

**Young Carers: Self-image and Psychological Well-being  
amongst Adolescents with a Care Role.**

**A thesis submitted to the Faculty of Medicine of the University of Leicester for  
the degree of Doctor of Clinical Psychology**

**by**

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**July 1999**

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## **Acknowledgements**

My sincere thanks go to a number of people who have provided invaluable support and advice throughout the various stages of this study. I am indebted to Dr Mike Hodgkinson, who has been a supportive and dedicated supervisor from the beginning. Thank you for being such an encouragement.

I would also like to thank Aftab Laher for his constructive and detailed advice. Your support has been greatly appreciated. I would like to express my gratitude to Keith Turner and Stephen Wright for their advice with draft versions of the research.

Special thanks go to the young people, not only for agreeing to take part in the study, but for allowing me the privilege of learning more about their experiences. The research would not have been possible without their help. I also appreciate the willingness of Young Carer Group Managers and Schools in enabling this research to be completed and for being so interested in the process. In addition, I thank Saul Becker and Dr Polnay for their time during the very initial stages.

To my friends who have tried at all times to keep me smiling, thank you. And finally, but immensely, my family and partner Peter who have known the way to support me before this work began. Thank you for encouraging me and being so understanding and sensitive throughout the research process. I dedicate this to you.

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**ABSTRACT**

The main aim of this study was to determine whether adolescents who were caring for a parent with a chronic health problem or physical disability were experiencing problems with self-image and psychological health. The research aims were twofold: (1) to examine whether adolescent carers differed on key variables, namely self-image and anxiety and depression, when compared with age-related peers without a care role and (2) to explore whether there were differences between adolescent carers according to parental physical or mental health condition. The study was based on 121 male and female participants, comprising 61 adolescent carers and 60 participants without a care responsibility for an ill or disabled parent. Results suggest that there are a number of important differences between adolescent carers and age-related peers, the former showing a greater tendency to perceive their family and social relationships more negatively, in addition to a poorer overall self-image. Depression and anxiety scores were also higher amongst teenagers with a care role. Finally, care-giving in the context of a chronic mental health problem created higher scores on depression than for adolescents whose parent's had a physical illness or disability. No significant differences were found between levels of anxiety in the two sub-groups of carers. The findings are discussed in relation to the implications of a care role upon adolescent development. Areas for future research, service delivery and clinical intervention are suggested for this relatively uninvestigated carer population.

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## **1.1 Précis**

Acknowledging the needs of adult carers has been an important service and policy priority over the last decade (Department of Health, 1989; Symonds & Kelly, 1998). It is the intention of this research to consider a population that has remained unrecognised within the academic and legislative arena. Issues pertinent to the role of young people involved in significant responsibilities of providing care for a family member will be addressed. The very nature of chronic illness or disability dictates changes in roles and responsibilities within a family, an experience from which children are not exempt. Clearly, many families within which illness or disability exists will not be familiar with their children fulfilling 'young carer' roles. Moreover, parents often go to great efforts to prevent this. However, it has been a grave oversight to omit from community care policy and practice a vast population of childhood carers that are more than familiar with a commitment to parental care.

The study will address the role of adolescent carers, meeting responsibilities for a parent enduring chronic physical illness or disability and/or mental ill health. It will seek to critically review changes in social policy and statutory services that have led to a growing reality and awareness of young carer issues. Developmental literature on family adjustment and change exacerbated by chronic ill-health will be presented. Primary emphasis will be placed on whether, in the context of being a young carer and being first and foremost an adolescent, the prerequisites for healthy psychosocial development through adolescence are compromised or restricted by the role of providing care. Contemporary tensions within the young carer literature concerning the characteristics and impact of caring for a parent are discussed as they relate to adolescent development.

## **1.2 Informal Care: Law, Policy and Custom**

Current Parliamentary debate regarding how best to provide long-term support to families meeting the care needs of an ill or disabled family member has a complex socio-political history. Family carers, and more recently, children as caregivers, are beginning to be recognised as a significant resource, vital to the stability of the state. The growing concern in government that informal carers are a group whose civil rights need to be protected

occurs in the context of a shifting sense of obligation between the family and the state that has existed for decades. Who should take responsibility for the ill, disabled and vulnerable members of society?

Preceding current day emphasis on treatment, mandates of social control aimed to institutionalise vulnerable groups and withhold the care rights of their families and communities (Busfield, 1986). Mental health services were largely defined by the need to control rather than offer treatment. Post-war reform and social upheaval, supported by a myriad of civil rights advocates, led the state to rekindle the centrality of the family as most advantageous in providing informal and unpaid care. With this came the promise of community and state support systems.

The notion of 'community care' has largely obscured the reality of the excessive responsibility upon families for relatives with protracted health care needs. Indeed, the government have emphasised that 'care in the community must increasingly mean care *by* the community' (Department of Health, 1981, paragraph 1.9). Baldwin (1993) advocates that this largely derives from the ambiguity of what constitutes community care, a limited model with a medical and economic, rather than psychosocial framework.

Radical changes in legislation are enabling the 'euphemism of a community model' (Finch & Grove, 1980) to be reviewed, having acknowledged that families have long been obliged to resource the failings of a mixed economy of welfare. Clearly, encouraging people to stay in the community for as long as possible imposes a key role for family carers. In addition, this brings a hidden reality. Children belong in families and are thus exposed to meeting the care needs within some households, unseen by the outside world.

The recent acknowledgement of childhood carers in academic literature and social policy derives essentially from three main developments. Changes in the stability of the family unit, concern towards protecting children and their development (Zigler, Kagan, & Klugman, 1983), and state changes towards families caring for their own members as an outgrowth of deinstitutionalisation. Since the identification of 'young carers' in the late 1980's (HMSO, 1990; O'Neill, 1988), it has now been recognised that children of all ages can be, and are, involved in significant care roles. Advocates of the children's-rights perspective endorse the view that many young carers experience restrictions on their

childhood development and require the protection of government legislation (Aldridge & Becker, 1993b).

Childhood caring is not a recent social phenomenon. Children are likely to have met care responsibilities for decades, not least through economic duties of supporting family subsistence in the earlier nineteenth century. However, an interesting and alternative social construction of needing to protect the rights of children has occurred in the western world that is pertinent to considering the issue of 'young carers'. Emphasis on legislation to protect childhood development, such as The Children Act 1989 (HMSO, 1989) has replaced an earlier view of children as useful economic currency, employed in exploitative forms of labour. The reader is referred to Olsen (In press) for a more comprehensive account of how the concept of "childhood" has progressed to being more of a moral and emotive issue.

Defining the rights of children and offering a safe and protected childhood is paramount within existing social policy. Conversely, the rights of family carers in the community appear to be less clearly defined. Strengthening and supporting the hidden networks of unpaid and untrained adult informal carers only recently became a legislative priority, proceeding from the 1988 Griffiths Report (HMSO, 1988). Social Services Departments within local authorities were assigned the task of deciding how best to provide services for the ill or disabled person, and their carer, in the community.

Intrinsic to the problem of satisfactory service delivery is the controversial definition of what constitutes care. Psychological research, concerning the detrimental impact of informal care roles upon adult psychosocial well-being is well documented (Kahana, Biegel, & Wykle, 1994; Orbell & Gillies, 1993; Nolan, Grant & Keady, 1996) and has been influential in helping to define how care roles are perceived. However, the utility of psychological research in developing state policy and community care practice to reduce the stress of caregiving has only recently been considered (Lee, 1999; Orbell, 1999).

Since the implementation of the NHS and Community Care Act (1990), asserting the rights of carers alongside those they provide care for, has required further legislation. The Carers (Recognition and Services) Act (1995) is testimony to the continued governmental struggle to protect the interests of family carers, concurrent with those of service users and

providers. The identification of young carers is bound up, legally, in these two Acts. A contradiction exists however, when considering their position. Is their need to be protected in their status as children, through the Children Act 1989 (HMSO, 1989) compromised by the recent emphasis within community care legislation of supporting child carers in their role (Carers (Recognition and Services) Act (1995)? Clearly, these tensions will continue to be integral to child and family welfare debates and issues of service delivery well into the next decade.

Before highlighting current research on young carers, there is a need to consider the way in which chronic ill-health or disability introduce changes to a family and their individual tasks of development.

### **1.3 Chronic Illness and Disability within Families**

The process of socialisation into caring roles for some young people develops because they belong within a family. How these care roles are acquired can be understood by drawing, for the first time within any young carer research, upon developmental theories and family theory research (Brown, 1980; Rolland, 1987). This theoretical framework is pertinent to understanding how families are affected by chronic health problems and the interface between disease and disability, family processes and the life cycle of the family.

The experience of illness is one that is rarely faced alone. This, in part, is due to the way in which illness elicits attachment behaviour, which, according to Byng-Hall (1995), leads the ill person, child or adult, to seek care from other members of the family. Whilst families are different across cultures, 'temporary illness' scripts are familiar to most, if not all, families (Byng-Hall, 1995). Scripts define the way in which members collectively organise, operate and give meaning to their experiences. Acute illness experienced by one member is likely to *temporarily* shift the roles and usual momentum of the family, in order that the short term needs of the ill member be accommodated. However, in the context of a chronic illness and/or disability, both sudden and progressive changes occur that are likely to induce considerable stress and long-term role changes. In accordance, these changes may also introduce lasting implications for the relationships of authority, discipline and nurturance that sustain the security of most family units. Spouses and

children are fundamental to this role redefinition, often being drawn into unfamiliar positions of providing tangible and emotional support (Dunkel-Schetter, 1984).

It is recognized that the presence and duration of an illness or disability can affect the developmental growth of a family (Thurman, 1985). Rolland (1987) highlights an important longitudinal view of chronic disease, conceptualised in terms of developmental phases. His model integrates well with considering how young carers, particularly during adolescence, need to negotiate specific developmental tasks of separation and identity.

Rolland's (1987) model identifies illness, the individual and the family as all having their own developmental phases, each involving tasks of adjustment. Three illness phases are proposed: crisis or prediagnosis phase, which often requires the family to pull together, reorganise and meet immediate needs. The second 'chronic' developmental stage is typically characterised by permanent changes and active role re-organisation, chronic care responsibilities and actual or anticipatory loss. This stage is most central to the current study. Finally, certain illnesses then go on to result in death, the terminal phase, which introduces further tasks of grieving and eventual acceptance for family members.

If the development and autonomy of individuals in the family is disrupted by illness changes, how much more vulnerable is the adolescent in that family, whose central task is to achieve independence? This is likely to be made more acute when the adolescent is in the role of carer. However, there is little research evidence regarding the developmental process of adolescent carers.

Whilst there are several approaches to analyzing the way in which a family interact, the model of family functioning proposed by Minuchin *et al.* (1975) offers interesting insights into the context of families managing illness or disability. His concept of "enmeshment" within a family is of particular relevance to considering the roles for an adolescent in the position of caregiver to their mother or father. 'Enmeshment' is defined by a high degree of involvement, intrusions on personal boundaries and poorly differentiated self-perceptions of who one member is, independent from other family members. Illness and the need to offer care may exacerbate confusion over who is in the position of parent. Whilst the model is not without its limitations (Woods, 1994), it offers an interesting template for considering how family interaction can become confused, merging separate parent and child roles. Combrinck-Graham's (1985) theory of family cohesion develops

this notion further. He differentiates between high (centripetal) and low (centrifugal) cohesion within a family, which coincide with shifts in family development. Intense periods of cohesion (centripetal), such as early child rearing are distinguished from the developing autonomy of adolescents (centrifugal phase). An application of this model within Rolland's (1987) developmental theory concerns the way in which family cohesion and normative times of transition, such as adolescence or employment, are often required to change on account of other disruptive family circumstances, such as chronic illness or disability. He proposes that chronic illness tends to exert a centripetal pull on families, bringing them into close proximity, as practical and emotional roles adjust and new coping skills are accommodated (Rolland, 1994).

The nature and onset of chronic health problems are also likely to influence these new roles. Disease can be differentiated by its progressive, constant or episodic and relapsing course (Raker, 1990). Studies propose that episodic and relapsing chronic illnesses are associated with the highest degree of instability, uncertainty and family stress (Lyons, Sullivan, & Ritvo, 1995). The young carer literature (Aldridge & Becker, 1993a; Meredith, 1991a) has yet to differentiate factors such as onset, timing and disease processes of parental illnesses as predictors for increased stress and uncertainty upon young people offering care. Moreover, whether care roles differ according to relapsing mental ill-health or more progressive physical health problems has not been researched. This will later be discussed with regards to implications for clinical and service intervention.

In essence, these models, and additional family development models (Carter & McGoldrick, 1988; L'Abate, 1994) are integral to understanding the potential not only for healthy realignment following illness, but for the manner in which physical illness and disability can disturb family adaptation and direct the family in maladaptive ways. Clearly, the "type" of illness and the flexibility of pre-illness family roles is central in determining the strength of its impact. The reader is referred to Rolland (1987, 1994) and Altshuler (1997) for a more extensive review of illness and the family life cycle.

It is evident that developmental transitions are made more difficult if the particular illness is progressive, relapsing, incapacitating and/or life threatening (Rolland, 1994). In practice, it may therefore be likely that young carers, whose parents have episodic and

recurrent conditions, are required to oscillate between being drawn into care, and having long periods of respite. It could be inferred that these conditions are the most disruptive to their own developmental tasks. What is known from wider literature is that illness or disability can profoundly affect the developmental goals of family members. The shift to a more autonomous phase, at a time when developmentally appropriate changes are expected to occur can become difficult to negotiate. This is of particular importance when considering the effect upon adolescent carers who may meet the family obligation of care, whilst neglecting the developmental task of disengagement and peer integration that the social norm of adolescence demands.

In summary, adolescent carers face the same developmental tasks and challenges as adolescents without a care role. It is necessary to first consider what is meant by the term 'young carer' before the potential implications of this role upon adolescent development can be considered.

The preference in the literature for terms such as 'carer', 'care-giver', and 'care-receiver' will be maintained. Reference to adolescents without a care role, as 'non-carers' will be used for the purpose of the current study.

### **1.4 Young Carers: Definition and Role**

The existence of children who care, to whatever degree and at however young an age, continues to be largely unrecognised. The chronology of young carer research has primarily been a literature of concern, and by implication pressure, for awareness and intervention (Aldridge & Becker, 1993a,c; Fallon, 1990; Meredith, 1991b). Five years of academic interest in 'young carers' has redressed the neglect within adult care-giving literature of this hidden population of young people offering informal family care.

Two opposing perspectives (Aldridge & Becker, 1993b; Olsen, 1996) have essentially governed the small, but growing body of literature. Their disparity is based on whether the rights of the ill or disabled parent (Olsen, 1996), or alternatively, of the child carer (Aldridge & Becker, 1993b) should be prioritised and protected by professional and

agency action. This clearly raises conflicting implications for how legislation and services respond to the needs of young carers and their families.

The catalyst for identifying children as a discrete and invisible group of carers in the community, living out the experiences of parental illness upon family life, was initiated by the Carers National Association (CNA) and the Young Carers Research Group (Loughborough). Advocating on behalf of their neglected position as ‘children’ and as ‘carers’, has been the essence of a developing body of literature, policy and campaign.

In contemporary western society, children are regarded as being both vulnerable and needing protection, whilst having rights to participate and be autonomous in preparation for maturity and adulthood. The 1989 Children Act (HMSO, 1989) is testimony to these aims, in addition to intending to provide a safety net for families. The premise of young carer literature from a child-centred perspective (Aldridge & Becker, 1993a,b; Meredith, 1991a) essentially seeks to address the ways in which the lives of young people who are care-givers do not fit with the notion of protected childhood.

Through research developments and legislative changes, the definition of ‘young carer’ has been refined. However, there are complex conceptual issues to consider about any carer, adult or child, particularly as caring is not a uniform role. One working definition states that young carers are children and young people under the age of eighteen who provide care to a family member, usually a parent, who has a physical or mental illness or disability, a sensory or learning impairment, or problems with substance misuse (Becker, Aldridge & Dearden, 1998). Concurrent psychiatric disorders are also likely to be prevalent. Whilst physical health problems and disabilities are the predominant conditions with which young carers are involved, a significant number are also caring for someone with a mental health problem, including substance dependency and misuse (Aldridge & Becker, 1993a). An understanding of whether these may bring different responsibilities and care implications is still very incomplete.

The age at which young people are no longer classed as a “young carer” is interesting. The cut-off of eighteen years of age is more likely to be a reflection of service organisation than the young person’s care responsibility actually having ceased. A large-scale survey conducted by Dearden and Becker (1995) highlighted the proportion of young people, by

age, that were meeting care roles for a family member. Of six hundred and forty-one young carers, one percent were under the age of five years, twenty-eight percent were between five and ten years of age, fifty percent were in the eleven and fifteen age cohort and sixteen to eighteen year olds constituted twenty percent. Five percent were identified as being from black and ethnic minority communities.

