding how supporting or caring for a parent affects growing-up

Research Project

Would you like to help with an important research project?
Your views are important!

WHAT IS THE PROJECT ABOUT?
The project is looking at what growing-up is like for young people who help out or care for a parent with a health problem. The research is interested in how the young carers feel about themselves and their caring role, in terms of school, social life, relationships, work and moving away from home, and how they feel about growing-up and becoming an adult.

CONFIDENTIAL

WHAT DO I HAVE TO DO?

You would be asked to take part in a **one-to-one confidential chat** with Emma Christie, who's carrying-out the project. This would take about 45 minutes of your time, at a place and time to suit you. The information you give would only be used for the research.
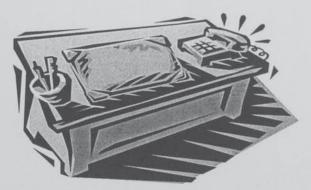
WHO IS DOING IT?

The project is being carried out by Emma Christie, The Robert Gordon University, Aberdeen.

WHY IS IT IMPORTANT?

The research is important because it is only by listening to young people that a better understanding of the experience of young caring can be gained. As such, YOUR help would be welcomed.

WHAT DO I DO NEXT?

Please complete the enclosed form stating whether you would like to take part in the study or contact Emma on the number below. Also, if you have any questions, please feel welcome to call.

Emma Christie,
The Robert Gordon University,
Faculty of Health and Social Care,
School of Applied Social Studies,
Garthdee Road,
Garthdee,
Aberdeen,
AB10 7QG
Tel:(01224) 263228 (direct) or 263200 (office)
E-mail: e.christie@rgu.ac.uk

Table 1

	Young carer	Young Caregiver	Child Carer	Child Caregiver	Teenage Carer	Adolescent Carer	Young Caring	Young Caregiving	Child Caring	Child Caregiving	Adolescent Caring	Teenage Caring
AMED												
ASLIB												
Arts + Humanities												
ASSIA												
Br. Newspaper I												
BNI												
Caredata												
CINAHL												
Daily Telegraph												
Guardian												
Independent												
Independent on Sunday												
Ingenta												
Science Direct												
SSCI												
Times												
Times and Sunday Times												
Web of Knowledge												
Zetoc												

Table 2

	Parentification	Parent-Child Reversals Role	Parentification and Young Caring	Parent-Child Role Reversals and Young Caring	Parentification Young Carer	Parent-Child Role Reversals and Young Caregiver	Parentification and Child Carer	Parent-Child Role Reversals and Child caregiving
AMED								
ASLIB								
Arts + Humanities								
ASSIA								
Br. Newspaper I								
BNI								
Caredata								
CINAHL								
Daily Telegraph								
Guardian								
Independent								
Independent on Sunday								
Ingenta								
Science Direct								
SSCI								
Times								
Zetoc								

Appendix 2 – Matrix for Literature Search

From: Moira Swanson [mailto:moira.swanson@west-dunbarton.gov.uk]
Sent: 31 July 2006 12:24
To: Emma Christie (assec)
Subject: ADSW Approval

Dear Emma,

I can confirm that your research proposal on Young Carers was supported by the ADSW Standing Committee for Standards Training and Research in March 2004. I hope that this is helpfull and look forward to hearing the findings of your research.

Yours,

Moira Swanson, Chair ADSW Research Sub-group

British Association of Social Workers (BASW) Code of Ethics for Social Work (2003)

Research

In applying the general provisions of this Code, social workers engaged in research will observe the following specific ethical responsibilities.

1. At all stages of the research process, from inception and resourcing through design and investigation to dissemination, social work researchers have a duty to maintain an active, personal and disciplined ethical awareness and to take practical and moral responsibility for their work.

2. The aims and process of social work research, including choice of methodology, and the use made of findings, will be congruent with the social work values of respect for human dignity and worth and commitment to social justice. Social work researchers will therefore:

3. Predicate their work on the perspectives and lived experience of the research subject except where this is not appropriate;

4. Seek to ensure that the research in which they are engaged contributes to empowering service users, to promoting their welfare and to improving their access to economic and social resources;

5. Seek to work together with disempowered groups, individuals and communities to devise, articulate and achieve research agendas which respect fundamental human rights and aim towards social justice;

6. Retain a primary concern for the welfare of research subjects and actively protect them from harm, particularly those who are disadvantaged, vulnerable or oppressed or have exceptional needs;

7. Consider and set out clearly how they would deal with the ascertainable consequences of proposed research activity for service users, in order to ensure that their legitimate interests are not unwarrantably compromised or prejudiced by the proposed investigation;

8. Not use procedures involving concealment except where no alternative strategy is feasible, where no harm to the research subject can be foreseen and where the greater good is self-evidently served.

9. In accordance with their duty of competence, social work researchers will, in their chosen methodology and in every other aspect of their research, ensure that they are technically competent to carry out the particular investigation to a high standard.

10. Where research is carried out primarily as an educational or instructional tool, this responsibility also falls on the student's supervisor.

11. In accordance with their duty of integrity, social work researchers have a duty to:

12. deal openly and fairly with every participant in the research process, including participants, service users, colleagues, funders and employers;

13. Inform every participant of all features of the research which might be expected to influence willingness to participate, especially but not exclusively when access to services may be, or be perceived to be, affected by or dependent on participation;

14. In all cases respect participants' absolute right to decline to take part in or to withdraw from the research programme, with special attention to situations in which the researcher is in any way in authority over the participant;

15. Ensure that subjects' participation in a programme is based on freely given, informed and acknowledged consent, secured through the use of language or other appropriate means of communication readily comprehensible to the research subject, conveying an adequate explanation of the purpose of the research and the procedures to be followed;

16. Seek to exclude from their work any unacknowledged bias;

17. Report findings accurately, avoiding distortion whether by omission or otherwise, including any findings which reflect unfavourably on any influential body or research sponsor, on the researcher's own interests or on prevailing wisdom or orthodox opinion;

18. Seek to ensure that their findings are not misused or misrepresented;

19. Acknowledge when publishing findings the part played by all participants and never take credit for the work of others.

20. In accordance with their duty of confidentiality, social work researchers will respect and maintain the confidentiality of all data or information produced in the course of their research, except as agreed in advance with participants (including research subjects) or as prescribed by law.

Full Code Available from: www.basw.co.uk/articles.php?articleId=2&page=1

British Sociological Association Statement of Ethical Practice (2002)

Professional Integrity

1. Sociological research is a valuable activity and contributes to the well-being of society. Members should strive to maintain the integrity of sociological inquiry as a discipline, the freedom to research and study, and to publish and promote the results of sociological research including making data available for the use of researchers in the future.

2. Members have a responsibility both to safeguard the proper interests of those involved in or affected by their work, and to report their findings accurately and truthfully. They need to consider the effects of their involvements and the consequences of their work or its misuse for those they study and other interested parties.

3. While recognising that training and skill are necessary to the conduct of social research, members should themselves recognise the boundaries of their professional competence. They should not accept work of a kind that they are not qualified to carry out. Members should satisfy themselves that the research they undertake is worthwhile and that the techniques proposed are appropriate. They should be clear about the limits of their detachment from and involvement in their areas of study.

4. Social researchers face a range of potential risks to their safety. Safety issues need to be considered in the design and conduct of social research projects and procedures should be adopted to reduce the risk to researchers.

5. In their relations with the media, members should have regard for the reputation of the discipline and refrain from offering expert commentaries in a form that would appear to give credence to material that, as researchers, they would regard as comprising inadequate or tendentious evidence.

Relations with and Responsibilities towards Research Participants

6. Sociologists, when they carry out research, enter into personal and moral relationships with those they study, be they individuals, households, social groups or corporate entities.

7. Although sociologists, like other researchers are committed to the advancement of knowledge, that goal does not, of itself, provide an entitlement to override the rights of others.

8. Members should be aware that they have some responsibility for the use to which their data may be put and for how the research is to be disseminated. Discharging that responsibility may on occasion be difficult, especially in situations of social conflict, competing social interests or where there is unanticipated misuse of the research by third parties.

Relationships with research participants

9. Sociologists have a responsibility to ensure that the physical, social and psychological well-being of research participants is not adversely affected by the research. They should strive to protect the rights of those they study, their interests, sensitivities and privacy, while recognising the difficulty of balancing potentially conflicting interests.

10. Because sociologists study the relatively powerless as well as those more powerful than themselves, research relationships are frequently characterised by disparities of power and status. Despite this, research relationships should be characterised, whenever possible, by trust and integrity.

11. In some cases, where the public interest dictates otherwise and particularly where power is being abused, obligations of trust and protection may weigh less heavily. Nevertheless, these obligations should not be discarded lightly.

12. As far as possible participation in sociological research should be based on the freely given informed consent of those studied. This implies a responsibility on the sociologist to explain in appropriate detail, and in

terms meaningful to participants, what the research is about, who is undertaking and financing it, why it is being undertaken, and how it is to be disseminated and used.

13. Research participants should be made aware of their right to refuse participation whenever and for whatever reason they wish.

14. Research participants should understand how far they will be afforded anonymity and confidentiality and should be able to reject the use of data-gathering devices such as tape recorders and video cameras.

15. Sociologists should be careful, on the one hand, not to give unrealistic guarantees of confidentiality and, on the other, not to permit communication of research films or records to audiences other than those to which the research participants have agreed.

16. Where there is a likelihood that data may be shared with other researchers, the potential uses to which the data might be put must be discussed with research participants and their consent obtained for the future use of the material. When making notes, filming or recording for research purposes, sociologists should make clear to research participants the purpose of the notes, filming or recording, and, as precisely as possible, to whom it will be communicated. It should be recognised that research participants have contractual and/or legal interests and rights in data, recordings and publications.

17. The interviewer should inform the interviewee of their rights under any copyright or data protection laws.

18. Researchers making audio or video recordings should obtain appropriate copyright clearances.

19. Interviewers should clarify whether, and if so, the extent to which research participants are allowed to see transcripts of interviews and field notes and to alter the content, withdraw statements, to provide additional information or to add glosses on interpretations.

20. Clarification should also be given to research participants regarding the degree to which they will be consulted prior to publication. Where

possible, participants should be offered feedback on findings, for example in the form of a summary report.

21. It should also be borne in mind that in some research contexts, especially those involving field research, it may be necessary for the obtaining of consent to be regarded, not as a once-and-for-all prior event, but as a process, subject to renegotiation over time. In addition, particular care may need to be taken during periods of prolonged fieldwork where it is easy for research participants to forget that they are being studied.

22. In some situations access to a research setting is gained via a 'gatekeeper'. In these situations members should adhere to the principle of obtaining informed consent directly from the research participants to whom access is required, while at the same time taking account of the gatekeepers' interest.

23. Since the relationship between the research participant and the gatekeeper may continue long after the sociologist has left the research setting, care should be taken not to compromise existing relationships within the research setting

24. It is, therefore, incumbent upon members to be aware of the possible consequences of their work. Wherever possible they should attempt to anticipate, and to guard against, consequences for research participants that can be predicted to be harmful. Members are not absolved from this responsibility by the consent given by research participants.

25. In many of its forms, social research intrudes into the lives of those studied. While some participants in sociological research may find the experience a positive and welcome one, for others, the experience may be disturbing. Even if not harmed, those studied may feel wronged by aspects of the research process. This can be particularly so if they perceive apparent intrusions into their private and personal worlds, or where research gives rise to false hopes, uncalled for self-knowledge, or unnecessary anxiety.

26. Members should consider carefully the possibility that the research experience may be a disturbing one and should attempt, where necessary,

to find ways to minimise or alleviate any distress caused to those participating in research. It should be borne in mind that decisions made on the basis of research may have effects on individuals as members of a group, even if individual research participants are protected by confidentiality and anonymity.

27. Special care should be taken where research participants are particularly vulnerable by virtue of factors such as age, disability, their physical or mental health. Researchers will need to take into account the legal and ethical complexities involved in those circumstances where there are particular difficulties in eliciting fully informed consent. In some situations proxies may need to be used in order to gather data. Where proxies are used, care should be taken not to intrude on the personal space of the person to whom the data ultimately refer, or to disturb the relationship between this person and the proxy. Where it can be inferred that the person about whom data are sought would object to supplying certain kinds of information, that material should not be sought from the proxy.

28. Research involving children requires particular care. The consent of the child should be sought in addition to that of the parent. Researchers should use their skills to provide information that could be understood by the child, and their judgement to decide on the child's capacity to understand what is being proposed. Specialist advice and expertise should be sought where relevant. Researchers should have regard for issues of child protection and make provision for the potential disclosure of abuse.

Covert Research

29. There are serious ethical and legal issues in the use of covert research but the use of covert methods may be justified in certain circumstances. For example, difficulties arise when research participants change their behaviour because they know they are being studied. Researchers may also face problems when access to spheres of social life is closed to social scientists by powerful or secretive interests.

30. However, covert methods violate the principles of informed consent and may invade the privacy of those being studied. Covert researchers might need to take into account the emerging legal frameworks surrounding the right to privacy. Participant or non-participant observation in non-public spaces or experimental manipulation of research participants without their knowledge should be resorted to only where it is impossible to use other methods to obtain essential data. In such studies it is important to safeguard the anonymity of research participants. Ideally, where informed consent has not been obtained prior to the research it should be obtained post-hoc.

Anonymity, privacy and confidentiality

31. The anonymity and privacy of those who participate in the research process should be respected. Personal information concerning research participants should be kept confidential. In some cases it may be necessary to decide whether it is proper or appropriate even to record certain kinds of sensitive information.

32. Where possible, threats to the confidentiality and anonymity of research data should be anticipated by researchers. The identities and research records of those participating in research should be kept confidential whether or not an explicit pledge of confidentiality has been given.

33. Appropriate measures should be taken to store research data in a secure manner. Members should have regard to their obligations under the Data Protection Acts. Where appropriate and practicable, methods for preserving anonymity should be used including the removal of identifiers, the use of pseudonyms and other technical means for breaking the link between data and identifiable individuals. Members should also take care to prevent data being published or released in a form that would permit the actual or potential identification of research participants without prior written consent of the participants. Potential informants and research participants, especially those possessing a combination of attributes that make them readily identifiable, may need to be reminded that it can be

difficult to disguise their identity without introducing an unacceptably large measure of distortion into the data.

34. Guarantees of confidentiality and anonymity given to research participants must be honoured, unless there are clear and overriding reasons to do otherwise, for example in relation to the abuse of children. Other people, such as colleagues, research staff or others, given access to the data must also be made aware of their obligations in this respect. By the same token, sociologists should respect the efforts taken by other researchers to maintain anonymity.

35. Research data given in confidence do not enjoy legal privilege, that is they may be liable to subpoena by a court and research participants should be informed of this.

36. There may be fewer compelling grounds for extending guarantees of privacy or confidentiality to public organisations, collectivises, governments, officials or agencies than to individuals or small groups. Nevertheless, where guarantees have been given they should be honoured, unless there are clear and compelling public interest reasons not to do so.

37. During their research members should avoid, where they can, actions which may have deleterious consequences for sociologists who come after them or which might undermine the reputation of sociology as a discipline.

38. Members should take special care when carrying out research via the Internet. Ethical standards for internet research are not well developed as yet. Eliciting informed consent, negotiating access agreements, assessing the boundaries between the public and the private, and ensuring the security of data transmissions are all problematic in Internet research. Members who carry out research online should ensure that they are familiar with ongoing debates on the ethics of Internet research, and might wish to consider erring on the side of caution in making judgements affecting the well-being of online research participants.

Available in full from:
www.britsoc.co.uk/user_doc/Statement%20of%20Ethical%20Practice.doc

Scottish Social Services Council (SSSC) Code of Practice for Social Service Workers (2002)

As a social service worker you must protect the rights and promote the interests of service users and carers. This includes:

1. Treating each person as an individual;
2. Respecting and, where appropriate, promoting the individual views and wishes of both service users and carers;
3. Supporting service users' rights to control their lives and make informed choices about the services they receive;
4. Respecting and maintaining the dignity and privacy of service users;
5. Promoting equal opportunities for service users and carers; and,
6. Respecting diversity and different cultures and values.

As a social service worker you must strive to establish and maintain the trust and confidence of service users and carers. This includes:

7. Being honest and trustworthy;
8. Communicating in an appropriate, open, accurate and straightforward way;
9. Respecting confidential information and clearly explaining agency policies about confidentiality to services users and carers;
10. Being reliable and dependable;
11. Honouring work commitments, agreements and arrangements and when it is not possible to do so, explaining why to service users and carers;
12. Declaring issues that might create conflicts of interest and making sure that they do not influence your judgement or practice;
13. Adhering to policies and procedures about accepting gifts and money from service users and carers.

As a social service worker you must promote the independence of service users while protecting them as far as possible from danger or harm. This includes:

14. Promoting the independence of service users and assisting them to understand and exercise their rights;

15. Using established processes and procedures to challenge and report dangerous, abusive, discriminatory or exploitative behaviour and practice;

16. Following practice and procedures designed to keep you and other people safe from violent and abusive behaviour at work;

17. Bringing to the attention of your employer or the appropriate authority resource of operational difficulties that might get in the way of the delivery of safe care;

18. Informing your employer or an appropriate authority where the practice of colleagues may be unsafe or adversely affecting standards of care;

19. Complying with employers' health and safety policies including those relating to substance abuse;

20. Helping service users and carers to make complaints, taking complaints seriously and responding to them or passing them to the appropriate person; and,

21. Recognising and using responsibly the power that comes from your work with service users and carers.

As a social service worker you must respect the rights of service users while seeking to ensure that their behaviour does not harm themselves or other people. This includes:

22. Recognising that service users have the right to take risks and helping them to identify and manage potential and actual risks to themselves and others;

23. Following risk assessment policies and procedures to assess whether the behaviour of service users presents a risk of harm to themselves or others;

24. Taking necessary steps to minimise the risks of service users from doing actual or potential harm to themselves or other people; and,

25. Ensuring that relevant colleagues and agencies are informed about the outcomes and implications of risk assessments.

As a social service worker you must uphold public trust and confidence in social services. In particular you must not:

26. Abuse, neglect or harm service users, carers or colleagues;

27. Exploit service users, carers or colleagues in any way;

28. Abuse the trust of service users and carers or the access you have to personal information about them, or to their property, home or workplace;

29. Form inappropriate personal relationships with services users;

30. Discriminate unlawfully or unjustifiably against service users, carers or colleagues;

31. Condone any unlawful or unjustifiable discrimination by service users, carers or colleagues;

32. Put yourself or other people at unnecessary risk; or,

33. Behave in a way, in work or outside work, which would call into question your suitability to work in social services.

As a social service worker you must be accountable for the quality of your work and take responsibility for maintaining and improving your knowledge and skills. This includes:

34. Meeting relevant standards of practice, and working in a lawful, safe and effective way;

35. Maintaining clear and accurate records as required by procedures established for your work;

36. Informing your employer or the appropriate authority about any personal difficulties that might affect your ability to do your job competently and safely;

37. Seeking assistance from your employer or the appropriate authority if you do not feel able or adequately prepared to carry out any aspect of your work or you are not sure about how to proceed in a work matter;

38. Working openly and co-operatively with colleagues and treating them with respect;

39. Recognising that you remain responsible for the work that you have delegated to other workers;

40. Recognising and respecting the roles and expertise of workers from other agencies and working in partnership with them; and,

41. Undertaking relevant training to maintain and improve your knowledge and skills and contributing to the learning and development of others.

Available in full from: www.sssc.uk.com/NR/rdonlyres/294F3E3F-D74B-44FE-B49E-676C98F75703/0/CodesofPractice.doc

Social Research Association (SRA) Ethical Guidelines (2003)

Obligations to Society

If social research is to remain of benefit to society and the groups and individuals within it, then social researchers must conduct their work responsibly and in light of the moral and legal order of the society in which they practice.They have a responsibility to maintain high scientific standards in the methods employed in the collection and analysis of data and the impartial assessment and dissemination of findings.

1. In general, researchers have an obligation to conform to the ethical standards of the society in which they conduct their work. In particular, researchers have an obligation to ensure that they are informed about the appropriate legislation of the country in which they are conducting research and how that legislation might affect the conduct of their research. Researchers should not knowingly contravene such legislation.

Considering conflicting interests

2. Nonetheless, in planning all phases of an inquiry, from design to presentation of findings, social researchers should consider the likely consequences for society at large, groups and categories of persons within it, respondents or other subjects, and possible future research.

3. No generic formula or guidelines exist for assessing the likely benefit or risk of various types of social enquiry. Nonetheless, social researchers must be sensitive to the possible consequences of their work and should as far as possible, guard against predictably harmful effects.

Pursuing objectivity

4. While social researchers operate within the value systems of their societies, they should attempt to uphold their professional integrity without fear or favour. They must also not engage or collude in selecting methods

designed to produce misleading results, or in misrepresenting findings by commission or omission.

5. Research can never be entirely objective, and social research is no exception. The selection of topics for attention may reflect a systematic bias in favour of certain cultural or personal values. In addition, the employment base of the researcher, the source of funding and a range of other factors may impose certain priorities, obligations and prohibitions. Even so, the social researcher is never free of a responsibility to pursue objectivity and to be open about known barriers to its achievement. In particular social researchers are bound by a professional obligation to resist approaches to problem formulation, data collection or analysis, interpretation and publication of results that are likely (explicitly or implicitly) to misinform or to mislead rather than to advance knowledge.

Obligations to Colleagues

Social research depends upon the maintenance of standards and of appropriate professional behaviour that is shared amongst the professional research community. Without compromising obligations to funders/employers, subjects or society at large, this requires methods, procedures and findings to be open to collegial review. It also requires concern for the safety and security of colleagues when conducting field research.

Communicating ethical principles

6. To conduct certain inquiries social researchers need to collaborate with colleagues in other disciplines, as well as interviewers, clerical staff, students, etc. In these cases social researchers should make their own ethical principles clear and take account of the ethical principles of their collaborators.