Caring for a parent with a chronic disabling illness may have begun at a very early age (Fallon, 1990), necessitating adaptations and a gradual increase in task and responsibility over time. This gradual socialisation is consistently documented (Aldridge & Becker, 1993a; Fox, 1995) and causes the reader to re-visit the question of how the normative tasks of adolescent development, such as self-image and independence, are negotiated.

#### 1.4.1 Care Tasks and Responsibilities

It must not be implied that every child in a family affected by chronic illness or disability will become a carer. However, there remain on-going difficulties in conceptualising and identifying child carers due to the very hidden nature of their lives. In addition, their fear of professional input and potential separation of their families have been documented (Elliott, 1992; Frank, 1995; Meredith, 1992), which may result in under-reporting of children committed to care roles.

Critical reviews of earlier small scale survey research, estimating the extent of childhood care-giving at a figure of 10, 000 children and adolescents nationally (O'Neill, 1988), have radically revised the figures in response to inaccuracy and methodological shortcomings (Mahon & Higgins, 1995). Eurostat (1997, cited in Becker, *et al.*, 1998) figures for the United Kingdom indicate that 2.8 million children under the age of sixteen (23% of all children) live in households where one person experiences restrictions in daily activities on account of a chronic illness or disability.

A certain degree of caring in childhood is functional to development, and is thus endorsed. However, a fundamental distinction is made in the young carer literature between normative or usual, and exaggerated, extraordinary levels of care-giving (Siddall, 1994). Clearly, children will and do offer help to parents or siblings, yet this is regarded as assisting in, rather than restricting their own development. Such involvement rarely

impacts upon or endangers their opportunities to engage in developmentally appropriate experiences. It is this inherent tension, where young carers' needs as children are compromised by the responsibilities of their caring roles that is intrinsic to much of the young carer literature. Essentially, the reality of young people involved in age-inappropriate tasks challenges the view of how the 'ideal' family should be.

Extraordinary *levels* of care-giving are not the only issues raised by the literature. In review of care tasks and responsibilities (Bilsborrow, 1992; Dearden & Becker, 1995; Siddall, 1994), children involved in care-giving roles tend to undertake a variety of tasks within and outside of the home. These have been broadly categorised as domestic, personal, social and emotional care responsibilities.

Large and small scale studies have attempted to collate a profile of care tasks which have been invaluable in removing some of the invisibility of children's lifestyles (Dearden & Becker, 1995). In addition, conceptualising care tasks by category has enabled a clearer understanding of how young carers may be considered to be different to their peers. The majority of young people are involved in domestic roles, such as cooking, cleaning, preparing meals which, it could be argued, do not particularly differentiate them from children or adolescents in other households. This is where similarities appear to end. The frequency of these tasks and the likelihood that they would not be accomplished without the child's involvement is likely to be a fundamental difference when living in the context of family illness and/or disability. Many young carers are familiar with performing general health-related tasks, such as giving medication, lifting and helping with mobility, in addition to offering emotional support, meeting sibling care obligations and providing intimate, personal care tasks such as toileting, bathing and dressing. These, and most significantly responsibilities for intimate care needs, distinguish young carers from other children and adolescents that are not accountable to offer care.

Multi-faceted care roles are not rare among childhood carers. The nature of the parental condition often defines the type and frequency of care needs, thus, young people are more likely to provide intimate care where there are physical, rather than mental health problems (Dearden & Becker, 1995). Of six hundred and forty-one carers included in a study by Dearden and Becker (1995), meeting general care needs and offering emotional support, in addition to domestic help, were familiar to over half of the young people. One fifth

provided for intimate, personal care needs. Involvement in personal care was seen to be a likely predictor for the young person being the main, primary carer, and thus being involved in multiple care tasks (Mahon & Higgins, 1995). Where parental views have been sought (Aldridge & Becker, 1994), the most distress and embarrassment was provoked by having personal care needs met by their own children.

The greater attention now given to qualitative studies rather than survey research reflects a move to understanding the *experience* of a care role for young people. This shift also recognises that there are complex factors that contribute to why such roles emerge. It fails however, to acknowledge the significance for parents of receiving care. The challenge that parents and siblings face are no less significant. It follows that if this neglect is not addressed, even fewer families affected by chronic health problems will seek therapeutic and practical support for themselves or their children. Disability rights advocates (Olsen & Parker, 1997) have raised an important critique of the young carer literature that will be later discussed.

Further important gaps in earlier literature concern a more developmental understanding of the psychosocial impact of care-giving for children and adolescents. It is of clinical concern that developmental theories are still lacking in the literature and that issues pertinent to adolescence are not differentiated from generic young carer issues. However a number of qualitative studies have been of more clinical utility in seeking to define how young people experience their role.

### 1.4.2 Caring and Developmental Issues in Adolescence

There are many areas that remain controversial in relation to an only recently identified population. Adolescent development in the context of a care role is one such area.

Studies have typically emphasised the potential risk for young carers to their physical and psychosocial wellbeing (Aldridge & Becker, 1993b, 1993d). Siddall (1994) equated their position with a “lost childhood”, a unique role with detrimental implications for social and educational development. Physical, social, emotional and educational restrictions are seen to emanate from care-giving in the context of family illness and disability. A premature

responsibility of care is emphasised as a prerequisite for adverse experiences of lost opportunities, isolation, educational interruptions, exclusion from peers and limited time for activities and leisure interests of their own (Fox, 1995; Frank, 1995).

The Department of Health study (ONS, 1996) reiterated this notion of sacrificed opportunities, concluding that 'helping in the care of the disabled person adversely affected (a young carer's) social life, education or restricted their freedom to take part time jobs' (ONS, pg 1). A slow but growing appreciation of disruption to peer relationships and educational attainment has occurred. Dearden and Becker (1995) identified the degree of academic disruption, according to age, within a cohort of six hundred and forty-one young carers. Twenty percent of young carers aged between 5-10 years, 42 percent of 11-15 year olds and 30 percent of 16-18 year olds missed school, experienced educational problems or were receiving educational welfare services. It cannot be assumed, however, that having a care role is the only causal factor producing these problems, given the complexity of factors in households with chronic illness and disability.

Galloway (1985) referred to the lack of professional attention within educational services in spite of high absenteeism and persistent lateness, on account of children having to meet care demands. Child psychiatric and educational psychology services were cited as particularly remiss in recognising caring issues as a factor in school disruption.

### 1.4.3 'Caring' as a Full-time Responsibility

Much of the task-based literature presumes a narrow definition of what constitutes care. High value is likely to be placed within future research on making more explicit the indirect impact that a care role can have. It is difficult to imagine how, once caring tasks are completed for the day, 'normal' life resumes. Respite from particular tasks cannot be assumed to indicate the end of a care role. An underdeveloped theme in the literature is the continual sense of duty or responsibility that some young people are likely to feel, despite being separated from the parent. Morris (1993) introduces the difficulty of distinguishing between 'caring for' someone and 'caring about' someone which has many implications, both theoretically and clinically, for periods of time spent away from an ill or disabled parent. The emotional implications of being 'on duty', even if at school or involved in

other activities need to be considered fully. Drawing from wider psychological literature, separation anxiety studies (Bowlby, 1973) may help to inform the carer literature in understanding fears and anxieties that may be exacerbated by separation from an ill parent. This may be particularly pronounced if the young people are primary care-givers in receipt of low levels of statutory or voluntary service support.

In families affected by chronic health conditions, there is no 'typical' case, and thus no 'typical' carer. However, factors that are more likely to determine whether families will experience care from a child or adolescent offspring have been identified within existing young carer research. Whilst not exhaustive, several economic, social and personal characteristics contribute to, and often maintain, their position as carers.

#### **1.4.4 Characteristics of Families with Child and Adolescent Carers**

Children and adolescents have taken on care roles within families for centuries, determined not least by the social and economic climate in which they live. The view that over-involvement is to some degree restrictive and pathological is a social construction, both culture and context specific, by contemporary society.

Many forces external to family size significantly contribute to how care will be negotiated. Changes in the social structure, employment opportunities, wealth and the breakdown of the family unit have been similarly identified as key characteristics in exacerbating the likelihood of childhood carers within a family (Becker, *et al.*, 1998). A complex relationship exists between medical, economic, social and personal family dynamics that defines why some young people become, and often remain as carers whilst others never experience it. There are numerous associated economic and social disadvantages related to chronic illness and disability, a reality that advocates from a disability rights perspective (Morris, 1993; Olsen, 1996) consider to be largely ignored within existing young carer literature. These factors are central to the availability, duration, and quality of informal and statutory care provision. Significant disadvantage beset households of younger disabled mothers, on the basis of them being far less likely to receive necessary economic entitlements, domestic, nursing and personal care services than other groups (Beardshaw, 1988).

The type and accessibility of formal care services continues to be the most significant determinant of whether or not a young person will become, and remain a young carer. The implications of this for preventative services are wide ranging. The type, onset and prognosis of chronic health problems are also likely to be inextricably related to the degree and intensity of the care role. As previously highlighted, care intensity often changes more in response to a relapsing, episodic illness as opposed to a chronic and degenerative condition (Wills, 1996).

Not enough attention has been placed on whether care roles, and their impact, can be differentiated according to a family member's mental health or physical health condition.

Whilst the onset and nature of parental ill-health or disability may be an initial trigger for meeting care needs, key factors such as family structure, relationships within the family and the position of the child amongst siblings are similarly contributory. The presence of another adult, and whether or not they partake in care activities is fundamental to the position of children. Meredith (1992a) refers to a disabling illness in single-parenthood as being a common predictor for the presence of a young carer. He identifies being an only child, regardless of gender, as a further significant factor in terms of the nature and the extent of care-related responsibility.

Gender assumptions are an important issue to consider, given the lack of specific research into gender and childhood carers. Consistently, girls caring for women, usually mothers, predominate (Beach, 1997; Dearden & Becker, 1995), a finding which reflects the bias in the adult carer literature of women meeting the majority of community care needs (Finch & Groves, 1980). This stereotype can be prevalent within families to the extent that in the presence of several siblings, both male and female, girls can be 'elected' to care.

Fathers with a disabling illness are more likely to receive care from their partner or spouse, with children offering additional care where required (Dearden & Becker, 1995). It has been found in some cases that young carers are also involved in offering care for both parents (Becker *et al.*, 1998). Males do become young carers and are not exempt from care responsibilities, in some cases, of intimate care tasks such as dressing or bathing. Figures identify a range of 35-39 percent of samples to include male carers (Mahon & Higgins,

1995). It is also not uncommon for male and female siblings to have simultaneous care responsibilities, often negotiated by gender role stereotypes.

Although much of the research has been based in Britain and Australia, care-giving is clearly a transcultural phenomenon. Countries such as Ireland, Malta, Germany, France and the United States are beginning to acknowledge the existence of young carers in light of research conducted within Britain and Australia. The reader is referred to a more comprehensive account of the international perspective on the issue of young carers (Becker, 1995).

Assumptions about the family structure in minority cultures perpetuate cultural myths. Child and adolescent carers within black and minority ethnic communities contradict the belief that large extended families prevail and thus ensure that adult members take care of each other. Despite the paucity of literature on informal care-giving in minority communities, young people are meeting significant care needs and acting as interpreters on behalf of their parent and professionals in the absence of a common language (McCalman, 1990). Future research on supporting carers from minority families through access to culturally sensitive and appropriately resourced services is long overdue. The issues facing professionals in adult services about a reduced uptake of services by minority groups (Beliappa, 1991) are likely to be of importance when considering how young carers from these families are reached.

Young carers commonly have multiple care roles, meeting obligations of emotional and practical support for siblings and adult family members (Dearden & Becker, 1998). The clinical implications of this, in considering how professionals can best support families, are fundamental to the issue of young carers and the priority of its place in clinical practice. The 1995 Social Services Inspectorate Report, 'Young Carers: Something To Think About', states: " In the context of services for young carers, it is important to remember that the definition of 'need' in the Children Act includes a consideration of the impact on the child of not receiving services" (Department of Health, 1995a: Pg 5). Clearly, professionals are likely to encounter young people with caring roles in several different contexts. Psychological services need to be particularly astute to acknowledging potential childhood carers within family services, adult mental health, physical illness and health psychology disciplines.

#### 1.4.5 Disability Rights: Challenging Young Carer Research

Olsen (1996) considers that little insight has been gained into the nature of childhood caring. Two themes emerge from his critique. Firstly, society lacks a normative definition of what constitutes 'reasonable' levels of involvement in household tasks in accordance with developmental stage, gender and culture. Thus, claims that young carers are involved in exaggerated and extraordinary levels of care lack any form of appropriate comparison. Secondly, the literature assumes that the remainder of children in society are experiencing positive, non-disadvantaged environments within which to develop. How would young carers compare with children in other families affected by poverty and discrimination?

The existing young carer literature has been heavily criticised for failing to recognise the disempowered position of parents in the context of a disability or ill health (Parker & Olsen, 1995). Recognition of the disabled adult is frequently overlooked by the children's rights philosophy, often to the detriment of their position, first and foremost as parents. Moreover, it has been suggested that the literature negates the reality of reciprocal relationships of caring and dependency between members in a family (Walmsley, 1993). Assumptions may be too readily made that the presence of a disability or chronic illness serves as a precursor for adults to relinquish or be prevented from responsibilities as a parent.

The protection of children from over-involvement in care tasks is a priority for many parents living with an illness or disability, yet choice is commonly restricted (Morris, 1993). Whilst some of the more routine aspects of child-care can become more time-consuming for parents in the context of illness, these limitations have been too readily equated with inadequacy, and by implication, neglect (Kelley, Sikka & Venkatesan, 1997).

This literature seeks to ask questions about how ill or disabled adults in society have been failed by the welfare state in being able to negotiate how they would like their care to be provided. Essentially, in the context of a lack of choice and discrimination of social opportunities and support for disabled or marginalised adults, families meet their own significant care responsibilities. The term 'young carer' is antithetical to the disability rights model, given their claim that it is not caring *per se* that restricts children's lives, but rather the failure of a mixed welfare state to remove 'barriers' in order to support ill or

disabled parents (Morris, 1989). Tolerating the existence of young carers, it is argued, would not have to occur if comprehensive adult support systems were appropriately available. Viewing children and adolescents as a separate welfare category, as advocated by the child-centred paradigm, positively reinforces the neglect of state services in meeting the needs of disabled adults and maintains discrimination against their position as parents (Parker & Olsen, 1995).

Exclusive concern for the child is regarded by Keith and Morris (1995) as a “disablist philosophy” which occludes the central issue of how parental dependence for care has arisen and thus what service responses are needed to prevent this. In addition, positive implications of having a care role for a parent are largely ignored by the literature. Whilst not widely researched, findings have alluded to some beneficial aspects of caring in childhood, including a sense of commitment to, and satisfaction from, their role and a perceived closeness in relationship (Aldridge & Becker, 1993a; Mahon & Higgins, 1995).

Drawing the distinction between ‘carer’ and ‘cared-for’ is problematic (Walmsley, 1993). Caring and dependency are commonly reciprocal and the idea of mutual interdependence, of both individuals giving and receiving care, is an invaluable argument that could inform literature on children in the position of being young carers. Certain caring experiences between a parent and child, such as being bathed or dressed, may be difficult for some parents with a disability or illness to perform. However, a disabling illness *per se* does not inevitably preclude a parent from being the provider of care as well as the recipient of it from others.

The first issue of *The Journal of Young Carer Work* (1998) acknowledges a process of refinement between the two philosophies. Emphasis has been placed on the need to adopt and incorporate a family-based approach (Becker, *et al.*, 1998; Campbell, 1995). Policy and practice changes, initiated through the Carers (Recognition and Services) Act 1995, seek the same holistic end.

However the term is currently regarded, the reality of childhood carers in society is borne out by contemporary research, Young Carer Group initiatives and renewed social policy. There is clearly a complex inter-relationship between family, social and economic factors that determine the choices and autonomy available to parents living with a disabling

illness. In some families, one factor will be more significant than another. However, the majority are more than familiar with the interaction of multiple issues in determining who will become, and remain, a young carer. The implications of this upon adolescent development, specifically the development of self-image, will be considered.

### **1.5 Adolescence: A Developmental Transition**

The position of being a childhood carer has been intrinsically linked, in the child-centred literature (Meredith, 1991a) with associated negative implications for social, educational and physical development. The studies consistently provoke questions for the reader regarding the implications of curtailed opportunities and care responsibilities upon adolescence *per se*, as a developmental process.

Any one of two main factors, the presence of a parental illness and secondly, the stage of adolescence may be problematic to an individual. Attempts to understand adolescent adjustment in the context of parental illness remain fragmented. Research on parental cancer (Wellisch, 1979), Huntington's Disease (Power, 1977) and Multiple Sclerosis (Peters & Esses, 1985) indicate the vulnerability of adolescents to behavioural problems and poorer psychological adjustment. However, these adverse experiences have not been corroborated in other studies (Beardslee & Podorefsky, 1989; Buck & Hohmann, 1982).

What remains unknown is whether the cumulative effect of being an adolescent; having a parent with an illness or disability; and the roles acquired through being a young carer, place the adolescent at developmental risk. Are adolescent carers experiencing difficulties in the development of self-identity and psychological well-being, integral to the "tasks" of maturity into adulthood (Erikson, 1968)?

The following section will review influential theories of normative development during adolescence that have dominated the literature. More specifically, the development of self-image, as a major determinant of social behaviour, will be considered, primarily through parental and peer relationships. It has previously been highlighted that relationships, critical in shaping how an adolescent comes to view themselves, are prone to change in the context of an illness (Rolland, 1987). The implications of how this process may be

compromised for adolescent carers remain uninvestigated. It is imperative that this is examined given that factors integral to achieving a concept of the self are considered to be disrupted for a number of young people caring for an ill or disabled parent (Aldridge & Becker, 1993a).

### 1.5.1 Adolescent Maturation

‘Adolescence’ is commonly regarded as a span of time in the physical and psychological development of an individual. It is difficult to specify clear boundaries that regulate when adolescence begins and ends, due to individual and cultural differences. More commonly, adolescence is defined by biological age and social maturity. The present study is concerned with young people aged between twelve and eighteen years of age.

The scientific study of adolescence has radically challenged the previously prevailing view of adolescence as a period of storm and stress (Hall, 1904, cited in Kimmel & Weiner, 1985), involving ‘crises’ in identity, as a prerequisite to successful maturation. This pathologised view has been elaborated in other models by eminent theorists such as Blos (1962), Erikson (1968) and Marcia (1980). Whilst the view of adolescence as a time of turmoil has strengthened the academic contribution to understanding young people with serious problems, researchers have clearly failed to support this general theory of inevitable adolescent trauma (Coleman, 1980; Offer, Ostrov & Howard, 1981).

Emphasis on resilience, coping and adjustment in contemporary studies (Hauser, Vieyra, Jacobson & Wertlieb, 1985) conceptualises adolescence as a normative transitional process of adaptation to new demands. These are usually defined by changes in physical, social and sexual maturity. It is important to reiterate that this stage of transition through the life-span, like any other, is not exempt from disruption. Clearly, extreme behaviours and emotions can, and do, occur for adolescents during maturation that resemble clinical pathology; however, the sources of stress, emanating from family, school and peer groups are seldom clinically relevant. Given the majority of young people do cope reasonably well with “developmental tasks” (Coleman, 1993; Rutter, Graham, Chadwick, & Yule, 1976), classical theories remain an inadequate framework for gaining a developmental understanding of adolescence.

Focal theory of change, proposed by Coleman (1974) is not in accord with defining adolescence as inevitably pathological. He suggests that adaptive maturity emanates from having a focus on one developmental issue at a time, whilst being flexible enough to change as new challenges come into focus at different ages. In this way, the need to adapt accordingly is not concentrated all at one time, there is no fixed sequence and the resolution of one issue, such as intimacy in a friendship, is not essential to facing another. “Adolescents spread the process of adaptation over a span of years, attempting to resolve one issue and then the next” (Coleman & Hendry, 1990: pg 207). Whilst Coleman (1974) has re-focussed attention away from turmoil there is an underlying simplicity to this model, which assumes that life struggles and challenges do not occur abruptly and simultaneously. Coffield, Borrill and Marshall (1986) outline a similar critique.

There are important parallels with Coleman’s (1974) model of change and those introduced by Offer, Ostrov, Howard, and Dolan (1989b) in review of the development of adolescent self-image. Extensive research by Offer *et al.* (1981) examines the adolescents’ own views of themselves, making explicit the fact that a teenager can master one aspect of their psychosocial world while failing to adjust in another.

### 1.5.2 Self-Image: Definition and Development

A number of biological, social and cognitive processes have each been the subject of extensive research into the development of self-image in adolescence (Adams, 1992; Waterman, 1982). Whilst these interrelated processes need to be acknowledged, it is beyond the scope of this study to offer a detailed review.

It is well accepted that a central change in self-awareness occurs during adolescence (Dusek & Flaherty, 1981). Self-image, or views of oneself, has been defined in several ways, notable among which are definitions by Allport (1960) and Maslow (1968). The terms ‘self-concept’ and ‘self-image’ have been used interchangeably (Petersen, 1981, cited in Offer, Ostrov, & Howard, 1984) to refer to the set of attitudes and beliefs a person holds towards themselves.

Self-image provides a detailed and specific assessment of how positively individuals view themselves in various domains of life. This will invariably differ according to the methods, questions and sample used. In seeking to operationalise and thus study adolescent self-image, Offer *et al.* (1981) proposed a template, whereby specific domains, such as family and peer relationships, coupled with more internal states such as mental health and impulse control, provided a window into the feelings and views young people held of themselves.

### **1.5.3 A Sense of Self: Parents and Peers**

There is consistent evidence of the critical role that self-identity and feelings for oneself serve as a predictor of future psychological well-being (Offer *et al.*, 1984) and this in itself provides a clinical rationale for the need to study how contemporary adolescents view themselves. Family climate and social networks are the most proximal influence upon this self-view, such that experiences within these relationships can be adaptive to psychosocial development (Youniss & Smollar, 1985), yet can also be a source of emotional and behavioural disturbance (Parker & Asher, 1987).

The influences of parent and peer relationships have been radically revisited in the literature, such that the previously held belief in their competitive and polarised positions in the life of a teenager has been refuted (Coleman, 1980; Nada Raja, McGee, & Stanton, 1992). Whilst parental relationships and friendships invariably meet different needs (Vernberg, 1990), both are regarded as being positively correlated and influential upon an emerging psychosocial identity.

Traditionally, parent-adolescent relationships have been proposed as conflict ridden, in part due to biological changes in aggression and sexuality (Hall, 1904, cited in Kimmel & Weiner, 1985), the search for identity (Erikson, 1968) and the need for independence. However, the classical view of inevitable and dramatic deterioration of the parent-child relationship during adolescence remains unsubstantiated (Steinberg, 1990). Good familial relationships and parental support predict positive self-esteem and peer integration (Dekovic & Meeus, 1997), cognitive and social development and academic achievement (Cussinato, 1994).

An almost universal feature of adolescence, frequently observed in a clinical context, is the search for greater autonomy from parental constraints. Disagreements and non-conformity to unilateral controls that were part of previous parent-child relationships facilitates this process of disengagement (Coleman, 1974). However, autonomy from parental control rarely equates with complete rejection of their authority, which helps to regulate safety and offers guidance throughout maturation into adulthood. If such independence brings with it the need for adolescents to begin to take responsibility for themselves, what are the implications for young people where this process towards maturity and responsibility may have occurred at a faster rate than they, or even the family, would prefer? Whilst some speculations may be elicited from research on teenage motherhood (Furstenberg, Brooks-Gunn & Morgan, 1987) or childhood illness (Bradford, 1997) a fundamental omission in the literature is the effect that premature responsibility has on adolescent development and independence through meeting a familial care role.

Erikson (1968) perceived that central to the psychosocial tasks of adolescence, particularly late adolescence, is the development of identity. His stage model predicts four identity statuses, through which many young people progress in the search for self. Optimally, a sense of uncertainty (identity diffusion) enables a teenager to adopt different roles and challenges until the eventual achievement of a relatively stable set of self-perceptions and goals (identity achievement). Based on his theory, the stage of premature commitment to beliefs or life goals (identity foreclosure) at the expense of experiencing alternative ideals is important to consider in the context of adolescent care-givers.

A common defining characteristic of adolescence is the amount of time individuals spend with their peers as a means of sharing experiences of leadership, intimacy and companionship (Bakken & Romig, 1992). The salience of peer and friendship groups shift according to age and gender. Clearly, male and female friendship groups vary in terms of size and function (Gilligan, 1982) but their role in helping adolescents to develop social skills, achieve a sense of personal identity and buffer against negative events appear comparable (Berndt, 1982).

Close friendship and peer group research is now well established and corroborates this orientation by adolescents towards their peers, relying upon this affiliation for a sense of self-worth (Hartup & Rubin, 1986). Harter (1983, cited in Hetherington, 1985) proposes

that learning about the self, at a time when sensitivity to social acceptability is excessive, is an irreplaceable experience afforded by the peer group.

Whilst family and peer relationships often promote positive adjustment and resilience to stress during adolescence, they are best construed as increasing the probability, rather than guaranteeing the result, of a successful adolescent transition.

#### 1.5.4 Low Self-Esteem, Isolation and Psychological Distress

It is important to reiterate that stressful, conflict-ridden situations within family and social networks are important to the course of normal adolescent development and a high proportion of adolescents do experience transient depressive mood, characterised by anger, sadness and fear (Coleman & Hendry, 1990). An important minority however, quoted as approximately 20% (Offer, Ostrov, Howard, & Atkinson, 1989), endure profound distress significant to their development.

It has long been established that negative self-attitudes confer vulnerability (Beck, 1967). Familial and peer relationships, as a critical source of how these self-views develop, have been correlated with vulnerability to depression and behavioural problems (Ollson, Nordstrom, Arinell, & Von Knorring, 1999). Overt depressive symptoms increase markedly over adolescence, particularly amongst girls (Rutter & Rutter, 1993).

Without inferring causality and thus blame, family characteristics are amongst the most consistent risk factors of adolescent behaviour problems (Feldman & Elliott, 1990). Family pathology, lack of parental support or over-involvement and over-protection by a parent is consistent with negative outcome for adolescents, in the form of low self-esteem and an increased risk of drug abuse (L'Abate, 1994). Peers can similarly have a substantial role to play in the development of psychological distress. Rejection or neglect by peers has been associated with suicidal ideation, delinquency and substance misuse (Reisman, 1985; Vernberg, 1990). Moreover, the absence of friendships is regarded as a predictor of later psychological problems in adulthood (Parker & Asher, 1987).

Thus, if popularity and peer group identity appear to strongly predict positive psychosocial adjustment and self-image, there are a number of important questions to consider about adolescents with a care role who are often found to be on the periphery of peer relationships (Aldridge & Becker, 1993a). Are they at risk of disturbance to the way in which they perceive and value themselves?

Further empirical validation of these controversial issues is a priority for research. Peer group literature has not taken account of young people who experience interrupted friendships, not due to rejection or exclusion, but as a consequence of events, such as illness, that preclude opportunities to belong. Studies concerned with adolescent chronic illness, where social relationships are found to often be restricted or problematic (Eiser, 1990) offer some directions. They are however, limited and inadequate as a framework for understanding how interrupted peer and family relationships affect the developmental tasks of adolescents who meet significant care responsibilities for another family member.

### **1.6 Summary and Aims of the Current Study**

Evidence has been reviewed from a number of distinct bodies of literature, which identify the need to adopt a multi-modal perspective in understanding adolescent carers. In most cases, illness has been shown to alter the organisation of our basic care-giving system, affecting roles and boundaries within a family. The normative experiences usually accentuated in adolescence, such as independence from parents, and extending relationships outside of the family towards peers, are recognised as being disrupted according to the demands of the illness. The care role may well keep the young person firmly engaged in a dependent relationship with the parent at a time when most adolescents would be beginning the process of disengagement. This is corroborated by what Aldridge and Becker (1993c) refer to as a “silent curfew” for many young carers that imposes a different set of rules for the duration of time away from home. It is more likely that the health condition and its associated care needs set the rules for proximity to a parent, rather than the adolescents need for growing independence.

It is also acknowledged that contexts, such as peer groups and school-life, where the psychosocial developments of young people are fostered are vulnerable to disruption.

Equally, the expression of feelings such as anger, resentment and frustration, are adaptive to the transition of adolescence, but often remain masked or repressed by young carers within their relationships with peers and parents (Bilsborrow, 1992). Secrecy with friends is likely to be maintained by the fear of stigma, whilst feelings of guilt have been implicated as the reasons for avoiding normative conflict when caring for an ill or disabled parent.

However, the view that adolescent carers are inevitably disadvantaged, and that their position is universally negative is both harmful and oversimplistic. Clearly, caring may be a particular problem for a small proportion of young carers with very high levels of responsibility. *A priori* assumptions of adverse effects upon adolescent psychosocial development may preclude identifying positive outcomes such as the potential for improved self-efficacy and confidence, or being afforded a higher status in the peer group. The same rich diversity that is observed in adolescence is equally applicable to the heterogeneity of young carers.

Many questions remain unanswered by the literature and there is a demonstrated need to consider the experience of meeting parental care needs in adolescence, upon an emerging self-image and mental health. Greater knowledge of this developmental process in the context of supporting an illness is a critical first step in acknowledging the young carer first and foremost as an adolescent.

The current research was designed to test the following hypotheses:-

- 1. The role of being a carer for a parent during adolescence will have an effect on individual self-image and psychological well-being when compared with age-related peers without a care responsibility.** More specifically, adolescent care-givers will demonstrate poorer self-image in areas related to family functioning and social relationships. These areas have been regarded as disrupted within the literature.

**2. There will be a higher prevalence of depression and anxiety amongst adolescents who have a care role for a parent with a physical illness/disability and/or a mental health problem in comparison with a normative school population of teenagers without a caring role.**

**3. Adolescents caring for a parent with mental health problems will have poorer psychological health than those caring for a parent with a physical disability.**

It is hypothesised that parental mental health problems create more unpredictability and uncertainty in care roles than those in the presence of a physical illness or disability. These disparate conditions are likely to accentuate differences in psychological well-being between the two carer groups. This hypothesis reflects speculations raised within wider literature.

**4. The psychological well-being of carers will be correlated with the level of perceived intrusiveness of the care role upon their life.**

It is expected that there will be a positive statistical relationship between how much carers feel anxious or depressed and the degree to which they feel their care role interrupts other areas of life (i.e. friendships, school).

## **METHOD**

### **2.1 Rationale for the Study**

Most of the young carer literature features small scale or qualitative studies. This research utilized quantitative methods to address two main limitations of existing methodology. Firstly, comparisons made with children, adolescents and adults from populations unaffected by chronic illness or disability have not been made. The current study included a comparison group of adolescents without a care role for a parent in order to begin to establish some normative data against which 'carer' data could be compared.

Standardised measurement of psychological well-being and adjustment amongst child or adolescent carers is lacking within the literature. This not only introduces implications for the assessment of needs within current adolescent populations, but also raises questions of clinical importance as regards the future mental health of carers into adulthood. The need to develop longitudinal research knowledge of the longer-term impact of childhood caring will be discussed.

### **2.2 Ethical Approval**

Prior to recruitment of participants, the University Clinical Psychology Ethical Committee and Leicestershire Health Research and Ethics Committee granted approval of the current study. An individual meeting with Fosse Health Medical Director secured research indemnity (see Appendix 9a).

The current study was conducted in two phases:

- 1) Piloting the measures and the interview protocol
- 2) The Main Research Study

## **2.3 THE PILOT STUDY**

### **Aims**

The pilot study was undertaken to assess the effectiveness and face validity of a number of outcome measures intended for inclusion within the main study. This was an important process given the fixed time period and limited availability of participants from this population.

### **Design of the Pilot Study**

#### **Inclusion criteria**

There were five criteria set for inclusion in the pilot and main study.

- i) Male or female participants, of any ethnic origin, belonging to a Young Carers Organisation.
- ii) Participants live with, and are caring for, a parent with a chronic illness, mental health problem and/or a physical disability
- iii) Carers are between twelve and eighteen years of age.
- iv) The chronicity of the parental condition exceeds three months duration.
- v) Participants do not have paid or voluntary employment in addition to their care responsibilities.

Young people caring for a parent whose predominant care needs related to having a learning disability, substance dependency or HIV were excluded from the sample population. This was on the basis that these conditions were likely to have required very specialised care needs.

### **Participants in the Pilot Study**

While participants were being recruited to the main research study (see Section 2.6), three carers from a Lincolnshire Organisation were approached for inclusion within the initial

pilot study. They were two females, aged 13 and 15 years, and one male, aged 16 years, selected by the Manager on account of geographical proximity. All three young people satisfied the inclusion criteria.