7. Each of these principles stems from the notion that social researchers derive their status and certain privileges of access to data not only by their personal standing but also by virtue of their professional citizenship. In acknowledging membership of a wider social research community, they

owe various obligations to that community and can expect consideration from it. Some form of independent ethical review is proposed as the best mechanism for addressing this. This in itself cannot absolve researchers from addressing moral dilemmas entailed in their work for themselves, as well as part of a community of peers.

8. Confidence in research findings depends critically on their faithful representation.

Ensuring safety and minimising risk of harm to field researchers

9. Social researchers have a moral obligation to attempt to minimise the risk of physical and/or mental harm to themselves and to their colleagues from the conduct of research.

10. All research entailing direct contact with the public presents a risk potential. Researchers should maintain awareness of such risk to themselves and their colleagues and make every effort to diminish the dangers.

Obligations to Subjects

Social researchers must strive to protect subjects from undue harm arising as a consequence of their participation in research. This requires that subjects' participation should be voluntary and as fully informed as possible and no group should be disadvantaged by routinely being excluded from consideration.

11. Even if research subjects do not perceive any danger to themselves of data disclosure, nevertheless it is the task of the researcher to maintain principles of confidentiality as far as possible so that the interests of subjects are protected.

Obtaining informed consent

12. Inquiries involving human subjects should be based as far as practicable on the freely given informed consent of subjects. In voluntary inquiries, subjects should not be under the impression that they are required to

participate. They should be aware of their entitlement to refuse at any stage for whatever reason and to withdraw data just supplied.

13. Information that would be likely to affect a subject's willingness to participate should not be deliberately withheld, since this would remove from subjects an important means of protecting their own interests. Gaining informed consent is a procedure for ensuring that research subjects understand what is being done to them, the limits to their participation and awareness of any potential risks they incur. The principle of informed consent from subjects is necessarily vague, since it depends for its interpretation on unstated assumptions about the amount of information and the nature of consent required to constitute acceptable practice. The amount of information needed to ensure that a subject is adequately informed about the purpose and nature of an inquiry is bound to vary from study to study.

14. The clarity and comprehensibility of the information provided are as important as the quantity.

15. An assessment needs to be made of what information is likely to be material to a subject's willingness to participate.

16. The boundary between tactical persuasion and duress is sometimes very fine and is probably easier to recognise in practice than to stipulate. In any event, the most specific generic statement that can be made about adequate consent is that it falls short both of implied coercion and of full-hearted participation.

17. In these cases, social researchers should not devolve their responsibility to protect the subject's interests on to the gatekeeper. They should also be wary of inadvertently disturbing the relationship between subject and gatekeeper. While respecting the gatekeeper's legitimate interests they should adhere to the principle of obtaining informed consent directly from subjects once they have gained access to them.

18. A major limitation upon gaining informed consent lies with "vulnerable" populations. Such groups include children, those with an intellectual disability, or those in a dependent relationship to the researcher or

commissioning body. In conducting research with vulnerable populations, extra care must be taken to protect their rights and ensure that their compliance is freely entered in to. Some would argue that sending a field researcher to ask a subject to participate in a study does not constitute informed consent since the researcher is seeking to persuade the subject to participate. The degree of "persuasion" might be enhanced with vulnerable groups.

19. In order to protect the researcher from accusations of failing to secure informed consent a practice has grown of having subjects sign a consent form.

20. It may be impossible to anticipate all potential harm to the subject from participation in a study – subjects in clinical trials, for example, are not guaranteed protection from harm. But there should, at least, be clarity about opt-in and opt-out arrangements, about the length and degree of commitment required of respondents, and about the precise goals of the research.

Modifications to informed consent

21. Covert observation and any other forms of research which use deception can only be justified where there is no other ethically sound way of collecting accurate and appropriate data. If research requires any kind of deception, then only by the clear demonstration of the benefits of the research can it be justified.

Protecting the interests of subjects

22. Neither the consent of the subjects nor the legal requirement to participate absolves the social researcher from an obligation to protect the subject as far as possible against potentially harmful effects of participating. The social researcher should try to minimise disturbance both to subjects themselves and to the subjects' relationships with their environment. Social researchers should help subjects to protect their own interests by giving them prior information about the consequences of participating.

Harm to subjects may arise from undue stress through participation, loss of self esteem, psychological injury or other side effects. Various factors may be important in assessing the risk benefit ratio of a particular inquiry, such as the probability of risk, the number of people at risk, the severity of the potential harm, the anticipated utility of the findings, few of which are usually quantifiable.

Maintaining confidentiality of records

23. The identities and records of co-operating (or non-cooperating) subjects must therefore be kept confidential, whether or not confidentiality has been explicitly pledged. Data that does not enable identification should not be passed on without consent and should be stored safely with restricted access.

24. It should be made clear in "informed consent" information to subjects that complex data sets with postcodes and other geographic identifiers applied to case records could be used to identify individuals. Although it has to be acknowledged that some risk of disclosure is always present, researchers should at least guarantee that they have taken all reasonable steps to prevent the disclosure of identities.

Preventing disclosure of identities

25. Social researchers should take appropriate measures to prevent their data from being published or otherwise released in a form that would allow any subject's identity to be disclosed or inferred. The disclosure of identity in itself represents a potential risk of harm to a subject.

26. Neither the use of subject pseudonyms nor anonymity alone is any guarantee of confidentiality. A particular configuration of attributes can, like a fingerprint, frequently identify its owner beyond reasonable doubt. So social researchers need to remove the opportunities for others to infer identities from their data.

Available in full from: www.the-sra.org.uk/documents/pdfs/ethics03.pdf

Understanding how 'Young Caring' affects Growing-Up

Consent Form

You are invited to take part in a research project being carried out by Emma Christie, The Robert Gordon University, School of Applied Social Studies. The research aims to understand how young caring affects the experience of growing up.

Emma Christie would like to talk to you for about an hour at a time and a place suitable to yourself. The interview is confidential, and your name will not be used in the report. The only case in which details would be shared would be if there was seen to be a risk of harm to you or another child. If this happened, Emma would discuss details with the Agency through through whom she made initial contact with you.

It is completely up to you whether you want to take part in the study and there will be no pressure to do so. Taking part in the study is unlikely to result in any direct benefit to you. If you would like to take part, you can change your mind at any time without giving any reason for doing so.

Please read the Information Sheet provided along with this form for further information.

I fully and freely consent to participate in the study, which has been clearly explained to me.

Signature of Participant :...

Name of Participant :..

Date :.....................................

Signature of the Researcher : ....

Date :...

For under 16's:

Signature of the Parent:..

Date : ....

You are invited to take part in an important research project about young caring

Hi. My name is Emma Christie and I am carrying-out a project about young carers. I am interested in finding out what life is like for you, growing-up as a young carer.

This would involve you taking part in a one-to-one interview with Emma. The interviews will be carried-out between February and March 2004, and would take about one hour of your time. You will also be asked to help in other ways like by keeping a diary of what you do at home to help your parent.

So are you interested......?
If so, please have a look at the information booklet enclosed, for more details.

So are you still interested....?
If you think that you may be interested in taking part and would like more information, please fill-in the form below and return it to Emma in the envelope provided. Emma will then contact you to tell you more about the project.

(Tear-off slip)

....

....

Get a voucher for a **free McDonald's meal** when you return this slip to Emma (in the envelope enclosed).

Name...
...

Address (where you want your McDonald's voucher sent)

....
....

I am interested in taking part and would like more information and would like Emma to

call me   (please tick box)   ☐
Telephone number (where Emma can call you)...............................

I am not interested in taking part in this research project (please tick box)   ☐
McDonald's have no access to or control over the information collected for this study

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Dear Sir/ Madam

I am writing to request your assistance with regards to a Ph.D. research project that I am currently undertaking looking at young caring.

My specific area of interest concerns the impacts of caring for parents with a broad range of illness and disability. These are physical disability, mental health problems, learning difficulties and problematic substance misuse.

I have already undertaken the first phase with young people caring for a parent with a physical condition and therefore, am about to begin the next stage looking-at the experience and impacts of caring for or assisting a parent with problematic substance misuse, learning difficulties or mental health problems.

This will involve 30 young carers (10 in each caring situation) aged between 12 and 25, who will each be asked to participate in a one-to-one interview lasting approximately one hour, at a time and place suitable to them. The information that they provide will be confidential and in the resulting dissertation, their details will be anonymous.

I appreciate that this is a highly sensitive issue which many young carers may feel unsure about discussing, but as minimal research has been undertaken looking specifically at the needs of young carers in various caring contexts, such research is essential. Also, I strive to make the interviews as relaxed and informal as possible, and indeed some of the youngsters involved in the first phase have indicated that they found the interview experience enjoyable.

Moreover, the current project has already highlighted various needs which may be addressed via specific services including the particular needs of those young carers aged 18-25 whose needs may not be adequately addressed by young carers' or adult carers services. This possibly highlights the need for a dedicated service for young adult carers.

Therefore, if you or your colleagues know of any young people aged 12-25 caring for a parent with problematic substance misuse, mental health problems or learning difficulties, who may wish to participate in the study, I would really appreciate your assistance. I am available to meet with you to discuss the project, their and your potential involvement.

Alternatively, as I appreciate that you are extremely busy, I have devised a system to minimise your time spent in the recruitment process. All that would be required of you would be to identify potential participants, provide them with an information booklet (see attached copy) and if they are interested, ask them to sign a consent form (see attached copy) so that their name and contact number could be passed onto me. I would then contact them directly. Also, details of any other agencies that may be able to assist would be gratefully received.

I can be contacted via e-mail at e.christie@rgu.ac.uk or telephone (01224) 263227. I look forward to your reply.

Kind regards

Emma Christie

CONSENT FOR SHARING OF CONTACT DETAILS

.... (worker's name) of .... (Agency) has informed me of a research project being carried-out by Emma Christie of the Robert Gordon University and discussed my potential involvement.

I agree that my name and contact details can be passed onto Emma Christie, so that she can contact me directly to tell me more about the project.

Young Person's
Signature...

Date..........................

Young Person's
Name...Age.................................

Contact Telephone
Number...

Comments..
....
....
....

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Young Caring in the Context of Parental Learning Difficulties

As described, it was not possible to recruit young carers in the context of parental learning difficulties into the study[16]. Therefore, both the experiences of young carers within this context and the reasons which underpinned their heightened level of hidden-ness were explored with a number of relevant professionals. Whilst the professional opinions provided an interesting insight, these could not be compared with the experiences reported by the young carers across the other three contexts. Fundamentally, this study was informed by a constructive-interpretive paradigm and therefore, sought to uncover and understand how the young carers themselves fashioned meaning in their own Worlds. Additionally, one young carer (Linda[17]) who supported both of her parents and her sister with learning difficulties was recruited into the study. She was accessed through a local young carer's project. As she was the sole young carer in this context, it was not appropriate to use her as a point of comparison with the other young carers. The findings in relation to this context are thus, presented here as an additional insight.