Parents were informed of the pilot study through a written summary of the research aims (see Appendix 4). Written parental consent was gained for the two females. The male participant completed a self-consent form (see Appendix 6). One of the two females was later unable to attend, due to parental illness. Consequently, no attempt was made to administer the measures to her.

### **Procedure**

Two participants attended an evening meeting in Lincoln. Following review of the aims and procedures, a pack comprising five measures was administered to the participants for completion without time restriction. The measures contained within the research pack are listed below and will be reviewed in a later section (see Section 2.5). Discussion with the author or Manager occurred only if clarification was requested.

- 1) Offer, Ostrov, & Howard (1993). The Offer Self-Image Questionnaire- Revised (Short Form).
- 2) Birlson (1981). The Birlson Depression Scale (BDS).
- 3) Spence (1994). The Spence Children's Anxiety Rating Scale (SCAS).
- 4) The Care-giving Intrusiveness Rating Scale (CIRS): Adapted for the current study (see Section 2.5).
- 5) Nouri & Lincoln (1987). Extended Activities of Daily Living Questionnaire (ADL). Adapted by Wright *et al.* (1995).

### **Semi-structured Interview**

One participant agreed to answer further questions within an optional semi-structured interview format. The remaining participant declined without reason. The interview was held in a separate room and was conducted by the author, according to an interview protocol (see Appendix 8b). Information about the format and rights of confidentiality were discussed. The interview was timed and consent was gained from the participant to audio-tape the dialogue for the purpose of post interview evaluation.

### **Evaluation of Measures**

The sample size precluded any statistical analyses of the data. Participants were asked for their views on the process of taking part and on the practical design of the packs. The questionnaires were not considered too lengthy or complicated in layout. Both participants felt that having the measures presented as a booklet, including age-appropriate cartoons and colour, had increased its face validity and appeal.

More importantly, none of the questions were regarded as provoking distress or being intrusive upon their role. Both participants considered that they had been led to think about their situation in more depth, such as how they perceived their future lifestyle. This was regarded as a positive experience. It is important to consider that the presence of the interviewer could have created a bias in these discussions.

The semi-structured interview was transcribed from audio-tape to ensure that the questions had been understood according to their intended meaning. The interview is reproduced in verbatim form in Appendix 8b (participant 1).

### **Development of the Measures arising from the Pilot Study**

Minor modifications were made to improve the clarity of questions within the American Offer *et al.* (1993) Self-image questionnaire. These amendments were made without altering the meaning of each item. Two filler items were included on this measure in consideration of primacy and recency effects. These alterations thus opened and ended the questionnaire with positive rather than the original negative self-statements.

An important issue arose concerning the validity of a mental health measure, given that it elicited information based on feelings within the previous *week*. The male participant described the inextricable link between his feelings and the rapidly fluctuating mental health of his mother, which he perceived to change from week to week. This issue resembles debates in the wider psychometric literature, such as for the Beck Depression Inventory (Beck, 1978) concerned with measurement of a current “state” or a more persistent “trait”. Whilst this measure was not amended for the main research, it remains

an important consideration for future measurement of psychological well-being with carer populations.

The extended Activities of Daily Living (Nouri & Lincoln, 1987) measure, adapted by Wright *et al.* (1995), failed to yield useful information and was thus removed from the pack. It was however substituted for one designed by the author. This will be described more fully in a later section (see Section 2.5 (6)).

## **2.4 THE MAIN STUDY**

### **2.4.1 Research Design**

A cross-sectional, between-subject's design investigated the proposed hypotheses through controlled comparison of two distinct groups of adolescents. This design aimed to:

- Investigate whether adolescent carers scored differently to the comparison population on various self-image dimensions
- Establish current levels of psychopathology in the two adolescent populations

It was hypothesised that:

- 1) The role of being a young carer will have an effect on individual self-image and psychological well being. Carers will demonstrate poorer overall self-image, and gain higher scores on perceived difficulties with social and family functioning.
- 2) There will be a higher prevalence of depression and anxiety amongst adolescents with a caring role in comparison to teenagers without a care responsibility.

In a second 'between-groups design', differences according to whether young people cared for a parent with a mental health problem or a physical disability were investigated.

It was hypothesised that:

- 1) Adolescents caring for parents with mental health problems will have poorer

psychological health (anxiety and depression) than those caring for a parent with physical disabilities.

- 2) There will be a relationship between how intrusive the care role is perceived to be and feelings of depression and anxiety.

#### **2.4.2 Participants**

A total of 121 adolescents participated in the study, categorised into two distinct research groups. The experimental group comprised a sample of sixty-one adolescents recruited from five Young Carer Group Organisations. A comparison group of sixty adolescents, who did not have a responsibility of care for a chronically ill or disabled parent were recruited from one of the following sources: i) a Leicestershire School and ii) a College of Further Education.

#### **Carer Group**

The Young Carer Organisations were selected from the National Young Carers Directory (Dearden & Becker, 1995), based on geographical proximity to Leicester. Recruitment difficulties over several months necessitated liaison with Organisations outside of the Trent region. Five of the original eight targeted Organisations agreed to participate in the research. These included Lincoln, Nottingham, Kettering, Northampton and Staffordshire. It was assumed that a cross section of adolescents from several groups were likely to be reasonably representative of identified young carers nationally.

Table 1 highlights the number of participants recruited from each Group and their individual characteristics according to gender and mean age. Caring-related variables such as the parent in receipt of care and the classification of their parent's condition, according to physical illness/disability or mental health problem are illustrated.

Table 1: Participant Characteristics for the Carer Group Cohort

Group	Female: Male	Mean Age	Parent Cared For (N)	Condition	
				PD/CI	MH
<b>Lincoln</b>	5 : 3	13 yrs	Mothers (8)	1	7
<b>Kettering</b>	7 : 4	13 yrs	Mothers (8) Fathers (2) Both parents (1)	7	4
<b>Stafford</b>	6 : 3	13 yrs	Mothers (8) Both parents (1)	5	4
<b>Northants</b>	2 : 3	13 yrs	Mothers (5)	4	1
<b>Nottingham</b>	18 : 10	14 yrs	Mothers (25) Fathers (3)	23	5

**Key:** PD/CI : Physical disability/ Chronic illness  
 MH : Mental Health Problem

The age range of participants from Lincoln, Kettering and Stafford was between 12 and 16 years. Ages ranged between 12 and 15 years (Northants) and 12 and 18 years (Nottingham) for the remaining two participant groups. Out of 61 participants, one male was Asian and one female was Afro-Caribbean. Two participants from Lincoln, and two from Northants were siblings.

### **2.4.3 Organisational Structure of the Young Carer Groups**

All of the Groups that were contacted were self-defined, thus there was no consistent model of service delivery. Largely, the Groups were a product of how the Manager operationally defined the Service. Clearly this had important implications for the research design and collation of data.

In order not to undermine the position of parents, all services operated on the consent of parents in working with their offspring. This relationship also enabled advocacy for additional family members if required.

Lincoln and Kettering

Groups were regularly run with a small sample of young carers for a fixed-term period of six weeks (Kettering) and ten weeks (Lincoln). The primary aims of a structured group were to enable the young people to experience short periods of respite through peer-related activities. These were divided according to age groups. Group members were empowered with choices, information and the experience of being together with other young people with a common, yet diverse range of care related experiences.

Data collection was incorporated into Week Three of a new programme for 12 to 16 year olds, at both localities.

Staffordshire

Collective Group meetings were held in school holidays, incorporating all age ranges of young carers within the Organisation. Regular telephone contact and individual visits by staff occurred during school terms.

Data collection relied on postal return of packs administered to interested members at a Health Promotion Day, attended by the author.

Northants

Social group contact amongst young carers did not occur within this Organisation. Individual based activities with staff members, in addition to regular telephone contact were preferred. Occasional group outings had been previously arranged.

A specific evening Group was convened for carers interested in participating in the research.

Nottingham

Following a radical change in service delivery, a community-based model had been established for this Organisation. Integrating young carers into mainstream youth services, rather than conducting specialised groups led regular meetings to cease.

All data collection occurred through postal questionnaire.

Table 2 summarises the delivery of services for the different carer groups, highlighting the method of data collection.

Table 2: Service Organisation for Young Carer Groups

<b>Organisation</b>	<b>Service Delivery</b>	<b>Data Collection</b>
<b>Lincoln</b>	Structured Groups (10wks)	Part of Group Programme (Week 3)
<b>Kettering</b>	Structured Groups (6 wks)	Part of Group Programme (Week 3)
<b>Staffordshire</b>	Holiday Groups	1 Day Group/ Postal return
<b>Northants</b>	Individual Contacts	Specifically Held Group
<b>Nottingham</b>	Postal Database	Postal Questionnaire

It is important to note that all Services, regardless of running Group Programmes, also met needs according to individual contacts, telephone contact and liaison with other services.

The nature of this hidden population of carers introduced two important implications for the research. Firstly, it was extremely difficult to recruit Organisations, in part due to members being protected from research studies and the media. In addition, different methods of collecting data had to be tolerated in order to access these young people. This will later be discussed.

Regardless of their diversity, all young carers within these Groups had one variable in common; some degree of care responsibility for a parent. The extent of their differences implied that it was not possible to form a control group, and thus a comparison group of adolescents without a care role was recruited.

**Comparison Group**

Classes from a Leicestershire School and One College of Further Education participated in the research. A cross section of sixty students were recruited from three classes, comprising mixed gender, ethnicity, social class and mixed academic ability.

Year 8 and Year 11 classes were selected on account of their age distribution. Two students described themselves as care-givers to their ill mothers and their data was thus excluded from the study. The remaining sixty students did not meet any of the inclusion criteria for the experimental group (see Section 2.3) other than being of similar age. Table 3 highlights the number of participants recruited from each class, in addition to ethnicity and mean age.

A Sixth Form class, of mixed gender, ethnicity, social class and academic ability was recruited from a College of Further Education. The participant characteristics are also represented in Table 3.

Table 3: Participant Characteristics for Comparison Group Cohort

<b>Participants</b>	<b>Female: Male</b>	<b>N.</b>	<b>Mean Age (range)</b>
<b><u>School:</u></b>			
<b>Year 8</b>	10 : 18	28	12 yrs (12-13 yrs)
<b>Year 11</b>	10 : 9	19	15 yrs (15-16 yrs)
<b><u>College:</u></b>			
<b>Sixth Form</b>	8 : 6	14	17 yrs (17-18 yrs)

Four participants were of Asian origin.

**2.5 Review of Measures**

**1) *Socio-demographic and family characteristics***

A questionnaire was constructed to elicit factual information pertaining to participant background details and family composition. The importance of a number of socio-demographic and support factors as predictors of adjustment to illness are well documented (Wallston, DeVellis, & DeVellis, 1983). In addition, the significance of family composition, particularly lone parenthood, gender and external social factors, such as

economic status and support systems have been highlighted as likely variables in determining why children take on care-giving roles (Blackford, 1988).

The questionnaire was completed by the Organisation Manager. This decision was supported by the wider research, acknowledging that childhood carers, socialised into a care position, frequently underestimate the magnitude of their role (Meredith, 1992a). The question relating to their perceived level of care responsibility may have therefore been difficult for them to answer accurately for themselves.

The questionnaire is presented in Appendix 9a in the form in which it was administered.

Order of Presentation

Five questionnaires were compiled into research packs to be completed by the adolescent carer sample. Two of the carer related measures were omitted from the comparison group packs as they were not applicable.

Table 4: Measures included in the Research Questionnaire Packs

<b>Measure</b>	<b>Construct being Measured</b>	<b>No. of Items</b>	<b>Key used in the Text</b>
<b>Offer Self-Image Questionnaire-Revised. Short Form (1993)</b>	Self-Image	52	OSIQ-R
<b>Birleson Depression Scale (Birleson, 1981)</b>	Depression	18	BDS
<b>The Spence Children's Anxiety Scale (Spence, 1994)</b>	Anxiety & Anxiety components	36	SCAS
<b>Care-giving Intrusiveness Rating Scale *</b>	Perceived Intrusiveness of care role	10	CIRS
<b>Care Task-Job Description *</b>	Care Tasks Performed	3	

The measures identified by \* are non-standardised.

**Adolescent Self-Image**

**2] Offer Self-Image Questionnaire- Revised (OSIQ-R, 1993: Short Form)**

**i) Description**

The Offer Self-Image Questionnaire- Revised (OSIQ-R) is a 129 item American self-report inventory for adolescents aged between thirteen and nineteen years. The scale can also be administered to adolescents aged 12 years. It is designed to measure self-image in multiple domains, whilst acknowledging that a teenager can achieve mastery in one area of their psychosocial world while failing to adjust in another. Originally developed for use with adolescents without the presence of pathology, the scale offers clinical utility in the differentiation of disturbed adolescents with neuroses, single episode and recurring depression from those not seen clinically.

Self-image is defined by Offer *et al.* (1989) as a multidimensional construct according to twelve important areas in the psychological world of the adolescent. These dimensions are presented in Table 5. Scores are obtained for each domain, in addition to yielding a total self-image scale (TSI) score. This is calculated by combining scores across the 10 component scales.

The participant is required to select a number from 1 to 6, according to how compatible it is believed to be to their individual circumstance(s). Responding with the number 1 denotes that the question is perceived to describe the person very well, ranging up to a response of 6, indicative of the question being 'not at all' descriptive of them. This procedure is followed for every item.

Table 5: Domains of self-image assessed by the OSIQ-R (1989)

<b>Sub-Item</b>	<b>Assessment/Measure of:</b>
<b>Emotional Tone (ET)</b>	The stability of emotions
<b>Impulse Control (IC)</b>	The management of internal/external pressures
<b>Mental Health (MH)</b>	Identifies absence/presence of severe psychopathology
<b>Social Functioning (SF)</b>	Object relations & friendship patterns
<b>Family Functioning (FF)</b>	The emotional atmosphere within family
<b>Vocational Attitudes (VA)</b>	The development of plans for future vocation
<b>Self-Confidence (SC)</b>	How efficiently the adolescent adapts to their environment
<b>Self-Reliance (SR)</b>	How well the adolescent copes with themselves and others
<b>Body Image (BI)</b>	Adjustment to one's own body
<b>Sexuality (SX)</b>	Attitudes, feelings & behaviour to opposite sex
<b>Ethical Values (EV)</b>	The morals of the self in relation to others
<b>Idealism (I)</b>	Ideals held by the self in helping others

ii) Psychometric Properties

The OSIQ-R has been developed over thirty years, and been widely used within American and international, cross-cultural research studies (Offer, Ostrov & Howard, 1977).

Previous research has demonstrated reliability coefficients across all of the scales (alpha 0.72, internal consistency) and (0.74, test-re-test reliability). This indicates that the scale is homogeneous and stable. Significant correlation analyses also exist with other measures such as the Beck Depression Inventory (Beck, 1978) and the Tennessee Self-Concept Scale (Fitts, 1965).

A short-form of the OSIQ-R was identified following personal communication with Dr Offer. The rationale for administering the shorter form within the current study was to minimise participant fatigue, enabling a range of measures to be incorporated into a single point of data collection.

The short form OSIQ-R (Offer *et al.*, 1993) consists of 58 questions comprising the same component scales as measured within the 129 item measure (see Appendix 9b). The

maximum score is 312. Studies to date have not used the short form and thus there were no norms available for this amended version.

With Dr Offer's permission, it was decided to amend the short form by excluding items relating to the sexual attitudes scale in order to be sensitive to ethical protocol. Whilst acknowledging that sexual development is an integral aspect of adolescent psychosocial development, removal of this domain did not invalidate the efficacy of the overall self-image rating. In addition, a number of ambiguous interpretations of the questions were clarified through correspondence with Dr Offer. The author also modified a selected number of words and phrases to make them more culturally appropriate to a British population.

A new design and layout of the questionnaire was devised to make it accessible to participants within the study. The principal change was an amendment from a verbal description of responses to the same responses reproduced within a numerical Likert scale. It was not deemed that the amendments made would compromise the validity or reliability of the measure.

### iii) Rationale

The selection of the OSIQ-R was based on three main factors.

- 1) An extensive literature search was inconclusive in identifying an English adolescent self-image questionnaire. Measurement of self-esteem, a similar but not equivocal concept to self-image, such as the American Rosenberg Self-Esteem Inventory (SEI; Rosenberg, 1965) was considered but measures failed to identify the constructs required.
- 2) The psychometric properties of the OSIQ-R were considered reliable and widely documented.
- 3) Finally, items directly measured on the inventory, such as family functioning, social relationships and mental health are hypothesised as being adversely affected within existing qualitative young carer literature (Becker & Aldridge, 1993c).

**Psychological Well-being**

The capacity for children and adolescents to reliably and validly report their emotional states in psychiatric interviews and self-report questionnaires has been emphasised in the literature (Kazdin, French, Unis, & Esveldt-Dawson, 1983). The concept of psychological well-being was measured according to the Birleson Depression Scale (Birleson, 1981) and the Spence Children's Anxiety Scale (Spence, 1994).

**3) Birleson Depression Scale (BDS, 1981)**

The Birleson Depression Scale was devised as a clinical instrument to assess the degree of depressive feelings prevalent in children and adolescents. Whilst it was originally designed for use with young people aged between 7 and 12 years of age, the scale has been successfully administered to a cohort of participants between the ages of 7 and 18 years (Firth & Chaplin, 1987). The self-rating instrument consists of 18 items which offers an operational definition of depression according to the most common symptoms of depression reported in children (see Appendix 9c).

Participants are required to select a response that best accords with their circumstances in the course of the previous *week*. Selection choices range from 'Never', 'Sometimes' and 'Most of the time'. Scores range from 0, 1 or 2 accordingly and yield a maximum score of 54. A score above 17 has been reported as an indicator of depressive symptomatology, yet this has been criticised as being too crude (Yule, 1992). A high score on the measure alone is not indicative of a clinical diagnosis of depression and the instrument is best employed as a complement to thorough mental health assessment.

The status of the BDS has been assessed, primarily with small samples of depressed and non-depressed groups. The scale is efficient in discriminating a depressed group from children within a mainstream school and from clinic referred peers with diagnoses other than depression (Birleson, 1981). The measure demonstrates good reliability (0.86) and test-retest reliability (0.80).

Birleson (1981) found items on the Depression Scale to resemble those used in adult depression scales, such as Zung's self-rating Depression Scale (1965) and The Beck

Depression Inventory (1978). Its properties correlate highly with other depression measures in children such as the Children's Depression Inventory (CDI: Kovacs, 1985). The CDI and the BDI were both reviewed as alternative measures to the BDS but were omitted on the basis of inappropriate age criterion.

One item was considered age-inappropriate for adolescents and was amended in this study from "I like to go out to play" to "I like to go out". Firth and Chaplin (1987) similarly made this modification in their use of the Birleson Depression Scale with an older teenage group.

#### **4] *Spence Children's Anxiety Scale (SCAS, 1994)***

The Spence Children's Anxiety Scale (SCAS, see Appendix 9d) is designed to provide an overall anxiety measure, in addition to scores on six specific components of child anxiety. Its relevance for measuring anxiety in a young adolescent population has been stated by Spence (1994). Based upon existing child anxiety assessment measures and structured clinical interviews, the SCAS was consolidated into a 38 item questionnaire, comprising six positively worded filler items and one open-ended, non scored item.

Responses are based on ticking a box of choice, ranging from 'Never', 'Sometimes', 'Often' and 'Always'. Scores are rated from 0,1,2,3 accordingly. This yields a maximum score of 114. The higher the score, the more this area induces high anxiety. No time criterion for the duration of these anxiety symptoms is specified.

The six sub-scale scores of the SCAS measure: (1) Panic attack and agoraphobia; (2) Separation anxiety; (3) Physical injury fear; (4) Social phobia; (5) Obsessive compulsivity and (6) Generalised anxiety disorder/Overanxious disorder.

##### **i) Psychometric Properties**

The SCAS has been standardised on a large Australian mixed gender population, demonstrating evidence of discriminant validity by differentiating between clinically anxious children and a matched group of non-clinical peers. Research with normative

samples of 851 males and 1201 females, aged between 8 and 12 years demonstrated sufficient psychometric properties, with good indices of internal reliability (0.92) and test-retest reliability (0.51) (Spence, 1997b).

Scores on the SCAS are shown to generally decline with age. Additional research by Spence (1997a) demonstrated that the SCAS correlated with additional measures such as the Revised Children's Manifest Anxiety Scale (RCMAS) (Reynolds and Richmond, 1978). Statistical analyses between the SCAS and the Child Depression Inventory (CDI) (Kovaks, 1983) were indicative of further strong correlation.

## ii) Rationale

The Spence Children's Anxiety Scale (SCAS) was selected for two reasons. The design of the scale, such that specific aspects of anxiety are highlighted, was important when considering issues of separation from an ill or disabled parent and disrupted opportunities to socialise with peers amongst a young carer population. The SCAS provides scores relevant to each of these domains in a person's life. Additionally, psychometric resources for adolescent anxiety or depression remain limited. A future research study might aim to standardise the tool on an adolescent population.

## Carer Role

The interference of care-giving upon other aspects of an individual's lifestyle is a concept that does not appear to have been measured within the young carer population. As a result, a newly devised measure, adapted from a measure of illness intrusiveness for adults, was designed for the current study.

## 5] *Care-giving Intrusiveness Rating Scale (CIRS)*

### i) Description

The Care-giving Intrusiveness Rating Scale (CIRS) is an assessment of ten central areas of life, considered vulnerable to disruption when adopting a care role for an ill or disabled

family member (see Appendix 9e). These central life domains have been identified as important to quality of life in health psychology research (Flannagan, 1978).

The CIRS was adapted for the current study from the Illness Intrusiveness Rating Scale (IIRS, Devins *et al.*, 1983), a 13 item American measure. Ratings are obtained for the degree to which the respondent's 'illness and/or treatment' interferes with 13 life domains. These include relationship with spouse/partner, family relationships, friendship/social relations, health, diet, work, sports/hobbies, relaxation, financial situation, sex life, religious expression, self-expression/self-improvement, and community and civic involvement.

Research studies conducted with adults with multiple sclerosis, end-stage renal failure, cancer and sleep disorders conclude that the IIRS has considerable face validity for chronically ill respondents (Devins, 1994). The scale has demonstrated internal consistency (0.80 to 0.95) and test-retest reliability ( $r = 0.80$  to  $0.85$  over 9 months).

Other life events, aside from illness or disability are known to be causal in disrupting these areas of life. However, the psychosocial impact introduced by a disease or disability *per se* is fundamental to this study, thus the devised measure.

The scale required the omission of three items, including 'spousal relationships' and, for ethical reasons, the 'sex life' item. 'Religious expression' was considered less important to English adolescents as American adults for whom the IIRS was intended and was therefore also excluded. The final items were modified to include 'developing your own independence' and 'making plans for the future'.

A rating is given for how much caring for a parent interferes with each of the 10 items highlighted. The perceived level of interference is rated according to a 7- point Likert scale, ranging from 1 (Very little) to 7 (Very much). In cases where a life domain is not perceived as applicable, a score of 1 is assigned to indicate that the illness/disability does not interfere very much with this particular area. Clearly, high scores are indicative of a high level of perceived intrusiveness. Ratings are assessed for each sub-item and summed to generate a total score.

ii) Rationale

Adapting this from a measure focussed on illness to consider how a care role in adolescence may be perceived to interfere with one's lifestyle aimed to advance theoretical and clinical knowledge. The lack of such assessment measures, particularly of areas considered important to quality of life, provided further rationale for its inclusion. The current study is the first time it has been utilised in its modified form, concerned specifically with the carer. Cronbach's alpha analysis confirmed internal reliability of the CIRS (alpha, 0.8). However, further psychometric properties cannot be presented.

**6) *The Types of Care Tasks Performed***

i) Description

A crude assessment of the type of tasks carried out by adolescents was initially attempted by measurement of parental independence across various tasks. This was assessed within the pilot study using the extended Activities of Daily Living Questionnaire (ADL, Nouri & Lincoln 1987), adapted by Wright *et al.* (1995). The 23 item ADL consists of five areas, such as self-care and domestic tasks, which are deemed important to one's ability to live independently within the community (see Appendix 9g). The participants were required to appraise the level of their parent's functional independence, such as being able to manage the task 'alone easily', 'alone with difficulty', 'with help' or 'not at all' on each domain. This was intended to provide an indicator of the areas where care needs might arise.

Following the pilot study, this measure was omitted from the research pack. The main critique concerned the inherent assumption that if a particular area did prove difficult for a parent, then the young carer would be involved in performing this task. This clearly was not a corollary. In addition, the ADL was found to be insensitive to the frequency and reason for the need for support, such as lack of motivation rather than ability. This is an important issue when considering the care needs of parents with mental health problems. There are potentially different types of care roles that may be required, including offering emotionally supportive care, reassurance or motivating a parent. However, these needs are not exclusive to parents with a mental health problem.

Following extensive liaison with mental health professionals, it was concluded that an equivalent measure of the ADL for psychiatric difficulties was not available. A creative tool to elicit similar information, whilst maintaining face validity for adolescents, was suggested by the research supervisor. This was designed by the author, requesting the participant to write a job description for someone that they could imagine as taking over their care role for one month. They were required to list all the tasks and skills they performed during a 'typical' day in caring for their parent. The questionnaire was structured according to three main task areas: (1) Domestic tasks, (2) Personal/hygiene tasks (3) Additional tasks (for example, emotional support, companionship, sibling care). Examples were not provided for the participants to encourage them to self-identify the tasks *they* performed. (refer to Appendix 9f). Results from this measure are represented as a descriptive summary rather than through empirical analysis. Examples of the responses, recorded as they were written, are provided in Appendix 7a & b.

## **7] *Semi-structured Interview***

### **i) Rationale**

A brief semi-structured interview was devised to gain individual accounts of the experiences of being an adolescent carer (see Appendix 8b). The rationale for this additional descriptive information from a small number of participants was to elaborate upon the issues introduced by the quantitative methodology. Statistical analyses were not conducted on the information elicited.

Emphasis upon the young carer *experience* was decided upon for three main reasons. Primarily, questionnaire measures had been included to inform the study of the perceived impact of performing a care role, in addition to what types of tasks were being met. Interview questions provided the opportunity to understand the experiential nature of meeting these responsibilities, whilst incorporating a developmental theme. In addition, there remains a need within the literature to understand a carer's perceived situation as a preliminary step in addressing how best to adequately provide for arising needs, both nationally and on a local service-based level. Finally, the use of interviews in previous studies with young people with a care responsibility has proven cathartic in providing them

with an opportunity to describe their position more fully (Aldridge & Becker, 1993a). However, it was made clear to participants that this was a research study rather than treatment.

Methodology that provides the opportunity for young carers themselves to provide individual descriptions about their lives is strongly endorsed by researchers such as Becker and Aldridge (1993a). Their qualitative research studies with young people in care roles is an attempt to both challenge the shortcomings of existing quantitative surveys and to reflect the reality of individual experiences.

Emphasis upon previously researched themes, such as care task information was avoided in the current study, whilst recognising that common themes and overlap in content could emerge. An extensive literature review informed the issues in need of being investigated within the protocol. Additionally, the continuity of themes raised within the questionnaire pack was important and this was extended into interview according to three main sections; 1) The individual, 2) Parent-child relationship and 3) Services.

1) Individual

Questions attempted to extract whether the adolescents perceived any differences between themselves and their peers without a care role. The interviewee was asked to consider activities that might be pursued if another person managed their role. Two questions concerning the adolescent's perceived future were included.

2) Parent-child relationship

This short section required the interviewee to choose five words to describe what their relationship was like with their ill or disabled parent.

3) Services

There exists a wide range of literature concerning services for carers (Twig, 1992), however systematic evaluation of services in meeting these needs has been sparse. It is clear that addressing the area of service provision for young carers evokes both a political, moral and social tension, and review of service needs is largely absent from this literature.

The interview protocol included questions about services that the young people were receiving, their appraisal of them and services that might be beneficial to them in supporting their care responsibility.

One question concerned their evaluation about the Young Carer Group to which they belonged. It was intended, with consent from interviewees, that any service implications arising from this would be discussed anonymously with the Group Manager.

## **2.6 Procedure**

### **Recruitment**

#### **Carer Group**

Recruitment occurred over several phases. Liaison with Organisation Managers continued over a three-month period, primarily through written correspondence of the research aims and objectives (see Appendix 2). The second recruitment phase involved brief research presentations given by the author. Finally, with the exception of the Nottingham sample, identified carers were sent a letter about the research study, complete with parental consent forms for individuals under the age of sixteen years (see Appendix 4). The total number of carers targeted were: Lincoln (n=8), Kettering (n=18), Northants (n=11) and Staffordshire (n=13).

Nottingham selected the first eighty young carers meeting the inclusion criteria from its Service database. Emphasis on recruiting participants whose parents had a physical illness or disability was specified for Nottingham to ensure a range of conditions were included in the total sample.

Following confirmation from adolescents willing to participate, the author met with different Managers to arrange data-collection procedures.

Eighty questionnaire packs, complete with a summary of the research aims, consent form and a stamped addressed envelope were sent to Nottingham participants. These were sent with a bimonthly edition of their Young Carer magazine. The adolescents were given a

three week deadline within which to respond. All responses were sent to the Nottingham Offices.

### Comparison Group

Initial liaison with the Head-teachers of a Leicestershire School and a College led to further meetings with elected Year Heads. Dates were negotiated for the author to integrate data collection into curriculum Personal and Social Education (PSE) lessons for two classes (n=46) meeting the research criteria at the School. The data was collected within a General Studies lesson for the College sample (n=14).

The associated Year Head informed pupils approximately three weeks prior to the lesson. Parents of these children were sent a letter from the School, informing them of the study and requesting them to send a reply if they wished their child to be excluded from the research (see Appendix 5). None of the parents objected. Students attending the College were all of consenting age and parental consent was not required.

### **2.7 Data Collection**

Prior to completing questionnaires, three issues were clarified. Firstly, every adolescent was required to have completed the consent form, or have had it completed by a parent where appropriate. A brief introduction to the research was then given. Finally, issues of confidentiality and anonymity were clarified, with any concerns about the research process being addressed in this introduction. Each participant was again given the option of declining to participate, without explanation. None declined.

### Carer Group

Anonymous questionnaire packs were administered to all participants, identifiable only to the author by numerical code. These were completed individually, however the author and Group Manager were present if required. The measures took approximately thirty minutes to complete. The Group Manager completed socio-demographic details for each carer during the evening.

The author facilitated a brief discussion to enable any questions to be raised and for participants to be fully thanked and debriefed. All Groups were made aware of the feedback that would be provided to the Group Managers on completion of the study.

Participants who expressed an interest in the interview were required to spend an extra ten minutes with the author in a separate part of the room. For practical reasons interviews could not be held with participants from Nottingham or Staffordshire. The same administration procedures were observed as those within the pilot study interview.

### Comparison Group

Shorter questionnaire packs, omitting two carer-related measures were administered to the comparison group population.

Data was collated from the two School classes on the same day. A brief introduction of the research aims and opportunity to decline participation was presented. All pupils participated (n= 46) and completed a brief form to elicit socio-demographic details (see Appendix 9a). Individuals completed them independently, taking approximately ten to twenty minutes. No attempt was made to administer the measures to pupils missing from the classes for various reasons.

All questionnaires and socio-demographic details were coded for participant anonymity. A brief discussion was held for pupils to ask questions provoked by the study. The classes were thanked for their participation and informed of the feedback that would be provided on completion of the research.

The same administration procedures were observed for the College sample. All students wished to participate in the research (n=14). A brief presentation about young carer issues followed the data collection as part of their general lesson.

## **RESULTS**

### **3.1 Participant Response Rate**

Table 6 highlights the total number of carers participating in the study from those originally targeted for inclusion.

Table 6: The Number of Participants from each Young Carer Organisation

<b>Group</b>	<b>Originally Targeted</b>	<b>Total Participating</b>
Lincoln	8	8
Kettering	18	11
Staffordshire	13	9
Northants	11	5
Nottingham	80 (postal)	28

Thirty-three of a potential eighty questionnaires sent to the Nottingham population were returned. Five of these were incomplete and thus omitted from the analyses. The total postal response rate was 35%.

100% of the adolescents attending the School and College classes participated.

### **3.2 Results of the Socio-demographic Questionnaire (1)**

Demographic information was elicited for the carer and comparison group and is represented in Table 7. The questionnaires differed marginally according to the relevance of collating care-related information (see Appendix 9a).

#### Carer Group

Inspection of the data indicated that the adolescent carer group were heterogeneous in terms of age, ethnicity, family composition, parental illness or disability, duration of time as a carer, economic status of the family, and the level of support from services. This confirmed that the participants differed from each other on a number of dimensions and represented a heterogeneous community population. In addition, their heterogeneity was

important in considering how far any statistical effects with this sample could be generalised to other similar populations.

### Comparison Group

Demographic questionnaire information demonstrated participant differences on a number of dimensions. These included age, ethnicity, family composition and economic status of the family.