Within this section, firstly, the case of 'Linda' and her caring situation and experiences will be outlined (see 'Box 1' below). Following this, in Table 1, the ten professionals involved in the study will be introduced, with reference to their background and related experiences. Thereafter, in Table 2, the common issues around the key areas previously defined (education, social life, health, spatial transitions and relationships), as discussed by the professionals, will be summarised. Lastly, the professional opinions regarding the increased invisibility of young carers of parents with learning difficulties will be summarised. The insights of the professionals were based on their experiences working with either young carers of parents with learning difficulties, or indeed such parents themselves.

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[16] See methodology Chapter for further description.
[17] In order to protect the participant's identity, the name 'Linda' as referred to within this section, was a pseudonym.

Case of Young Carer in the Context of Parental Learning Difficulties

Linda (13) was referred to the research project by a young carers' worker, on the basis of her caring role in respect to both of her parents as well as her younger sister with learning difficulties. It was explained by the young carers' worker that whilst both of her parents clearly had varying levels of learning difficulties and had attended 'special' schools in the past, this had not been explicitly acknowledged by Linda or her parents, or professionals involved with the family including the young carers' worker and teachers at Linda's school. Indeed, her contact with the young carers' service was initiated by Linda's teacher after it was discovered that she was caring for her sister.

Due to this, it was agreed that her parents' learning difficulties would not be explicitly discussed during the course of the interview. Instead, the interview focused on her young caring role in respect to her sister. However, whilst Linda did not refer to her parents learning difficulties, it was apparent that the tasks and roles that she undertook at home were directly linked to her parent's learning difficulties. The practical tasks she undertook largely involved utilising her literacy and numeracy skills. This included answering the telephone and taking telephone messages, as well as reading letters, food labels and instructions. In addition, she was required to undertake a range of domestic tasks, such as washing and cleaning. In terms of her caring role in respect to her younger sibling, Linda was involved in managing her daily routine which included helping prepare her meals, assisting with her homework, reading her bedtime stories and settling her down at night. Interestingly, Linda identified herself as her sister's main carer.

Apart from the young carers' worker, the family had no additional formal support and in terms of informal support, the only living relative - a grandmother - had sporadic contact with the family and thus, appeared to offer little assistance. Nevertheless, the key areas within Linda's life appeared to be unaffected by her caring role. The only area that was affected was her relationships with her parents and sister. W#However, whilst tensions were present, these appeared to be normative or perhaps only partly linked to her sisters' disability, rather than as a result of Linda's caring role. In support of this assertion, Linda herself stated that '...sometimes we have problems 'cause me and my sister sometimes fight, but sometimes it's good...' However, it is noteworthy that her career aspirations were influenced by her experiences as a young carer. Indeed she stated that she wished to pursue a career in nursing, due to having gained key skills through her caring role, in terms of '...the looking-after and the washing and stuff like that...'.

Table 1 – The Roles and Experiences of the Professionals

Worker Identity	Professional Role	Description of Contact(s) and Experience	Main Issues Identified Relating to Cases
LF	Social Worker based in a Community Learning Difficulties Team	Had previous contact with a family where both parents had learning difficulties as had their eldest daughter (17). Despite her own learning difficulties, the daughter fulfilled a young caring role for both parents, mainly aiding their comprehension of everyday events. Social Work involvement was initiated by teachers at the school, following concerns about the children being neglected by their parents, due to persistent head lice. The relationship between the daughter and mother broke down due to an incident concerning an accusation made by the daughter against a peer who she accused of sexual assault. It was asserted by professionals involved that the mother did not understand the 'process of events' and thus was unable to offer her daughter support.	Neglect of child Relationship difficulties between parent and child Multiple members of family with learning difficulties
BT	Manager of a Learning Difficulties Team	Did not discuss any specific cases, but had ongoing contact with numerous families with parental learning difficulties. Referred to specific issues such as the child experiencing neglect, stigma and embarrassment due to the parental condition, creating resentment. Highlighted that children's caring roles largely derived from the parents' lack of understanding, and thus, tasks related to reading and writing and generally assisting the parent to make sense of the world.	Neglect of child Courtesy stigma Interpretation and comprehension tasks Relationship difficulties between parent and child
MJ	Manager of a Learning Difficulties Team	Had previous contact with several families with parental learning difficulties. Recounted one family where both parents had learning difficulties and due to perceived neglect, their three children were eventually looked after by the local authority.	Neglect of child Child placed in care Multiple members of family with learning difficulties
KV	Health Visitor for Parents with Learning Difficulties/ University Lecturer	Had prior contact with a family which consisted of two parents with learning difficulties and a son (13). The son offered his parents support, particularly with tasks that required literacy and numeracy skills, such as the family's finances. However, due to his spending on a range of unnecessary luxuries with the family's budget, the family experienced major debt problems as well as relationship difficulties.	Interpretation and comprehension tasks Relationship difficulties between parent and child Multiple Members of Family with Learning Difficulties
GH	Young Carers Worker	Outlined two cases where a child in the family carried-out a young caring role. However in neither case was professional contact initiated due to the parental learning difficulties. In the first case, the parent had a dual diagnosis of both learning difficulties and mental health problems and the child had been referred to the young carers' worker by the community mental health team. The impact of the parental learning difficulties and the resultant additional caring responsibilities had been overlooked. In the second case, the young carer supported both her parent and sibling with learning difficulties – however, she had been referred for young carers support due to her role in relation to her sibling.	Young caring role overlooked Multiple members of family with learning difficulties Lack of acknowledgement of parental learning difficulties

TD	Young Carers Worker	Referred 'Linda' to the research project (see Box – Case Study of Linda).	Lack of acknowledgement of parental learning difficulties Lack of acknowledgement of young caring role Interpretation and comprehension tasks Parenting role for sibling Impact on career aspirations
NE	Senior Young Carers Worker	Discussed various young carers' families where there were suspected, yet unconfirmed parental learning difficulties. In each case, the child was in contact with the young carers' service on the basis of supporting a different family member – largely siblings with learning difficulties.	Lack of acknowledgement of parental learning difficulties Multiple members of family with learning difficulties
ZG	Young Carers Worker	Had contact with six families with parental learning difficulties, where potentially the young person had supported the parent as a result. However, in none of these cases had the parental learning difficulties been acknowledged. Instead, the reason for professional contact in all cases was because of their caring roles for siblings	Lack of acknowledgement of parental learning difficulties Multiple members of family with learning difficulties
IM	Carers Centre Manager	Line manages both carers centre staff and young carers' workers. Thus, referred to case of 'Linda' (see Box – Case Study of Linda).	Lack of acknowledgement of parental learning difficulties Lack of acknowledgement of young caring role Interpretation and comprehension tasks Parenting role for sibling Impact on career aspirations Multiple members of family with learning difficulties
CL	Carers Support Worker	Had contact with one young person who supported a parent with mild autism and associated learning difficulties. However, the caring role (which largely involved assisting the parent to interpret and comprehend everyday events) was not acknowledged within the family.	Interpretation and comprehension tasks Lack of acknowledgement of young caring role

Appendix 9 – Professional Insight into Young Caring in the Context of Learning Difficulties

Table 2 – Range of Issues Discussed by the Professionals

Area Discussed	Key Issues Identified	Discussion of Issues Identified
Educational Difficulties	i. Absenteeism and Lateness ii. Homework Difficulties iii. Lack of Parental Comprehension, iv. Support and Stimulation v. Separation and Worry vi. Courtesy Stigma and Bullying vii. Own Learning difficulties viii. Low Priority and Expectations Lack of Understanding of Teachers	In addition to the concerns and difficulties highlighted by other young carers, specific educational issues discussed in relation to children within this context included: i. Lack of parental comprehension regarding the importance of regular attendance at school and completion of homework tasks as well as an inability to support children in completing these tasks. ii. It was felt that children of parents with learning difficulties were at risk of their own learning difficulties too, which would compound the educational problems experienced; iii. Based on their own situation, parents may not regard educational attainment as particularly important, an attitude which can be transferred to the child in some cases.
Difficulties with Social Life	i. Social Isolation ii. Limited Peer Network iii. Courtesy Stigma and Bullying iv. Limited Awareness of Socially Acceptable Behaviour	As well as the issues identified by other young carers, specific concerns related to social functioning discussed included: i. Due to lack of modelling of acceptable social behaviour at home, children may be unaware of how to behave in social situations, potentially increasing the likelihood of bullying and stigma.
Difficulties with Romantic Relationships	i. Genetic Risk of Transference ii. Courtesy Stigma iii. Limited Network in Partner Selection iv. Lack of Parental Comprehension, Guidance and Support	In addition to the concerns and difficulties highlighted by other young carers, specific difficulties with romantic relationships discussed in relation to young people within this context included: i. tensions due to young person and partners' fears of 'passing on' learning difficulties to any children they may have in the future; ii. Lack of parental support and guidance in terms of issues relating to relationships such as emotions, sexual health, pregnancy, etc.
Employment Issues	i. Impact of Poor Educational Attainment ii. Low Priority and Expectations iii. Expectation to Work to Support Family 'versus' Difficulties Balancing Work and Caring Responsibilities	As well as the issues outlined by other young carers across the other caring contexts, specific concerns in relation to employment and one's finances were identified by the professionals: i. Similar to the low priority status assigned to education, parents may not actively encourage their child to seek employment; ii. The obvious implications of lack of employment include being caught in the benefits trap and failing to escape poverty.

Appendix 9 – Professional Insight into Young Caring in the Context of Learning Difficulties

Category	Sub-items	Description
Financial Issues and Concerns	i. Implications of Being Caught in the 'Benefits Trap' ii. Debt Problems iii. Financial Problems as Reflection of Difficulties Accessing Work	
Issues in Moving Away from the Parental Home	Moving away was perceived as being less problematic in the context of parental learning difficulties, than in other young caring contexts, due to 3 key reasons: i. Transient and Irregular Nature of Parental Care Needs; ii. Relatively Static Nature of Parental Condition; iii. Availability of an Established Parental Support Network enabled moves	In contrast to other caring contexts, it was perceived by the professionals that it may be easier for young carers and children of parents with learning difficulties to move away from home, because of the largely unchanging nature of their condition and their intermittent care needs.
Health Issues and Concerns	i. Difficulties Resulting From Lack of Parental Comprehension ii. Stress	As well as the impacts on health identified by other young carers across the other three contexts, one specific issue discussed related to a lack of parental comprehension over normative health and development. Thus, parents may be unable to offer advice on a range of health-related issues, such as sexual health, pregnancy, nutrition, exercise and disease or gauge indications of serious illness.
Familial Relationships in the Context of Parental Learning difficulties	i. Frictions Resulting From Lack of Parental Comprehension and Inappropriate Behaviour ii. Manipulation of the Parent 'versus' iii. Sympathy and Support iv. Lack of Boundaries and Parental Control	The issues highlighted by the professionals in relation to familial relationships were different from those highlighted by the young carers in other caring contexts. The specific issues highlighted related to: i. Lack of comprehension of the parent concerning normal social behaviour which may lead to stigma, embarrassment and bullying by peers and resenting the parent; ii. Due to the lack of parental comprehension or control, it was asserted that some children may take advantage or manipulate the parent for money or set their own boundaries, concerning school attendance, going out, etc. In contrast, others highlighted how children and young people show sympathy and become extremely protective of the parent.