#### **Gender**

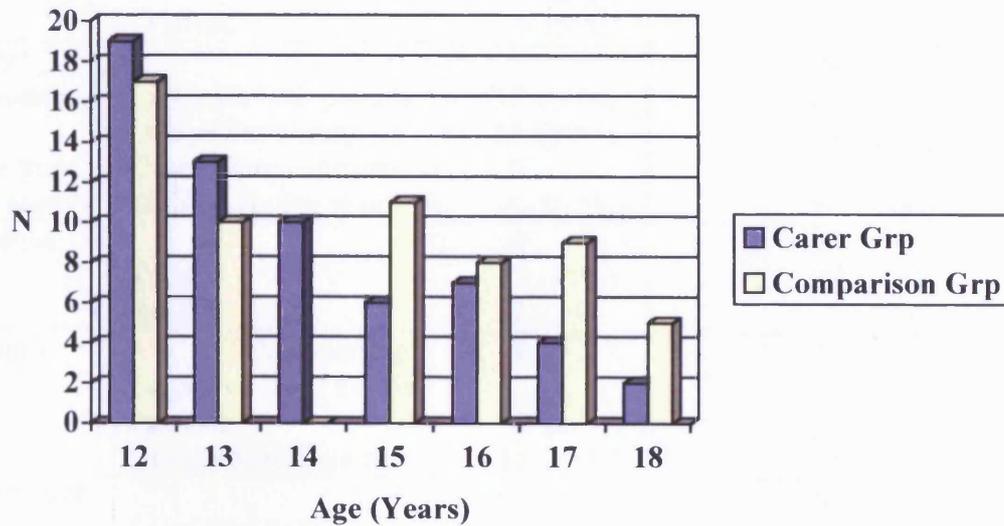
Thirty-seven of the adolescent carers were female and twenty-four were male adolescent caregivers. Thirty male and thirty female non-carers comprised the comparison group.

#### **Ethnicity**

Fifty-nine (97%) adolescent carers were white, one male carer was Asian and one female was of Afro-Caribbean descent. The comparison group population comprised 55 (92%) white adolescents and five Asian (8%) participants.

#### **Age**

The mean age of the adolescent carers was 13.8 years (range 12 to 18 years). The mean age of comparison group adolescents was 14.5 years (range 12 to 18 years). Figure 1 highlights the number of participants identified according to each age criteria.

Figure 1: Age Distribution of Participants

### Family Composition

The majority of adolescents from the carer and comparison cohorts were residing with both parents (61% and 77% respectively). A higher proportion of adolescent carers (39%) than non-carers (23%) were living in lone parent families. Fifty-four (88.5%) carers and 50 non-carers (83%) had siblings also living at home.

Table 7: Summary Statistics of Demographic Data

	<b>ADOLESCENT CARERS (n=61)</b>	<b>COMPARISON GROUP (n =60)</b>
<b>Gender</b>	<b>N</b>	<b>N</b>
	Male 24 (39%)	30 (50%)
	Female 37 (61%)	30 (50%)
<b>Family Composition (at the time of the study)</b>	<b>N</b>	<b>N</b>
	Live with both parents 37 (61%)	46 (77%)
	One parent family 24 (39%)	14 (23%)
	Other relatives/carers 0	0
	Siblings (living at home) 54 (88.5%)	50 (83%)
<b>Residence</b>	<b>N</b>	<b>N</b>
	Town 59 (97%)	58 (97%)
	Rural 2 (3%)	2 (3%)
<b>Economic Status</b>	<b>* Data missing</b> <b>N</b>	<b>N</b>
	Employed adult family member 9 (27%)	51 (85%)
	Unemployed/Benefits 24 (73%)	9 (15%)
<b>Educational Status</b>	<b>N</b>	<b>N</b>
	Secondary School 50 (82%)	46 (77%)
	Further Education 10 (16%)	14 (23%)
	Completed Education 1 (1.5%)	0

\* Nottingham Sample declined this information due to the Manager’s reservations regarding item content (n=28).

**Carer Population**

**Care Related Factors**

A number of differences were highlighted according to which parent was in receipt of care, the nature of their condition and additional support received within the family. Table 8 summarises the parent and care-giving characteristics.

Table 8: Parent Receiving Care and Reported Condition

	<b>Mothers</b>	<b>Fathers</b>	<b>Both Parents</b>	<b>Additional Care of Siblings</b>
<b>Care Role for:</b>	54 (88.5%)	5 (8%)	2 (3%)	23 (38%)
<b>Physical Disability/ Chronic illness</b>	29 (48%)	4 (6.5%)	1 (1.5%)	
<b>Mental Health Problem</b>	25 (41%)	1 (1.5%)	1 (1.5%)	

### **Parental Condition**

Adolescents were predominantly caring for their mothers. A higher proportion of parents endured a physical disability or chronic illness (n=34). It is likely that a higher percentage of co-morbidity would have been reported had the primary condition not been requested. Multiple Sclerosis was the most prevalent condition in the physical illness/disability group, and chronic depression was most commonly reported in parents with a mental health problem.

### **Primary Carer or Co-Carer**

Ten participants regarded their second parent as a carer for their ill/disabled parent. Thirty-seven adolescents also perceived their siblings to have a care role, in addition to their responsibilities within the home. Fourteen participants, six male and eight female, were identified as primary carers without support from other family members.

### **Types of Care Tasks**

Information was gained from Questionnaire 5 (see Appendix 9f) on the usual type of care tasks performed. It was designed to be a descriptive tool rather than a statistical measure. Three dominant care areas were identified, in accordance with those highlighted in the young carer literature.

These were:

- Domestic care responsibilities (i.e. cleaning, meal preparation)
- Personal care/hygiene tasks (i.e. bathing, medication, toileting)
- Additional, non-specific areas (emotional support, social and sibling care)

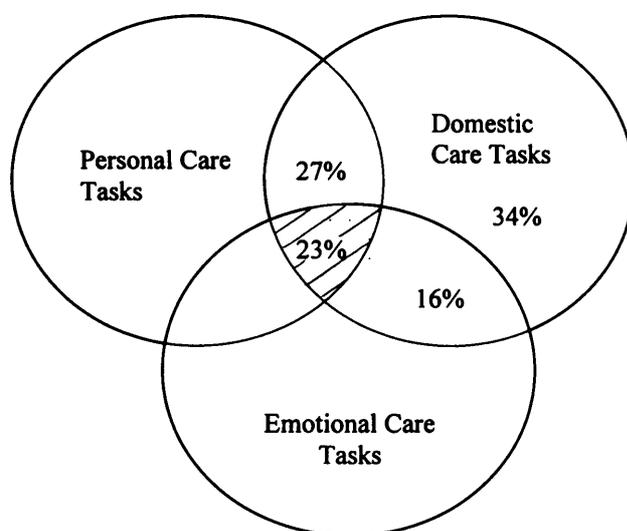
It is important to highlight that a number of chores are likely to be performed *within* these categories.

Every participant (100%, n=61) perceived themselves to be carrying out tasks or chores characteristic of domestic help. Involvement in providing personal care, such as supervising medication or bathing, was reported by 48% (n=29) of the sample. Just over a third of the sample (39%, n=24) described themselves as offering social or emotional support. A further 37% (n=23) referred to assisting with care for siblings in addition to tasks performed to support the ill or disabled parent. Of this 37% offering sibling care, 11% (n=7) were for siblings who had a chronic illness or learning disability.

It is likely that involvement in areas of personal, intimate care and emotional support were under-reported. This in part may be due to the stigma and secrecy that surround both types of care responsibility.

Figure 2 highlights the percentage of participants involved in one or more of these main care task categories. These were calculated for the three main care types offered to an ill/disabled parent. Additional sibling care responsibilities were omitted.

Figure 2: Percentage of participants involved in the three main care task domains.



All participants involved in only one type of task (34%) were performing domestic duties, such as cooking and washing clothes. The largest number were undertaking duties and responsibilities within two main task areas. These were either domestic and personal care (27%) or domestic and emotional support (16%). Twenty-three percent of adolescents were performing roles across all three main care tasks, several of whom were recorded as being primary carers in the absence of a second parent or other siblings.

The reader is referred to Appendix 7b for descriptions of care tasks provided by fifteen carers, selected at random. This was done in order to provide a cross section of verbatim examples of the care responsibilities met by adolescents for their ill or disabled parent.

### Non-Carers (Comparison Group)

Adolescents without a care role were asked to report on the types of tasks they were involved in at home. Forty-four (73%) adolescents perceived that they had some domestic chores to complete, which mostly entailed washing dishes or tidying their own bedrooms. Four of these also had sibling care responsibilities, such as babysitting or collecting siblings from school. Sixteen adolescents (27%) did not have any duties or chores at home.

### **Perceived Level of Care Responsibility**

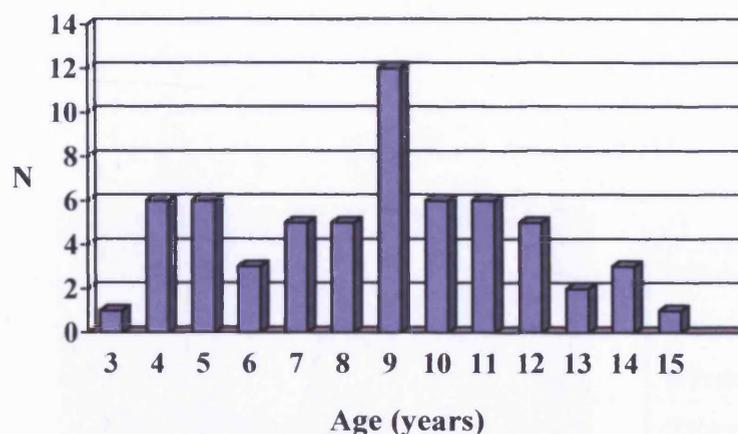
Young Carer Group Managers perceived the highest proportion of carers to have a *moderate* level of care responsibility (n= 26), whose role was supported by another adult or older sibling. Fourteen adolescents were identified as primary carers to their parent, and a further nineteen were rated as having a significant responsibility for providing care. Two adolescents were perceived to have minimal input.

### **Duration of Care Role**

The mean duration of time spent caring for a parent was 5 years (range 1–12 years). The level of responsibility and related tasks were likely to have increased or decreased over this duration, according to numerous factors (i.e. illness progression, additional help), and therefore cannot be assumed to have remained stable.

### **Age At Which Care Role Began**

A range of ages at which participants first became involved in care responsibilities for their parent were highlighted. Figure 3 represents the spread of ages, ranging from beginning a care role at the age of three years to this first being necessary at fifteen years of age. The mean age at which a care role began was 8.6 years. This is particularly striking given that at eight and a half years of age children are not judged by law to be competent to look after themselves.

Figure 3: The age at which the adolescents perceived their parental care role to have begun

### Support from Services

Information was elicited for 33 participants on the following service-related factors. Participants from one Group did not complete this information, on request of the Organisation Manager.

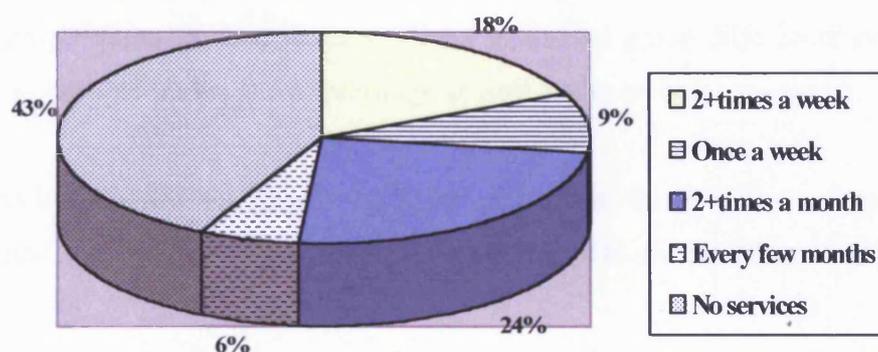
#### Membership within Young Carer Organisation

Participants had belonged to Organisations over the duration of six months to three years. The mean duration of time in receipt of support from a Young Carer Service was 1 year and 2 months.

#### Known Services Received by the Family

Nine families were identified as receiving Social Services input. NHS/Mental Health Services were involved with a further five families. Multi-agency support was highlighted for four families and one family was in receipt of help from voluntary services. Fourteen families were without any support from formal services.

The frequency of this service support is outlined in Figure 4.

Figure 4: Frequency of Support Offered to Families

Two-tailed independent t-tests and chi-square analysis revealed no significant differences between the adolescent carers and non-carers according to age, gender, ethnicity, family composition or educational status ( $t = 2.264, p < .05$ ).

### 3.3 Method of Data Analysis

Parametric statistics for analysis of the data were largely employed after careful consideration of a number of important criteria. The characteristics of the populations from which the samples were drawn met the three necessary conditions for parametric analysis (Bryman & Cramer, 1997; Howell, 1989).

The following conditions were satisfied by the data: (1) Questionnaire measures had interval properties (2) Sample scores were normally distributed for the majority of variables (qualified statistically and through visual inspection) and (3) The samples showed equal variance. A small number of sub-scale items on the outcome measures did not satisfy the criteria for parametric analysis and thus, Mann-Whitney U tests for unrelated samples were conducted.

### Group Analyses

Initial analyses concerned the exploration of *differences* between the adolescent carer population and the comparison group population.

Between-group analyses were conducted through independent sample t-tests and, where necessary, Mann-Whitney U tests. These examined group differences on each dependent variable for self-image and psychological well-being outcome measures.

One tailed significance levels were set given that the direction of relationships were predicted i.e. adolescent carers will exhibit poorer self-image and psychological health.

Two further levels of analyses were conducted for the carer sample. These examined:

- 1) Differences between adolescent carers, according to parental condition (physical illness/disability or mental health problem)
- 2) The relationship between psychological well-being and care role intrusiveness

Again, between-group analyses were conducted, using independent sample t-tests and Mann-Whitney U tests. These examined whether the two carer groups could be differentiated according to a number of outcome measures. One tailed tests were conducted as the hypotheses predicted the direction of the relationship i.e. caring for a parent with a mental health problem would be indicative of poorer self-image and psychological health than for adolescent carers with a chronically ill/physically disabled parent.

Pearson's Product Moment Correlation Coefficient (Pearson's  $r$ ) was used to investigate the existence of a relationship between psychological well-being and perceived interference of the care role.

A brief descriptive summary of the three care task areas identified by the 'job description' measure, Questionnaire (5), was conducted. Finally, semi-structured interview material (n=7) was analysed according to individual, family and service-based categories.

**3.4 Between-Group Analyses**

**Section 1**

Tests of statistical difference between the adolescent carer group and non-carers were conducted in order to test the following hypotheses.

**Self-Image**

**Hypothesis 1 : Adolescents with a care responsibility for a parent will have lower overall self-image than adolescents without a care role.**

Independent sample t-tests were conducted on the total scores of the self-image measure across the two groups. Table 9 highlights the data from this analysis. A key for abbreviated terms used is provided below each table.

Table 9: Total score summary statistics for the OSIQ-R (Short Form)

		Mean	S.D	Range	t
<b>OSIQ-R</b>	<b>Carer Grp (N=61)</b>	141.80	36.63	80-228	
<b>Total Score</b>	<b>Comparison Grp (N=60)</b>	131.08	26.33	83-191	1.85 *

Key: OSIQ-R: Offer Self-Image Questionnaire Revised (Short Form)  
 \*  $p < .05$

Maximum total scores on the OSIQ-R (Short Form: Offer *et al.*, 1993) are 324. The group mean scores were higher within the adolescent carer group than the non-carer sample, in addition to them obtaining a greater range of scores. T-test analyses confirmed that the adolescent carers were found to have significantly higher scores, indicating poorer overall self-image, than the adolescent comparison group who were not meeting this care responsibility (See Table 9).

Given the OSIQ-R also measures self-image in multiple areas, two component scales were specified for further analysis of Hypothesis One. These stated that when compared with the adolescent comparison group, adolescent carers would:

- a) Express poorer family relationships and emotional atmosphere in the home  
(Family Functioning Scale)
  
- b) Report less well-developed interpersonal relationships and friendships  
(Social Functioning Scale)

Independent sample t-tests revealed highly significant differences for family and social functioning between the two groups (see Table 10). Adolescent carers held more negative feelings about getting along well with their parents and the emotional atmosphere within the home than did the comparison group ( $t = 2.38, p < .01$ ). A lower mean score for adolescents without a care role indicated a better functioning within the family according to support, appropriate separation and positive alliance.

Adolescent carers were also found to experience poorer social functioning in interpersonal relationships and friendships than adolescents without a care role ( $t = 3.89, p < .001$ ).

#### Further Analyses of the OSIQ-R

The eight remaining component self-image scales were analysed to assess whether additional domains of self-image were different between the two groups. Independent t-tests were conducted for every scale except Mental Health and Self-Confidence. These scales did not satisfy conditions for parametric statistics and therefore a Mann-Whitney U test of two unrelated samples was conducted.