Appendix 9 – Professional Insight into Young Caring in the Context of Learning Difficulties

Hidden Caring in Relation to Learning Difficulties

Potential explanations for the increased hidden-ness of young carers in this context were explored. It became apparent through discussions with the professionals that such 'hidden-ness' may be attributed to one or more of the following reasons. Firstly, the changing social and political milieu is a relevant factor. Traditionally, people with learning difficulties have been subjected to prejudices and stereotypes concerning the desirability of and their ability to procreate. Thus, the notion of people with learning difficulties as parents has been frequently overlooked. Nevertheless, the 'deinstitutionalisation movement' of the 1980s and 1990s (which moved people with a range of disabilities from institutions to community settings) increased the autonomy of people with learning difficulties and enabled them to pursue relationships and have children. Thus, there was consensus amongst the professionals that whilst young caring in this context was not recognised, over time an increased number of children will be borne to parents with learning difficulties. On the basis of this, young caring in this context will become more evident in the future.

Secondly, a further major factor which underpins the invisibility of young carers in this context concerns a general lack of *awareness*, *acknowledgement* or *recognition* of the presence of parental learning difficulties and/ or the young caring role from both within and outside the family unit. This has been evidenced in three main ways: firstly, in terms of a lack of *professional* awareness; secondly, in terms of a lack of *professional* acknowledgement and recognition and thirdly, due to a lack of awareness, acknowledgement and recognition within the *family*. Thus, firstly, professionals may be unaware of parents with learning difficulties and their young carers in this context because of lack of contact with such families. This may be because families do not require outside assistance, particularly where the parental learning difficulties are mild or where adequate support is provided from the extended family. Alternatively, in the past parents may have failed to seek professional support or perhaps resisted professional intervention, due to concerns regarding their assessed capacity as parents and the removal of their child from their care. In relation to this, several professionals

discussed how parental learning difficulties were very often discovered inadvertently, because of problem behaviour or 'cues' exhibited by the child at school, such as their frequent absences or difficulties with homework tasks. Secondly, professionals may fail to acknowledge parental learning difficulties due to concerns about 'upsetting the parent' or fears about 'damaging their relationship with the family'. Thirdly, a further reason discussed concerned the lack of acknowledgement or recognition of the caring role by parents, children and the wider family. This was viewed as being particularly problematic where the parents were unaware or had not acknowledged their own learning difficulties.

PHASE 2

Initials:

Date:

Location:

SECTION A: About You

1. Are you...
Male   1
Female   2

2. What age are you?............ (age in years)

3. Which ethnic group do you belong to?
White   1
Other (please specify)
          2

4. Do you have any brothers or sisters?
Brother(s).....and Sister(s)....   1
(age(s).........................)
Brother(s) only....(age(s).......)   2
Sister(s) only....(age(s).......)   3
None   4

5. Do you have any children?
Yes   1
No   2

6. Are your parents still alive?
Father   1
Step-father   1
Mother   1
Step-mother   1

7. Who do you normally live with?
Alone 1   Partner 1   Mother 1   Father 1   Stepmother 1   Stepfather 1
Grandparents 1   Brother(s)...(how many) 1   Sister(s)...(how many)   1
Own Child(ren)........(how many) 1

8. Are you presently in full-time education, training or employment?
Primary School   1
Secondary School   2
College/ University   3
Training   4
Employment – full-time (16hrs+)   5
....(job)
Employment – part-time (<15hrs)   6
....(job)
Unemployed (i.e. looking for work)   7
Non-employed (i.e. sick, not looking)   8
Other (specify)
....   9

9. Is your Father/ Stepfather working or not?
In full-time work   1
....(job)
In part-time work   2
....(job)
Unemployed   3
Not employed (e.g. sick)   4

(specify why)......................................
N/A   5

10. Is your Mother/ Stepmother working or not?
In full-time work   1
....(job)
In part-time work   2
....(job)
Unemployed   3
Not employed (e.g. sick)   4
(specify why).....................................
N/A   5

11. Are you getting any State/ welfare benefits?
Yes   1
No   2

12. If yes, which ones?
Disability Living Allowance   1
Attendance Allowance   1
Incapacity Benefit/ SDA   1
Carers Allowance   1
Income Support   1
Tax Credits   1
Council Tax Benefit   1
Housing Benefit   1

13. Are your parent(s) getting any State/ welfare benefits?
Yes   1
No   2
Don't know   3

14. If yes, which ones?
Disability Living Allowance   1
Attendance Allowance   1
Incapacity Benefit/ SDA   1
Carers Allowance   1
Income Support   1
Tax Credits   1
Council Tax Benefit   1
Housing Benefit   1

15. Is your family home privately owned by your parent(s) or rented?
Owned by parents   1
Council House   2
Rented from private landlord   3
Housing Association   4
Don't know   5
Sheltered Housing   6

SECTION B: Parental Illness/ Disability

1. Which of your parents is ill or disabled?

2. What is their illness/ disability?
(Do they have any other illnesses?)

Mother/ Step-Mother		Father/ Step-father	
Physical	1	Physical	1
(specify illness)............................		(illness).........................	
Mental Health	1	Mental Health	1
(specify illness)............................		(illness)..........................	
Learning difficulty	1	Learning difficulty	1
(specify illness)............................		(illness)..........................	
Alcohol/Drug Misuse	1	Alcohol/Drug Misuse	1
(specify illness)............................		(specify)...........................	
Other	1	Other	1
(specify illness)............................		(illness)...............................	

3. How does the illness affect them?
(In severe pain, unable to walk, very tired, move arms and legs, has fits, memory problems, sad, depressed, tearful, etc)

4. Does their condition vary from time to time?
(How? Physically and/ or emotionally; relapsing-remitting)

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SECTION C: Young Caring Role

1. What does the term 'young carer' mean to you?

2. Do you feel that the term young carer is used to mean something other than a young person caring for someone else at home?

3. Do you see yourself as a young carer?

4. Have you ever been called a young carer by anyone else?
BY WHOM?

5. If YES - Do you mind being called a young carer?

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6. Have you heard of the young carers group?

7. Have you had contact with the group?

---

8. How long have you cared-for your parent? (family composition at that time)

9. Why did you start caring? (socialised; elected)

10. What do you do at home to help out?

11. Do you help your mum/ dad out with your sibling(s)?

12. You have taken a responsibility for caring for your parent. Do you think the amount that you do at home is ok?

13. It has been said that young people who are caring for a parent grow-up quicker than others. **What do you think?** (compared to peers)

13. **Do you still feel like a child in your family?** (WHY?)

Parent	1
Child	2
Both	3
Neither	4
Adult	5
Unsure	6

14. **It is said that young carers often feel different at school and around their friends. What do you think?** (carefree)

---

15. **Would you say you are your parent's main carer?**

16. **Does anyone else apart from you, offer care to your parent?**

17. **If yes, who also looks after your parent?**

Other Parent	1	Uncle(s)	1
Brother(s)	1	Neighbour(s)	1
Sister(s)	1	Family friend(s)	1
Grandmother(s)	1	Other(s) (specify)	1
Grandfather(s)	1	Formal Provision	1
Aunt(s)	1		

(**Specify Formal Services - Home care; CPN; SW; Physiotherapy; OT; Psychiatrist; Psychologist; Support worker; Counsellor; Other)

18. Informal - Do they live nearby?

19. When and how often do they help out?
(During the day, evenings, weekends, every day, once weekly?)

20. Out of all the help that you/ your parent gets (LIST formal and informal), which do you find most helpful? Why?

21. How helpful do you think each service is? (DISCUSS EACH MENTIONED – Formal and Informal)

22. In what ways does each help you and your family (as well as parent)?

23. Who/ What do you think helps most? (Informal or Formal care)

24. How does your parent feel about these services (Frees up young carer; prefers YC)

25. Do you think life would be different for you if your mum/ dad had a different type of illness? (Why?)

26. It has been said that young carers' might see their parents differently if they weren't ill. **What do you think? (How?)**

27. Does anyone else help out with things at home that your mum/ dad may do if they were well? (Who and What?)

SECTION D – Impacts of young caring

I'm interested in how caring for your parent whilst growing-up affects your life, in terms of school, work, health, your social life, friendships and relationships with your parent and family and other people, your health and leaving home.

D1

<u>School/Education:</u>

1. How {does/ did} caring affect school for you?
(Attendance – absent, late; homework; workload; extra-curricular activities; tiredness; lack of attention)

2. Does/ did your teacher(s) know that you care for your parent?

3. How is/ was your school/ teacher helpful or unhelpful to you as a young carer?
(Extra time to complete homework, tolerating/ letting you off with absences and lateness, extra support with exam preparation, etc, school as an outlet)

4. What do you think you'll do when you leave school?/ What did you do after school?
(College, university, employment, stay close to home or move away for college/ university/ employment or stay at home to care for parent?)

5. Do you feel that being a young carer {has affected/ will affect} what you {decided/ decide} to do after leaving school?

6. How? (In what ways?)
(Unable or unwilling to move away from parent, unable to spend time studying due to caring responsibilities, unable to commit to employment due to caring responsibilities)

D2

<u>Social Life, Friendships and Relationships:</u>

1. How does caring affect your friendships and social life?
(getting out – where, how often, with whom; mixing with peers; lack of time, money or energy to go out; friends understanding?; guilt going out; hobbies and interests)

2. Do you have a boyfriend/ girlfriend/ partner?

3. IF YES - How does caring affect your relationship?

4. How important is marriage/ long-term partnership to you? (parent/s attitudes and needs)

D3

<u>Employment/Vocations:</u>

1. I'm interested in how young caring affects paid work. For you, how {does/ do you think} caring {affects/ will affect} work?
(Never worked; P/T or F/T; limited job choices; lack of qualifications; workload; 'caring' job; employers understanding?)

D4

<u>Moving away from the parental home:</u>

1. How {did/ do you think} caring affects moving away from your parent(s) home?
(Feelings about move; early or late; responsibility for parent; concerns; physical proximity)

2. Have you thought about when you'll leave home?

(Age or stage – marriage, university, etc)

3. Have you ever lived away from your parent(s) home temporarily? (IF YES – WHY?)

D5

Money and Financial Issues:
1. How does caring affect your financial situation/ the money you have?
(Not enough money; Pocket money, household income; Work; Impacts of lack of money)

D6

Health:
1. In what ways do you think that caring has affected your health and/or wellbeing?
(Physically –skeletal/ back pain. Mentally/ emotionally – stress; tiredness; depression/ MH; anger, frustration; worry; fear of transmission)

D7

Family relations:
1. How does caring affect your relationship with your:
parent(s); and,
siblings?
(Closer relationship(s); relationship problems; parent as priority; tensions about share of care)

We have covered all of the areas I wanted to discuss. Is there anything else that you want to say…?

DIARY

NAME:

....

This diary is strictly confidential. Only the researcher Emma Christie and her supervisor Dr John Love will have access to the raw information. With your permission, the information that you provide in the diary will be used in the final research report, but in no way will you be identified. Your details will remain anonymous.

INSTRUCTIONS ON COMPLETING DIARY

Fill-out the diary for 7 days – such as, Monday, Tuesday, Wednesday, Thursday, Friday, Saturday and Sunday. It does not matter what day of the week you start on, but keep it running from one day to the next for 7 days. Each day, write the date in the box at the left of the page.

Heading 1 'Tasks I helped my parent with today':
The diary has a list of tasks that you might help your parent that you care for with. Each day if you help your parent with any of these tasks, place a tick (√) in the box under 'Tasks I helped my parent with today'.

Heading 2 'When I helped – morning/afternoon/evening/night':
For each of the tasks that you help your parent with, tick under the time of day that you help – morning/ afternoon/ evening/ during the night. If you help with something more than once, mark down each time. So, if you help your parent use the toilet 3 times in the evening, place 3 ticks in the box under 'evening'.

Heading 3 'How I felt about the task'
Write down how you felt carrying-out the task. So, if you felt annoyed that you were missing you're favourite TV programme or you couldn't get out with your mates, write that down. If you were late for school because of helping or felt tired because you'd had a busy day, write that down. If you felt happy to help with the task, write that down.

Did anyone else help with any of these tasks?
At the end of each section is a box asking if anyone else helped with any of the tasks. So, if someone else (like a parent, brother, sister, neighbour, relative or a home carer) does a task, write the name of the person or their job (such as 'Home carer') in this box. Also, if someone helps you with a task, write down who helps.

Try to fill-in the diary as soon as you can after helping your parent or doing the task. But if you help your parent during the night, maybe you could fill-in the details of this the following.

Try to be as truthful as possible when filling-in the diary, just write down what you normally do and how you feel about it.

By filling-in the diary, you are really helping with the research project and your help is GREATLY appreciated!

DAY 1 DATE	Tasks I helped my parent with today (Tick√)	When I helped (Tick each time you help)				How I felt doing the task (such as happy, annoyed, didn't mir... tired...)
		MORNING	AFTERNOON	EVENING	NIGHT	
Cleaning						
Cooking						
Clothes Washing						
Washing Dishes						
Ironing						
Organising family money						
Food Shopping						
Did anyone else help with any of these tasks?						
Help parent walk and get around (including pushing wheelchair)						
Give parent medication						
Dressing wounds						
Changing Catheter						
Did anyone else help with any of these tasks?						

Appendix 11   Self-Completion Diary

DAY 1
DATE ....

Tasks I helped my parent with today (Tick√)	When I helped (Tick each time you help)				How I felt doing the task (such as happy, annoyed, didn't mind, tired...)
	MORNING	AFTERNOON	EVENING	NIGHTTIME	
Helping parent wash, have a bath or shower					
Did anyone else help with any of these tasks?					
Supporting parent (listening to parents feelings, comforting parent if they are upset)					
Did anyone else help with any of these tasks?					
Childcare (looking after brothers and sisters)					
Did anyone else help with any of these tasks?					
Any other tasks					

Well Done! You have now finished filling-in the diary.

Lastly, can you now take a short time to think about the question below, please?

During an average week, do you normally help your parent with the tasks that you have helped with in the last 7 days? (Please tick a box below)

YES   ☐

NO   ☐

UNSURE   ☐

Please feel free to add any other comments or thoughts about your diary.
....
....
....
....
....
....
....

Thanks again for you~~~~ t~~ ~~~ help...it's appreciated!
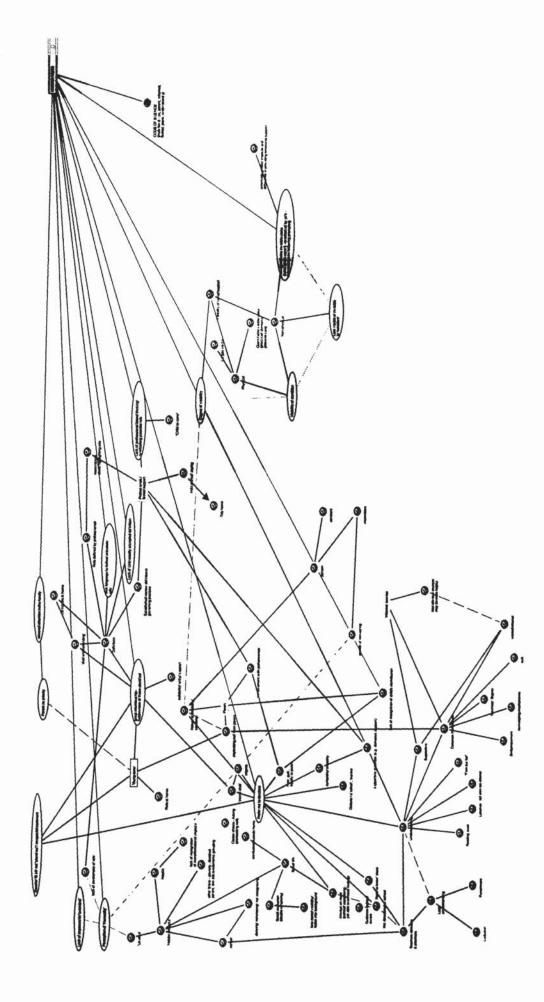
INSTRUCTIONS:
BELOW IS A LIST OF STATEMENTS DEALING WITH YOUR GENERAL
FEELINGS ABOUT YOURSELF. **FOR EACH STATEMENT:**
- IF YOU **STRONGLY AGREE**, CIRCLE **1**;
- IF YOU **AGREE**, CIRCLE **2**;
- IF YOU **DISAGREE**, CIRCLE **3**;
- IF YOU **STRONGLY DISAGREE**, CIRCLE **4**;

	STRONGLY AGREE	AGREE	DISAGREE	STRONGLY DISAGREE
1. On the whole, I am satisfied with myself.	1	2	3	4
2. At times, I think I am no good at all.	1	2	3	4
3. I feel that I have a number of good qualities.	1	2	3	4
4. I am able to do most things as well as most other people.	1	2	3	4
5. I feel I do not have much to be proud of.	1	2	3	4
6. I certainly feel useless at times.	1	2	3	4
7. I feel that I'm a person of worth, at least on an equal plane with others.	1	2	3	4
8. I wish I could have more respect for myself.	1	2	3	4
9. All in all, I am inclined to feel that I am a failure.	1	2	3	4
10. I take a positive attitude toward myself.	1	2	3	4

Appendix 13 – Model of Relationships between Categories

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Project: 2 feb 2   User: Administrator   Date: 20/11/2006 - 10:34:08

DOCUMENT CODING REPORT

        Document: 1P1~JAMES~PHY
        Created: 12/08/2004 - 10:53:50
        Modified: 03/02/2005 - 14:07:17

Node 1 of 285 (1 2 1 6) /Parental Illness/Blame/Sympathy for parent/bad luck
Passage 1 of 1 Section 10.10, Para 227, 124 chars.

227: cause we've had bad luck since the day I was born, just everything going wrong all the time really…one thing after the other

---

Node 2 of 285 (1 3) /Parental Illness/lack of formal provision~understanding
Passage 1 of 1 Section 7, Paras 166 to 172, 180 chars.

166: Ok, and what about when your dad was depressed, did he have contact with the CPN
167: §87 JAMES
168: Erm…No (whispering tone)[][10]
169: §88 EMMA
170: Or did he see anybody at Cornhill?
171: §89 JAMES
172: No (whispering tone)

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[10]   Document: AAP1~KR~PHY~rt - Memo 10
Node 3 of 285 (2 11 3) /Descriptive areas/Formal and informal support/family members
Passage 1 of 1 Section 6.6, Para 119, 41 chars.

119: He's got only his mum and dad really, so…

Node 4 of 285 (2 11 4) /Descriptive areas/Formal and informal support/physiotherapy
Passage 1 of 1 Section 7, Paras 178 to 180, 118 chars.

178: Did your mum get physiotherapy?
179: §93 JAMES
180: She was getting it before she got really bad, but that didn't really help either

---

Node 5 of 285 (2 11 5 1) /Descriptive areas/Formal and informal support/Utility of support/Formal Support
Passage 1 of 1 Section 9, Paras 187 to 194, 373 chars.

187: §98 EMMA
188: So, the home care was quite helpful, but you didn't want them coming in during the night as well...it was too much. But, what they provided during the day. would you say that was quite helpful
189: §99 JAMES
190: Yeah, it was, it was for us to really get a break, so me and my dad could go out. to town or somewhere
191: §100 EMMA
192: Sure, and did that allow you also to get to school?
193: §101 JAMES
194: Yeah

Node 6 of 285 (2 11 6) /**Descriptive areas/Formal and informal support/OT**
Passage 1 of 1 Section 0, Paras 182 to 185, 540 chars.

182: and was there an OT that came round and made adjustments to your house?
183: §95 Aids and adaptations
184: §96 JAMES
185: There was someone came round, they were wanting to knock certain walls down and everything, but it was for access for the wheelchair...erm (sighs), but we decided No. Cause, like they were thinking of putting her into the nursing home then and hospital and we thought No, there's not much point cause if she's only going to be here for another 6 months, then the house is going to get demolished, so there's not much point, so we didn't do it

---

Node 7 of 285 (2 11 11) /**Descriptive areas/Formal and informal support/Social Worker**
Passage 1 of 3 Section 7.14, Para 156, 14 chars.

156: Social Worker,

Passage 2 of 3 Section 7.23, Para 174, 41 chars.

174: So, it was really just the social worker

Passage 3 of 3 Section 9, Paras 196 to 202, 283 chars.

196: What about the social worker, would you say she was helpful?
197: §103 JAMES
198: Erm (long pause), to some extent
199: §104 EMMA
200: Right, so did she just basically organise for the home care and OT come?
201: §105 JAMES
202: Yeah. To look after my mum really. to make sure she was getting all the proper treatment and stuff

---

Node 8 of 285 (2 11 12) /**Descriptive areas/Formal and informal support/home care**

Passage 1 of 2 Section 7.2, Para 132, 116 chars.

132: When mum was living at home, she got a home carer in that came about 3 times a week. During the day from about 1-4.

Passage 2 of 2 Section 7.4, Para 136, 262 chars.

136: Erm…they just looked-after her, sit down, watch a bit of telly, done the dishes, hoovering, polish, make sure mym mum got about the house and stuff, if she wanted the toilet or something…erm, we were going to get other people in at night time to look-after her.

Node 9 of 285 (2 11 17) **/Descriptive areas/Formal and informal support/identity of main carer**
Passage 1 of 1 Section 3, Paras 73 to 76, 227 chars.

73: §38 EMMA
74: So would you say that you and your dad shared the caring for your mum? Did you do equal amounts?
75: §39 JAMES
76: I would do quite a lot, but eventually I left it to him to do quite a lot as well. Erm…but yeah, it was sort of equal

---

Node 11 of 285 (2 23 1) /Descriptive areas/**Basis of young carer role/adopted**
Passage 1 of 1 Section 3, Paras 66 to 76, 762 chars.