The summary statistics for scores that achieved significance on these scales are represented in Table 10.

Table 10: Differences in self-image component scales between adolescent carers and non-carers

OSIQ-R Sub-Scale Item	Grp 1 (Carers) Grp 2 (Comparison)	Mean	S.D	Range	t
<b>Family Function</b>	Grp 1 N=61	27.26	9.91	11-51	2.38 **
	Grp 2 N=60	23.50	7.26	11-41	
<b>Social Function</b>	Grp 1 N=61	16.56	6.07	6-32	3.89***
	Grp 2 N=60	12.57	5.16	6-28	
<b>Emotional Tone</b>	Grp 1 N= 61	14.38	6.43	5-29	2.15*
	2 N= 60	12.15	4.83	5-24	
<b>Impulse Control</b>	Grp 1 N= 61	13.66	4.55	6-30	0.854 NS
	2 N= 60	13.52	3.96	6-24	
<b>Mental Health</b>	Grp 1 N= 61	13.95	5.82	6-29	Z 2.562**
	2 N= 60	11.33	4.45	5-24	
<b>Vocational Attitudes</b>	Grp 1 N= 61	10.10	4.10	5-24	- 2.219*
	2 N= 60	11.68	3.75	6-22	
<b>Self Confidence</b>	Grp 1 N= 61	15.03	13.19	6-43	Z 0.282 NS
	2 N= 60	13.65	3.73	5-25	
<b>Self Reliance</b>	Grp 1 N= 61	12.00	3.51	5-23	-1.803*
	2 N= 60	13.15	3.50	5-23	
<b>Body Image</b>	Grp 1 N= 61	12.54	4.55	5-24	2.217*
	2 N= 60	10.73	4.41	4-22	
<b>Idealism</b>	Grp 1 N= 61	8.30	2.54	3-15	-3.061**
	2 N= 60	9.80	2.86	3-17	

\* $p < .05$ , \*\*  $p < .01$ , \*\*\*  $p < .001$  NS: Non-significant

Key: Grp 1: Carer Sample  
Grp 2: Non-Carer Sample

Adolescent carers were found to differ significantly on the multiple areas of self-image shown in Table 10. Higher scores for Emotional Tone and Mental Health were indicative of poorer affective state and greater emotional fluctuation than for adolescent non-carers. A significantly greater degree of symptoms perceived as cognitively and interpersonally disruptive to mental health were found for adolescent carers ( $z = 2.562$ ,  $p < .01$ ). Adolescents with a care responsibility also reported less adjustment to their body image than the comparison group, assessing themselves as unattractive, weak or in some way physically unacceptable ( $t = 2.217$ ,  $p < .05$ ).

Interestingly, converse significant findings were found on self-image scales measuring confidence in planning a future vocation, self-reliance and willingness to help other people. Adolescents caring for a parent were found to be significantly different to young people without a care responsibility according to:

- (i) A greater orientation towards a future vocation ( $t = -2.219, p < .05$ )
- (ii) Achievement of greater self-reliance and ability to cope with themselves and their environment ( $t = -1.803, p < .05$ )
- (iii) A deeper concern of social problems and motivation to help others (non ego-centric) ( $t = -3.061, p < .01$ )

No significant differences were found between the two adolescent groups on self-image scales of Self-Confidence or managing and tolerating frustration (Impulse Control).

**Psychological Well-being**

**Hypothesis 2: Adolescents with a care role for a parent with a chronic physical illness/disability or mental health problem will experience poorer psychological well-being than adolescents who do not provide parental care.**

Psychological well-being was measured according to depression and anxiety symptomatology. Summary statistics for both adolescent groups on the Birleson Depression Scale (BDS) and The Spence Children’s Anxiety Scale (SCAS) are shown in Table 11.

**Table 11: Significant differences in Depression and Anxiety Scores for adolescent carers and adolescents without a care role**

Outcome Variable		Mean	S.D	Range (Max Score)	t
<b>BDS</b>	Carer Grp N = 61	11.67	6.29	2-30 36	3.384 **
	Non-Carer Grp 60	8.18	4.96	1-21	
<b>SCAS</b>	Carer Grp 61	33.41	19.79	5-85 114	2.175 *
	Non-Carer Grp 60	26.43	15.22	10-84	

\*  $p < .05$ , \*\*  $p < .001$

## **Depression**

High scores on the BDS (maximum 36) are indicative of a greater degree of depressive symptomatology. Neither group obtained scores that were indicative of clinical depression although cut off scores for the measure remain ambiguous. No “normal” child was found to score above 11, and only those diagnosed with clinical depression scored above 17 in the small standardisation study (Birleson, 1981).

A mean score of 11.67 (range 2-30) signified that adolescent carers reported moderately higher levels of depression in comparison to non-carers. Independent sample t-test analysis confirmed a significant difference between reported levels of depression for the two adolescent groups ( $t = 3.384, p < .001$ ).

A higher degree of depressive feelings were reported by adolescent carers in this study when compared with normative data from adolescent participants in a study of 250 secondary school children by Yule (1992). Yule (1992) also found girls reported more depressive feelings than boys. This gender difference was found to be significant within the current study, with girls ( $n=67$ ) obtaining higher scores than boys ( $n=54$ ), regardless of age ( $t = -2.426, p < .05$ ). The mean values were 8.52 (male carers) and 11.09 (female carers).

## **Anxiety**

Adolescent carers were found to report more anxiety than non-carers. The discrepancy in their mean scores of 33.41 and 26.43 respectively was highly significant ( $t = 2.175, p < .05$ ). Mean scores for clinically anxious children, aged between 8 and 13 years was 42.48 in the standardisation study by Spence (1997). However, there is a lack of clinical norms for an adolescent population.

The SCAS also measures subtypes of anxiety problems, as classified by DSM IV (APA, 1994). Two of these anxiety subtypes were identified for further analysis of Hypothesis Two. This was conducted in order to establish whether, when compared with teenagers without a care role, adolescent carers experienced specific sub-categories of anxiety as more problematic.

It was predicted that carers would:

- 1) Express higher ratings of social phobia
- 2) Experience greater separation anxiety from their family

One-tailed tests were employed as the aforementioned hypotheses predicted the direction of difference. Adolescent carers were not found to significantly differ in relation to levels of social phobia when compared with their peers without a care role ( $t = 1.402, p > .05$ ). The mean scores were 7.02 (carers) and 6.07 (comparison group).

A Mann-Whitney U test for unrelated samples was conducted for the separation anxiety sub-scale as it failed to meet conditions for parametric statistical analysis. Adolescents who were caring for a parent reported higher levels of separation anxiety from family in comparison to the teenagers unfamiliar with this responsibility (mean scores 4.75 and 2.82 respectively). The difference was statistically significant ( $Z = -3.049, p < .001$ ).

#### Further Analyses of the SCAS

Additional analyses were conducted to establish whether further anxiety subtypes could be statistically differentiated between the two adolescent populations. Summary statistics for the scales where this significance was confirmed are represented in Table 12.

Table 12: Summary statistics for additional SCAS anxiety sub-scales that were significantly different between the two adolescent groups

Anxiety Sub-scale		N	Mean	Range (Max Score)	t
Obsessive- Compulsive Disorder	Carer Grp	61	5.23	0-15	1.850*
	Comparison Grp	60	4.05	0-17 18	
Panic/Agoraphobia	Carer Grp	61	5.28	0-23	Z = -1.85*
	Comparison Grp	60	3.53	0-18 27	

\*  $p < .05$

Adolescents with a care responsibility were significantly more likely to report higher levels of obsessive-compulsive anxiety and panic/agoraphobia. No significant differences were found between carers and comparison adolescents on the Physical Injury Fears (mean scores 4.15 and 3.87 respectively) and Generalised Anxiety Disorder anxiety subtypes (mean scores 6.97 and 6.13 respectively).

### **3.5 Tests of Statistical Difference between Carer Groups**

#### **Section 2**

Adolescent caregivers were categorised into two groups according to whether their parents were primarily experiencing a chronic physical illness/disability or a mental health problem. Between-group comparisons of psychological health were conducted using one tailed, independent sample t-tests.

**Hypothesis 3: Adolescents caring for a parent with mental health problems will have poorer psychological health than those caring for a parent with a physical illness or disability.**

Table 13 highlights the summary statistics following analysis.

Table 13: Depression and Anxiety Scores for Carer Groups

		N	Mean	S.D	Range (Max score)	t
BDS	Grp 1 PD/CI	34	10.18	5.28	2-28 36	-2.144*
	Grp 2 MH	27	13.56	7.03	4-30	
SCAS	Grp 1 PD/CI	34	33.50	20.94	5-78 114	0.04 NS
	Grp 2 MH	27	33.30	18.64	5-85	

\*  $p < .05$

**Key**

PD/CI - Care role for parent with physical disability/chronic illness

MH - Care role for parent with a mental health problem

NS - Non-significant

### **Depression**

The mean depression score for adolescents with a care role for a parent with a chronic mental health problem was moderately higher than those caring for a parent with a physical disability or chronic illness. Their range of scores was similar. The analysis indicated that the difference in reported depressive feelings was statistically significant ( $t = -2.144$ ,  $p < .05$ ).

### **Anxiety**

Differences in levels of reported anxiety were not statistically significant between adolescents offering care in the context of a mental health problem in comparison to adolescents caring for a parent with a physical disability or illness. Thus, the null hypothesis that there will be no difference in anxiety between the two types of carer groups cannot be rejected.

In addition, no significant differences were observed between the two carer groups on the six subtypes of anxiety problems, as measured by the SCAS (Spence, 1994). An unexpected finding revealed that adolescents with a care responsibility for a parent with a mental health problem had significantly poorer overall self-image than adolescent carers in the context of a physical disability or chronic illness ( $t = -2.108$ ,  $p < .05$ ). The mean scores were 133.24 (physical disability carers) and 152.59 (mental health carers).

### **Gender related Differences**

Male carers consistently obtained slightly higher mean scores than female carers across the ten component self-image scales on the OSIQ-R (Short Form: Offer, 1993). This gender difference was not found to be significant.

Female carers were found to have higher mean scores than male carers for psychological health, as measured by the BDS and the SCAS. This was found to be significant for levels of reported overall anxiety ( $t = -2.466$ ,  $p < .01$ ) and for the social phobia and generalised anxiety sub-scales. No significant differences were found between the genders for level of depression.

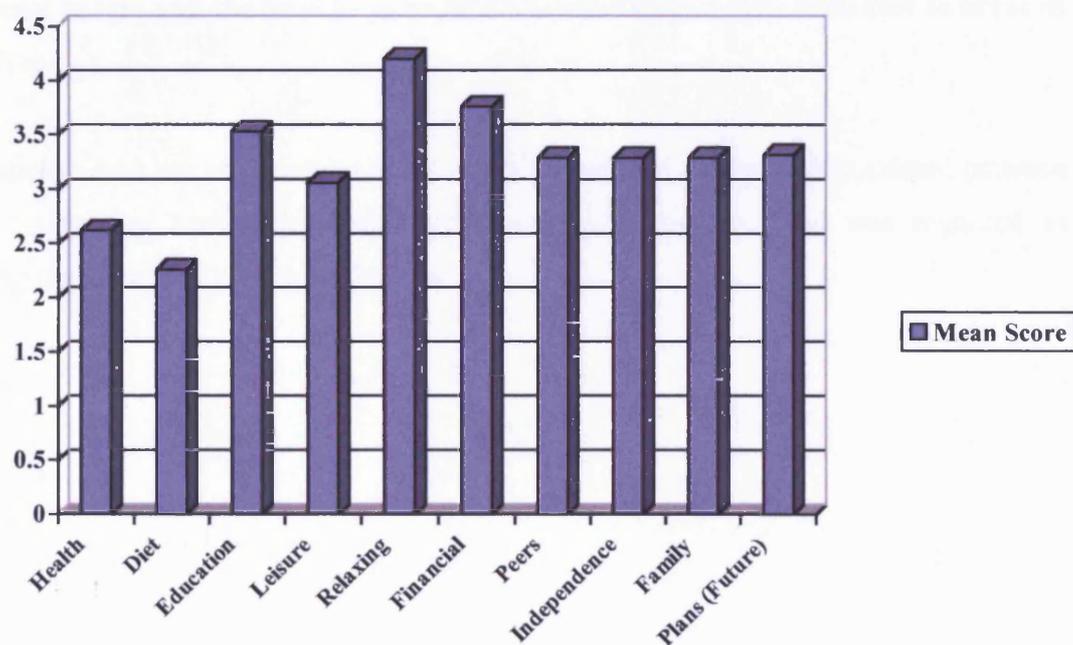
### Analysis of Perceived Intrusiveness of Care Role

The adolescent carer cohort (n=61) completed an additional measure, The Care-giving Intrusiveness Rating Scale (CIRS). The CIRS examined the level of perceived interference that the role of care-giver had upon ten aspects of life, deemed important for quality of life (Flanagan, 1978). Analyses of the scale highlighted that conditions for parametric tests were not satisfied and therefore non-parametric statistics were conducted.

The mean figures for the total carer sample (n=61) were calculated to examine how adolescent carers considered their care role to affect areas like friendships, school work, relaxing and making plans for the future.

Scores on each scale ranged from 1 'interferes very little' to 7 'interferes very much'. The maximum score achievable on the scale is 70 and 7 on each item. Adolescent carers obtained a mean score of 32.6 on the CIRS total score, indicating that the care role was perceived as moderately intrusive to areas of life when these were accumulated. The mean scores for the separate CIRS scales are highlighted in Figure 5.

Figure 5: Mean Scores for Areas of Life Perceived to be affected by Carer Role (CIRS)



## ***Results***

Areas perceived as the most intruded upon on account of the care role were relaxing (4.11), finances (3.59) and school and college work (3.51). Interference with health (2.59) and diet (2.29) were the least affected.

Further analyses were carried out to examine whether caring for a parent with a mental health problem was perceived to be more or less intrusive to areas of life than having a care role within the context of parental physical disability or chronic illness.

Mann-Whitney U tests for unrelated samples were conducted. There were no significant differences between the two carer groups (mental health vs physical disability/illness) on any of the carer intrusiveness items or for the total scale score. Both care groups, regardless of parental condition, found the role interfered most with their ability to relax. The second highest areas affected by having a care role were sports and hobbies (parents with a mental health problem) and finances (parents with a physical disability/chronic illness). Common to both groups, interference with school and college work was the third area of life affected most strongly by having a care role.

No significant differences were found between male and female carers according to how much the care role affected the ten areas of their life ( $t = 0.350, p > .05$ ).

**Hypothesis 4: There will be a correlation between the psychological health of adolescent carers and the level of perceived intrusiveness of their care role to areas of their lives.**

Correlational analyses were conducted to examine whether a relationship existed between reported levels of anxiety/depression and how much the care role was regarded as intruding upon areas of life for adolescents.