67: §35 JAMES
68: Yeah…I did a lot, I even took time off school to help him out he still didn't appreciate it. So really, I like doing it, but I just felt like I couldn't be bothered[][3]
69: §36 EMMA
70: So, was that helping him to care for your mum?
71: §37 JAMES
72: Yeah, cause I was doing it for him, so he could take care of my mum as well, but he still wouldn't like, appreciate it. I wasn't looking for nothing, but…but just a little thanks, just saying thanks or something.[][4] But, just nothing like that happened, so I just sort of…didn't like doing it anymore
73: §38 EMMA
74: So would you say that you and your dad shared the caring for your mum? Did you do equal amounts?
75: §39 JAMES
76: I would do quite a lot, but eventually I left it to him to do quite a lot as well. Erm…but yeah, it was sort of equal

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| [3] | Document: | AAP1~KR~PHY~rt - Memo 3 |
| [4] | Document: | AAP1~KR~PHY~rt - Memo 4 |

Node 12 of 285 (2 23 2) /Descriptive areas/**Basis of young carer role/assigned**
Passage 1 of 1 Section 3, Paras 64 to 76, 1129 chars.

64: Well...to be honest with you, I liked doing it...but I didn't like doing it, because my dad really didn't appreciate it and it's quite a long story like, but he took his aggression out on me all the time really, all the time. Just never thanked for nothing, I did everything I could to help him out, it just didn't work...

65: §34 EMMA

66: So, you must have felt really unappreciated?

67: §35 JAMES

68: Yeah...I did a lot, I even took time off school to help him out he still didn't appreciate it. So really, I like doing it, but I just felt like I couldn't be bothered[][3]

69: §36 EMMA

70: So, was that helping him to care for your mum?

71: §37 JAMES

72: Yeah, cause I was doing it for him, so he could take care of my mum as well, but he still wouldn't like, appreciate it. I wasn't looking for nothing, but...but just a little thanks, just saying thanks or something.[][4] But, just nothing like that happened, so I just sort of...didn't like doing it anymore

73: §38 EMMA

74: So would you say that you and your dad shared the caring for your mum? Did you do equal amounts?

75: §39 JAMES

76: I would do quite a lot, but eventually I left it to him to do quite a lot as well. Erm...but yeah, it was sort of equal

---

[3] Document: AAP1~KR~PHY~rt - Memo 3
[4] Document: AAP1~KR~PHY~rt - Memo 4

Node 13 of 285   (3 4 7) /Search Results/Matrix Intersection 4/Matrix Intersection 4[3,1]
Passage 1 of 1 Section 3, Paras 54 to 56, 168 chars.

54: And when your dad was suffering his bouts of depression, did you find that you were spending a lot of time supporting him, listening to him

55: §29 JAMES

56: Yeah (in whisper tone)

Node 14 of 285   (3 4 10) /Search Results/Matrix Intersection 4/Matrix Intersection 4[4,1]
Passage 1 of 1 Section 3.12, Para 60, 33 chars.

60: Emotional support...a lot of that

Node 15 of 285   (10 5 1 3) /Understanding and acknowledgement/need for acknowledgement/Acknowledgement+understanding/relationships
Passage 1 of 1 Section 10.6, Para 219, 368 chars.

219: Mmm, meeting others in the same situation and everything and eh, I got to speak to some of the folk, the young carers...in the same situation...they understood the stuff that I've been through, what they've been going through as well, both the same

really. And I've had a lot of support and stuff and everything, folk helping with stuff so it's yeah, quite a good thing

---

Node 16 of 285   (10 5 2 1) /Understanding and **acknowledgement/need for acknowledgement/overlooked/school overlooked**
Passage 1 of 4 Section 12.4, Para 273, 88 chars.

273: some of the teachers as well at school, they just…they didn't really know the situation…

Passage 2 of 4 Section 12, Paras 297 to 299, 113 chars.

297: So you were saying that your teachers weren't very sympathtic, they didn't know what was going on at home
298: §155 EMMA
299: No

Passage 3 of 4 Section 12, Paras 313 to 315, 84 chars.

313: And how did they treat absences off school?
314: §163 JAMES
315: Erm, they really didn't mention it

Passage 4 of 4 Section 12, Paras 316 to 319, 76 chars.

316: §164 EMMA
317: And did they give you any extra support or help at exam times?
318: §165 JAMES
319: No

Node 17 of 285   (10 5 3 3) /**Understanding and acknowledgement/need for acknowledgement/lack of u~standing/relationships lack~undestanding**
Passage 1 of 1 Section 14.2, Para 349, 90 chars.

349: I didn't tell anybody much about it, they didn't really understand the situation I was in.

Node 18 of 285   (10 12) /**Understanding and acknowledgement/exposure increases understanding**
Passage 1 of 1 Section 14.4, Para 353, 151 chars.

353: didn't really tell anybody much about it…they didn't understand…one of them does now though. So he understands it, cause he's seen it for himself.

Node 19 of 285   (11) /**alternative reason for issues**
Passage 1 of 6 Section 12.4, Para 273, 350 chars.

273: Sometimes I deliberately slept in cause I was so tired, not bothered getting up and stuff and with some of the teachers as well at school, they just…they didn't really

know the situation....and there was some teachers that took really...well, one teacher for sure, he always took his anger out on us, know, everybody in the class and I was tired of it.

Passage 2 of 6 Section 12.6, Para 277, 118 chars.

277: if I didn't have that teacher, I probably liked school a bit better as well, but because of that I just didn't like it

---

Passage 3 of 6 Section 13, Paras 333 to 344, 499 chars.

333: §173 EMMA
334: So your folks health affected what you did after you left school? (Silence) Do you think that had that not been the case, you'd have got a job or have done something different after leaving school?
335: §174 JAMES
336: I'd have liked to have been able to get a job and stuff afterwards, but I don't think I'd have got one anyway?
337: §175 EMMA
338: Right, so had you not been a young carer, you wouldn't have done anything differently?
339: §176 JAMES
340: No
341: §177 EMMA
342: So, you might have been at home, but not necessarily caring?
343: §178 JAMES
344: Yeah

Passage 4 of 6 Section 15, Paras 363 to 374, 216 chars.

363: §189 EMMA
364: And what about girlfriends? Did that not happen for you cause you were busy at home?
365: §190 JAMES
366: (Pause) Erm...No
367: §191 EMMA
368: Do you think being a carer affected that?
369: §192 JAMES
370: No
371: §193 EMMA
372: Were you shy in that way anyway?
373: §194 JAMES
374: Yeah

Passage 5 of 6 Section 16, Paras 375 to 383, 269 chars.

375: §195 Work
376: §196 EMMA
377: What about paid work? You said that even if you weren't caring, you don't think you'd have got a paid job after leaving school?

378: §197 JAMES
379: No, I don't think so
380: §198 EMMA
381: And do you think that's because of your own health or a lack of confidence in yourself?
382: §199 JAMES
383: Both

Passage 6 of 6 Section 16, Paras 396 to 407, 264 chars.

396: §206 EMMA
397: Do you think that missing school had an impact upon your job prospects?
398: §207 JAMES
399: No
400: §208 EMMA
401: So, if you had been at school more, that wouldn't have improved your chances of getting a job
402: §209 JAMES
403: No
404: §210 EMMA
405: So it's really down to how you feel as a person
406: §211 JAMES
407: (Nods) Yeah

Node 20 of 285   (16 19 2) /Work/Life choices linked to caring/other life choices skills
Passage 1 of 1 Section 19.3, Para 450, 257 chars.

450: And I still know that today, when folk can tell when folk are getting pretty annoyed or stuff and how to avoid it and stuff so…really it's a good thing, but bad thing, like it's handy to have, you know…it's a weird thing until you're in the same situation[][17]

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[17]   Document: AAP1~KR~PHY~rt - Memo 15

Node 21 of 285   (20 1 29 7 4 5 2) /Family relationships/relationship with parent/Parentification/types of parental roles/Welfare/Worrying/worry
Passage 1 of 1 Section 10.12, Para 231, 38 chars.

231: It's constantly stressful and I worry
232: §121

Node 22 of 285   (20 1 29 7 5 1) /Family relationships/relationship with parent/Parentification/types of parental roles/Adult responsibility/financial obligations
Passage 1 of 1 Section 6.10, Para 127, 282 chars.

127: Maybe a little bit of shopping, just a little bit…maybe help him out with a bit of money as well if I can, but if I do that, that lowers me. And he does pay me

back...eventually, but then he's out of pocket again and then I have to give him money back, so it just doesn't work really

---

Node 23 of 285   (20 1 29 7 10) /**Family relationships/relationship with parent/Parentification/types of parental roles/adultification**
Passage 1 of 1 Section 5.2, Para 106, 321 chars.

106: Probably when my mum went into hospital and I was looking-after my dad that's probably when I felt different, cause I had to grow-up sort of quicker. Think on a lot of stuff to do and everything, yeah, I felt like I had to grow-up quicker. Probably when he was depressed I'd be taking on more of an adult role...Mmm-Mmm[][7]

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[7]   Document: AAP1~KR~PHY~rt - Memo 7

Node 24 of 285   (20 1 29 7 10 11) /**Family relationships/relationship with parent/Parentification/types of parental roles/adultification/early maturity**
Passage 1 of 1 Section 5.2, Para 106, 89 chars.

106: Think on a lot of stuff to do and everything, yeah, I felt like I had to grow-up quicker.

Node 25 of 285   (20 4 4) /**Family relationships/caring creates tensions/Tension-R~ship with parent**
Passage 1 of 2 Section 3.14, Para 64, 238 chars.

64: my dad really didn't appreciate it and it's quite a long story like, but he took his aggression out on me all the time really, all the time. Just never thanked for nothing, I did everything I could to help him out, it just didn't work...
65: §34

Passage 2 of 2 Section 19.1, Para 446, 185 chars.

446: cause certain subjects if you speak about it, can trigger him off and he starts getting all nasty and aggressive and bawling and shouting...and I know how to get him off certain subjects...

Node 26 of 285   (22 1 1 12 2) /**Hidden-ness/cues/visual cues/Aids and adaptations/utility of aids~adaptations**
Passage 1 of 1 Section 8.1, Para 185, 441 chars.

185: There was someone came round, they were wanting to knock certain walls down and everything, but it was for access for the wheelchair...erm (sighs), but we decided No. Cause, like they were thinking of putting her into the nursing home then and hospital and we thought No, there's not much point cause if she's only going to be here for another 6 months, then the house is going to get demolished, so there's not much point, so we didn't do it

---

Node 27 of 285   (22 1 8 2 5 1 5) /**Hidden-ness/cues/subtle cues/parental illness/mental~emotional/Harm/abuse**
Passage 1 of 1 Section 19.1, Para 446, 267 chars.

446: eventually, know how to go round stuff and that and what subjects not to go into, cause certain subjects if you speak about it, can trigger him off and he starts getting all nasty and aggressive and bawling and shouting...and I know how to get him off certain subjects...

Node 28 of 285   (22 1 8 2 5 8) **/Hidden-ness/cues/subtle cues/parental illness/mental~emotional/angry~ mad**
     Passage 1 of 1 Section 19.1, Para 446, 98 chars.

446: I've sort of learnt and I could tell like if he's going to get angry, what to say to calm him down

---

Node 29 of 285   (22 6 8 2) **/Hidden-ness/yc role associated with physical/Types of care provided/domestic support**
     Passage 1 of 1 Section 3, Paras 36 to 40, 215 chars.

36: §19 Help young carer provides
37: §20 EMMA
38: So what sort of tasks did you help out with at home? (pause) You were saying housework.
39: §21 JAMES
40: Yeah, shopping as well...cleaning, dishes, hoovering, erm, just everything really, basically

---

Node 30 of 285   (22 6 8 4 2) **/Hidden-ness/yc role associated with physical/Types of care provided/personal care/bathing**
     Passage 1 of 1 Section 3, Paras 41 to 48, 166 chars.

41: §22 EMMA
42: And were you involved in any personal care tasks, like helping with bathing
43: §23 JAMES
44: No[][2]
45: §24 EMMA
46: So would your dad have normally helped your mum with that?
47: §25 JAMES
48: Yeah

---

     [2]   Document: AAP1~KR~PHY~rt - Memo 2

Node 31 of 285   (22 6 8 5 2) **/Hidden-ness/yc role associated with physical/Types of care provided/Emotional Support/manifestations of emotional support**
     Passage 1 of 1 Section 3, Paras 54 to 56, 168 chars.

54: And when your dad was suffering his bouts of depression, did you find that you were spending a lot of time supporting him, listening to him
55: §29 JAMES
56: Yeah (in whisper tone)

Node 32 of 285   (22 6 8 5 3) /Hidden-ness/yc role associated with physical/Types of care provided/Emotional Support/recognition of role in emotional support
Passage 1 of 1 Section 3.12, Para 60, 33 chars.

60: Emotional support...a lot of that

Node 33 of 285   (22 6 8 6) /Hidden-ness/yc role associated with physical/Types of care provided/nursing care
Passage 1 of 1 Section 3, Paras 49 to 52, 306 chars.

49: §26 EMMA
50: Ok. What about giving out medication?
51: §27 JAMES
52: Erm, yeah I would take the tablets through to like my mum. Erm, and at that time she knew which ones to take and stuff. But when she started going downhill even further dad would have to know which tablets was which and everything, which ones to give her

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Node 34 of 285   (22 15 7 1) /Hidden-ness/Skewed attention in the family/Parent~ caring as priority/caring priority over social life
Passage 1 of 3 Section 4.2, Para 97, 159 chars.

97: I'd say that it was quite reasonable, erm...but there was a thing, I liked going out with my mates as well, so that sort of stopped me mixing with folk as well.

Passage 2 of 3 Section 4.2, Para 97, 41 chars.

97: Didn't get a chance to go out much either

Passage 3 of 3 Section 14.2, Para 349, 71 chars.

349: Just didn't have time really to mix with my friends or nothing as well.

Node 35 of 285   (22 15 7 8 15 1) /Hidden-ness/Skewed attention in the family/Parent~ caring as priority/caring priority over education/School and Further Education/Homework~ workload
Passage 1 of 3 Section 12.9, Para 283, 1 chars.

283:
284: §148

Passage 2 of 3 Section 12.10, Paras 284 to 285, 122 chars.

284: §148
285: Homework, erm, sort of had time to do it, but there was like distractions always going on as well, when I took it home.

Passage 3 of 3 Section 12.10, Para 285, 64 chars.

285: I hadn't really got much time to do it all, with me helping out

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Node 36 of 285   (22 15 7 8 15 2) **/Hidden-ness/Skewed attention in the family/Parent~ caring as priority/caring priority over education/School and Further Education/Absences**
Passage 1 of 3 Section 3.16, Para 68, 92 chars.

68: Yeah…I did a lot, I even took time off school to help him out he still didn't appreciate it.

Passage 2 of 3 Section 12.2, Para 269, 117 chars.

269: missed lots of school…cause my mum…helping out really with stuff around the house, doing shopping and stuff like that

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Passage 3 of 3 Section 12.4, Para 273, 80 chars.

273: Sometimes I deliberately slept in cause I was so tired, not bothered getting up

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Node 37 of 285   (22 15 7 8 15 3) **/Hidden-ness/Skewed attention in the family/Parent~ caring as priority/caring priority over education/School and Further Education/Lateness**
Passage 1 of 2 Section 12.4, Para 273, 80 chars.

273: Sometimes I deliberately slept in cause I was so tired, not bothered getting up

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Passage 2 of 2 Section 12.15, Para 295, 16 chars.

295: I was often late

Node 38 of 285   (22 15 7 8 15 6) **/Hidden-ness/Skewed attention in the family/Parent~ caring as priority/caring priority over education/School and Further Education/concentration probs at school**
Passage 1 of 1 Section 12, Paras 279 to 281, 78 chars.

279: Sure…so tiredness must have affected how well you could concentrate
280: §146 JAMES
281: Yeah

Node 39 of 285   (22 17 1) **/Hidden-ness/definition/association of term with group membership**
Passage 1 of 4 Section 1.12, Paras 25 to 26, 43 chars.

25: §13
26: I've been a young carer for about 4 years

Passage 2 of 4 Section 10.1, Para 209, 89 chars.

209: So what do you think are the good things and the bad things about being a young carer?…

Passage 3 of 4 Section 10, Paras 209 to 211, 59 chars.

209:
210: §110 JAMES
211: (cuts in) I would say meeting new friends and stuff

Passage 4 of 4 Section 20, Paras 461 to 463, 154 chars.

461: Ok. Finally, as a young carer, would you advise other young people to become carers, if their parent became ill?
462: §241 JAMES
463: To become involved with the group?

Node 40 of 285   (22 19 3) /**Hidden-ness/keeping identity to self/details shared with guidance teacher**
Passage 1 of 1 Section 12.19, Para 303, 122 chars.

303: The guidance teacher knew a little bit, but not the full amount, erm...cause like, really...I sort of kept it all to myself...

Node 41 of 285   (22 19 4) /**Hidden-ness/keeping identity to self/disclose to select trusted individuals**
Passage 1 of 2 Section 12.19, Para 303, 150 chars.

303: even Jenny, I didn't tell her 'til about maybe, about a year as well or maybe half a year, I kept it all to myself exactly what was happening at home?

Passage 2 of 2 Section 14, Paras 349 to 353, 534 chars.

349: I didn't tell anybody much about it, they didn't really understand the situation I was in. Just didn't have time really to mix with my friends or nothing as well. So, yeah really all of them things
350: §182 EMMA
351: Had you told some of your closer friends what was happening at home, do you think they'd have understood?
352: §183 JAMES
353: Not really, no. I didn't really tell anybody much about it...they didn't understand...one of them does now though. So he understands it, cause he's seen it for himself. [][14] Erm, so yeah, he knows...he knows all about it

[14]   Document: AAP1~KR~PHY~rt - Memo 13

Node 42 of 285   (22 28 1) /**Hidden-ness/Spatial transitions/need for physical proximity**
Passage 1 of 1 Section 6.4, Para 115, 156 chars.

115: Yeah...still got a sort of responsibility feeling of looking-after my dad...erm, yeah, so still feel responsible for what he's doing, how's he feeling and stuff

Node 43 of 285   (22 28 9 1) /**Hidden-ness/Spatial transitions/Need own space and time/long-term**
        Passage 1 of 1 Section 17.8, Para 424, 95 chars.

424: But it was a relief to get my own space…peace and quiet and where I can sleep properly as well.

Node 44 of 285   (32 2) /**Health/tiredness**
        Passage 1 of 9 Section 10.10, Para 227, 91 chars.

227: one thing after the other…it's tiring and there's still stuff going on now, know constantly

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        Passage 2 of 9 Section 12, Paras 271 to 273, 93 chars.

271: Did you sometimes feel too tired to go to school?
272: §142 JAMES
273: I would say so, yeah…just knackered.

        Passage 3 of 9 Section 12.4, Para 273, 5 chars.

273: slept

        Passage 4 of 9 Section 12.4, Para 273, 5 chars.

273: tired

        Passage 5 of 9 Section 12.4, Para 273, 5 chars.

273: tired

        Passage 6 of 9 Section 17.8, Para 424, 5 chars.

424: sleep

        Passage 7 of 9 Section 18.2, Para 437, 150 chars.

437: Physically and mentally, really tired and everything…erm…there was some points that I just couldn't be bothered carrying-on with stuff and everything.

        Passage 8 of 9 Section 18.2, Para 437, 5 chars.

437: tired

        Passage 9 of 9 Section 19.1, Para 446, 5 chars.

446: sleep

Node 45 of 285   (32 3) /**Health/MH~depression**
        Passage 1 of 2 Section 18.2, Para 437, 338 chars.

437: Mentally, it was just…there was just some days it got too much, just sort of…(pause) just, well put it this way I saved up some tablets that I found and I was going to take all them…cause I'd had enough of it cause things were getting so bad. This was when I was just living with my dad…just tired of it, just couldn't hack it any longer

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Passage 2 of 2 Section 19.1, Para 446, 107 chars.

446: Sometimes I couldn't be bothered even wakening up. I was wishing I didn't wake up. I just wanted to sleep

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Node 46 of 285   (32 3 1) **/Health/MH~depression/stress**
Passage 1 of 1 Section 10.12, Para 231, 37 chars.

231: It's constantly stressful and I worry

Node 47 of 285   (32 4) /Health/musculoskeletal
Passage 1 of 1 Section 7.6, Para 140, 83 chars.

140: You got taught to lift them,[][9] erm…but she got so got disabled, I couldn't hack it

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[9]   Document: AAP1~KR~PHY~rt - Memo 9

Node 48 of 285   (32 6) **/Health/self-esteem**
Passage 1 of 4 Section 10.10, Para 227, 736 chars.

227: as well and eh, probably, obviously just the situation, why it had to happen to my mum and stuff really, just like…cause we've had bad luck since the day I was born, just everything going wrong all the time really…one thing after the other…it's tiring and there's still stuff going on now, know constantly. I mean once you see to one thing and that's over with, something comes up the next day…you would think it's exaggerated, but honestly it's not, like you see to one thing, the next day there's another, it's unbelievable, it just doesn't stop. Like problems continue to come up? Yeah…it's just constant all the way, there's never been at least one day I've had a break, there's always been something, honestly (whispering tone).

Passage 2 of 4 Section 13.8, Paras 335 to 336, 116 chars.

335: §174 JAMES
336: I'd have liked to have been able to get a job and stuff afterwards, but I don't think I'd have got one anyway?

Passage 3 of 4 Section 16, Paras 380 to 391, 278 chars.

380: §198 EMMA
381: And do you think that's because of your own health or a lack of confidence in yourself?
382: §199 JAMES

383: Both
384: §200 EMMA
385: Ok, yeah. So would you say you're confident as a person?
386: §201 JAMES
387: No
388: §202 EMMA
389: So, do you think that's partly because your dad never showed much appreciation at home?
390: §203 JAMES
391: Mmm

Passage 4 of 4 Section 16, Paras 392 to 395, 77 chars.

392: §204 EMMA
393: But you've got a huge range of skills?
394: §205 JAMES
395: Oh, I don't know about that