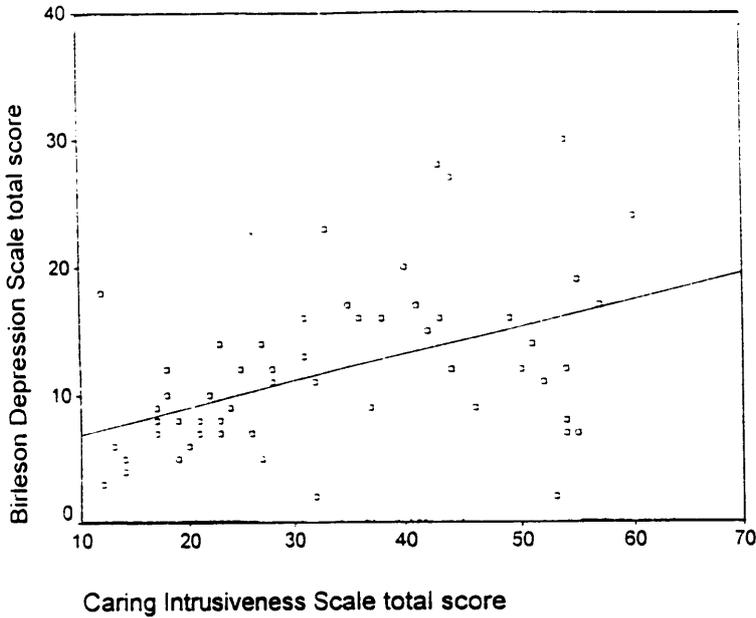


Figure 6a: Scattergram to show the relationship between scores on the BDS and the CIRS

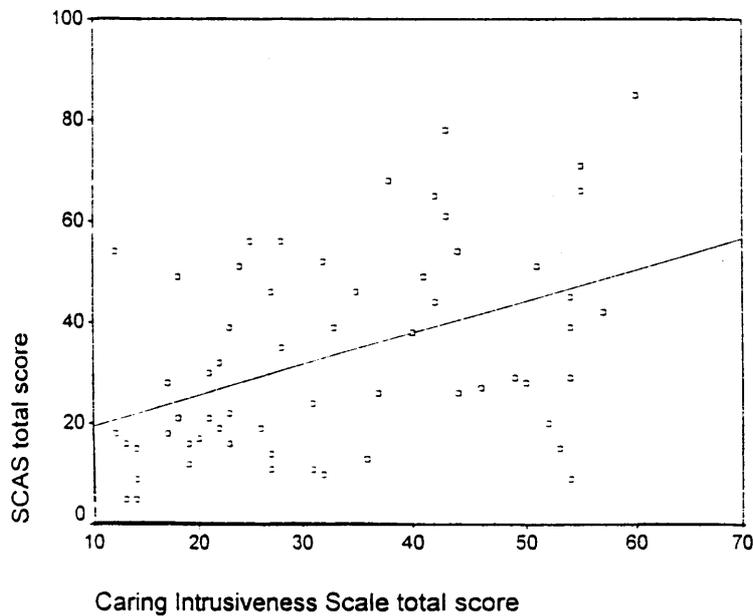


Figure 6b: Scattergram to show the relationship between scores on the SCAS and the CIRS

Levels of depression and the intrusion of the care role upon areas of life measured by the CIRS were highly correlated ( $r = 0.479, p < .01$ ). Anxiety in adolescent carers was also found to be highly correlated with care role intrusiveness ( $r = 0.448, p < .01$ ). This suggests that there is a relationship between psychological health in adolescent carers and

the extent to which caring for a parent is perceived to interfere with areas of their own life, such as relaxing, school work and making plans for the future. An adolescent who perceives the role to be intrusive is likely therefore to have associated high levels of depression and anxiety. However, from this relationship, it is not possible to infer causality.

Further analyses indicated that there was a strong positive correlation between self-image and depression ( $r = 0.751, p < .01$ ). A positive correlation was also found between self-image and anxiety ( $r = 0.537, p < .01$ ). Again, this association between poor self-image and higher levels of depression or anxiety cannot be taken as an indicator that one causes the other.

### **3.6 SEMI-STRUCTURED INTERVIEWS**

The predominant themes arising from the seven interviews conducted will be presented separately. Demographic data for the interview sample is represented in Table 15, Appendix 8a. Transcripts of the interviews are included as Appendix 8b.

#### **1. *Parent Supported***

Six of the seven interviewees were involved in providing care for their mothers. This finding is corroborated within the literature (Page, 1988). One female caring for her father with multiple sclerosis had significant help from her mother, which, according to Deardon and Becker (1995), is a situation more likely to occur in the event of a father's illness or disability.

Four adolescents were involved in the care of a parent with a physical disability and, in one case, co-existence of a mental health problem. The remaining three carers helped to support parents with chronic mental health problems.

Three interviewees were involved in significant levels of sibling care, in addition to supporting a parent. This is consistent with previous findings within the literature (Aldridge & Becker, 1993).

2. *Evolution and duration of the Care Role*

The duration of care roles ranged from two to eight years. Some adolescents began to be accustomed to care roles from the age of six or seven years. All but one interviewee had experienced a gradual increase in care tasks and, arguably, additional responsibility. This did not necessarily occur in conjunction with a decline in their parent's health. One male carer experienced a more sudden introduction to caring as a function of his mother's condition. He shared care responsibilities with his sister, negotiated between them according to gender stereotypes.

3. *Role Descriptions*

The physically demanding nature of the role ("hard", "tiring", "requires a lot of effort and thought") was consistently reported. Feelings of uncertainty, fear and loneliness were also expressed. Others considered the role to invoke feelings of frustration, fear and irritation. Additional comments included experiencing sadness, occasional happiness, and a sense of missing out on friendships and school-life. Three adolescents consistently selected negative descriptions. One adolescent expressed anger at the social assumptions made about the burden of being a young carer.

For the other participants (n=3) the role invoked a range of conflicting negative and positive emotions. Despite the negative feelings, one interviewee regarded the role as important. The implications of this emotional conflict will be considered in the discussion.

4. *Relationship with Parent Cared For*

Conflicting feelings of having a good and close relationship, in conjunction with feelings of anger, sadness, upset, and stress were expressed. This is consistent with feelings held about the role itself, as described above. One male considered that the relationship with his ill parent involved a lot of fighting, anger and upset. A further adolescent felt that he had a "stormy" and frequently changing relationship.

5. *Advantages/Benefits of Being a Carer*

Prominent themes included the improved quality of relationship with their ill or disabled parent as a function of being a young carer. Several considered that the role had drawn them closer to their parent and given them time together. A further theme (n=2) concerned a perceived increase in their level of maturity, ability to problem-solve and have empathy with others enduring health problems. Being prepared to manage future situations and learn how to deal with different challenges were provided as examples. One interviewee considered that the role lacked any advantages.

6. *Attribution of Difference to Peer Group*

All interviewees considered themselves to be different to their peers on account of numerous care-giving factors. Consistently, care roles were reported to create isolation, restrictions in friendships, leisure, and after school activities. One male indicated that participation with friends, through inviting them to telephone or call at his house was restricted in order to minimise disruption to his parent.

A different form of isolation emerged, such as fear of being ridiculed or feeling different because of the secrecy of the care role. The sense of reaching earlier maturation, as previously reported, could also be regarded as a contributory factor to isolation from peers.

7. *Perceived Lifestyle Without Care Role*

The opportunity to socialise and maintain friendships was consistently reported as an anticipated fundamental change should the care role end. One male carer of eight years described a perceived increase in choice, time, freedom and reduced responsibility without his role. However, this quite clearly created a conflict for several adolescents. Feelings of worry and guilt in seeking independence and increased opportunities were expressed.

One male was less able to tolerate this imaginary alternative lifestyle, given that he would need to know that care was being provided “properly”. A second interviewee was able to perceive a reduction in responsibility but did not wish to resume his role entirely. This

finding is important to highlight given that there is little attention to this within existing literature.

#### 8. Separation Anxiety

Distance from a parent, such as attending school or enjoying outside activities, caused worry and anxiety (n= 6). This primarily related to anticipatory harm, recurrence of illness or concern about who would be with their parent in their absence. Clearly, the presence of another adult, either the remaining parent or friend, significantly reduced their worry. The implications of this for services, not only in supporting the care receiver but also in enabling young people to concentrate at school or enjoy activities will later be discussed.

One male regarded the distance caused by attending school as escapism from thoughts and responsibilities created by his care role.

#### 9. Impact on School

Young carer responsibilities are frequently disruptive to school and academic life (Fox, 1995). Some level of disruption, in the form of absence, lateness, and concentration problems, was described by the present interview sample.

Prolonged absenteeism had occurred for one adolescent who remained at home to care for his mother during a period of ill health. Shorter absences were caused by being awake through the night due to parental illness or at times of hospitalisation. Intrusive, worrying thoughts affected concentration during lessons for two interviewees.

#### 10. Respite Activities

Activities such as listening to music, playing computer games and homework were enjoyed as a means of relinquishing their role for a short period of time. One male described the need to be in a different environment, away from home, in order to benefit from time off. One adolescent was unable to identify any activities that were enjoyable for him or provided him with a degree of respite.

11. *Future Aspirations/Career Path*

Most interviewees had considered what their future career might entail. Two adolescents were unable to imagine their future vocation. This appeared to relate to a difficulty in separating their future from the health of their parent. A description of rapid change and unpredictability in their present lifestyle was evidence of them being uncertain of their future situation.

12. *Perceived Future Care Role*

Uncertainty related to sudden health changes made this a difficult question to answer. Future parental health was intrinsically related to how the adolescents perceived their situation in the years ahead. All interviewees considered that they would still be involved as carers to their parent in the future, given the chronic nature of their condition. Three imagined themselves to be living at home in ten years. One described a probable decrease in role and care involvement on account of moving away from home.

13. *Ideal Future*

Two themes emerged regarding an idealised future. One concerned having the career of choice in later years. The second theme was illness oriented, considering that the best future would involve recovery of their mother and ill siblings. One male felt the ideal longer-term position would be for him to relinquish responsibility for his mother and for her to be responsible for him.

14. *Help From Outside Agencies in Alleviating Care Role*

Where help was being offered to the parent and/or carer, it was usually provided by a friend or relative of the family. This appeared to be rather irregular. One parent with a physical disability received a home carer service daily, excluding weekend help, for personal care and shopping needs. Three of the seven families did not receive any outside help, two of which contained adolescents with primary care responsibilities. Previous support from services such as social work or nursing input had terminated. One carer described social work support having been present for a time of crisis. The cost of having

to pay for care was provided as a reason for outside agency support not being available to this family.

15. *Recommendations For Improvements in Support*

Ambivalence about receiving additional help was reported by three carers due to them not being able to perceive how support would improve their situation. In part this was due to a concern that it might not be provided adequately. Several carers described that they would benefit from help with siblings, such as in the mornings before school or at bedtimes. One carer considered that a cleaner would reduce the strain upon his mother.

16. *Source*

Four interviewees preferred this help to be offered by someone already known to the family, such as a friend or relative. One stressed the need for trust, claiming that he lacked trust in outside agencies. Two adolescents considered help from someone unknown to the family, such as social services, as preferential.

17. *Positive and Negative Attribution of Young Carer Group*

The Carer Groups were considered to offer positive experiences for all interviewees. The time enabled them to make choices, such as going out, having fun and making friends. One considered that meeting people in the same situation was one important function of the Group. No one evaluated the Group negatively, which may have been as a result of the researcher being present.

A short evaluation of how the interview process was experienced is described by a number of interviewees and is presented at the end of individual transcripts (see Appendix 8b).

### **3.7 SUMMARY OF RESULTS OF STATISTICAL ANALYSES**

#### **Demographic Factors**

- The adolescent care group was heterogeneous, according to several socio-economic, demographic and care-related factors. In keeping with the literature, a higher percentage of female carers were present in the sample. This occurred without selecting for more female adolescents.
- Females, regardless of whether they were care-givers, were found to have significantly higher levels of anxiety than males. There were no gender-related differences on self-image or depressive symptoms.

#### **Between-Group Analyses: Carer Group and Comparison Group**

- The carer and comparison groups were discriminated according to perceived self-image. Compared to adolescents without a care role, care-givers had poorer overall self-image, social and family functioning. Additional areas of self-image were also found to differ. A number of these (vocational attitudes, self-reliance and motivation to help others) were significant in the direction of greater adjustment for adolescent carers when compared with adolescent without a care responsibility for a parent.
- There were no significant differences between the carer and the comparison groups on the dimensions of self-confidence or impulse control.
- Adolescents' reported levels of psychological well-being also differed between the groups. Carers displayed more depressive feelings and overall levels of anxiety than the comparison group. Separation anxiety was particularly pronounced in the carer population.

**Between-Group Analyses : Care Role (Mental Health vs Physical Disability/Illness)**

- Higher levels of depression were found amongst carers whose parents had a mental health problem as opposed to a physical disability or illness. This difference was not evident for anxiety.
- Overall self-image was different between the two adolescent care-giver groups. Teenagers with a care role for a parent with a mental health problem reported poorer mastery of self-image.
- Having a care role was found to be intrusive to other areas of the adolescent's lifestyle, regardless of parental condition. Areas that were most affected included being able to relax, finances, sports and hobbies and school or college work.
- A relationship was found between how intrusive the care role was perceived to be and how anxious and depressed the adolescent felt. This was regardless of whether the care responsibility was in the context of a physical disability/illness or mental health problem.

## **DISCUSSION**

The discussion will concern research findings that directly relate to the experimental hypotheses and those closely associated with them. Each hypothesis will initially be summarised, proceeding to a more detailed discussion of the major findings. Attention is given to the limitations of the study, as well as to its identifiable strengths. Finally, the theoretical and clinical implications of the research will be discussed.

### **4.1 Summary of Research Findings**

#### **Perceived Self-Image (Hypothesis 1)**

Based on the premise that adolescents with a care role for a disabled or ill parent experience adverse effects on their development, it was hypothesised that relationships and experiences that are critical to forming an identity and self-image in adolescence would be affected. Specifically, it was expected that adolescent carers would hold more negative views about themselves relative to adolescents without a care responsibility.

This difference was confirmed according to global self-image scores and on a number of several specific self-image domains. The most central findings according to Hypothesis 1 were that poorer scores on several specific aspects of self-image (e.g. family, social functioning, mental health) were prevalent for adolescent carers as predicted. However, three domains were perceived to be more *positive* for young people with a care role. Carers rated more highly on views about their own future vocation, having a concern for others (Idealism) and on their level of self-reliance. This result lends some support to a small body of literature that identified positive outcomes from meeting a young carer role, not least through the capacity for parent-child relationships to be enhanced (Beach, 1997). Responses from the interview material corroborate this for a number of adolescents.

Details of the major findings from Hypothesis 1 will be discussed following this initial summary.

### **Adolescence, Care-giving and Psychological Health (Hypothesis 2)**

The expected differences in psychological health (depression and anxiety) between adolescent carers and teenagers without a care role, predicted by Hypothesis 2, was confirmed. It would appear that being in the position of providing care to a disabled or ill parent in this sample had more of a detrimental effect on psychological well-being. This finding is supportive of speculations raised within the young carer literature (Meredith, 1991a).

It is important to reiterate that whilst feelings of depression were expressed by adolescents across both groups, the mean scores were not indicative of clinical depression. Finally, global anxiety ratings were higher amongst teenagers with a care role, as were a number of important sub-anxiety scales. Interestingly, carers were not more socially anxious or phobic, as might be expected from potentially restricted opportunities to socialize. However, separation anxiety was a factor in accounting for significant differences between the two adolescent groups.

Given this study appears to be the first to empirically measure psychological adjustment in adolescent carers, direct comparisons with other findings cannot be made. Discussion of these discrepancies in self-image and psychological health, according to relevant literature, will be addressed.

### **Psychological Health, Care Role and Parental Condition (Hypothesis 3)**

A further purpose of the current study was to determine whether psychological well-being (depression and anxiety) amongst adolescent carers could be differentiated according to parental condition. Clearly, this would have important clinical and service implications in terms of initial recognition and prevention, where previously this disparity may not have been considered. Furthermore, support services to alleviate potential distress may need to be resourced very differently according to whether a parent endures an intermittent mental health problem, or a more persistent, degenerative physical illness.

Care in the context of parental mental ill-health rather than physical illness/disability invoked significantly greater levels of depressive symptomatology amongst adolescents. No significant differences were observed according to reported anxiety.

This finding points to a potential vulnerability of individuals involved in the care of mental health problems, which has been noted in adult care-giving literature by several researchers (Judge, 1994; Lefley, 1996). A number of possible explanations for the discrepancy in feelings of depression between the two groups will be discussed relative to the wider literature.

#### **Perceived Caring Intrusiveness and Psychological Well-being (Hypothesis 4)**

The final hypothesis predicted that a relationship would exist between how intrusive the adolescents perceived their care role to be and their reported feelings of anxiety and depression. Firstly, young people did report this responsibility as disruptive to their continued involvement in valued activities and interests. Invariably, the extent of this interference, and the areas reported to be affected most strongly differed across the sample of carers.

As a group, the experience of a care role interfered most strongly with the adolescent's ability to relax. This was regardless of gender or parental condition. Additional aspects of life considered to be most affected were finances, participation in sports and hobbies, and interference with school and college work.

Finally, a relationship between carer intrusiveness and feelings of depression and anxiety was affirmed within the current study. Thus obtaining higher scores on the intrusiveness measure was likely to result in higher scores of psychological morbidity.

#### **Interpretation of Findings**

In seeking to draw the findings together, a number of pertinent issues that derive from the current study will be highlighted as they relate to existing literature. This will be

structured thematically rather than through detailed description according to each hypothesis. The sections will include: 1) Self-image: Care-giving, family and friendships 2) Impact of Care: Parental physical illness/disability or mental health needs and 3) Illness and disability in families: Care role intrusiveness.

#### **4.2 *Self-Image: Caregiving, Family and Friendships***

One of the most consistent themes to emerge from the present study suggests that adolescents, regardless of whether they had a care responsibility, were achieving mastery in certain areas of self-image whilst perceiving other areas to be less developed or even problematic. This supports the emphasis by contemporary researchers (Coleman 1993; Offer *et al.*, 1981; Rutter, 1989) upon adolescent development as a typically slow, steady process without excessive turmoil and emotional distress.

An important finding was that as a group, adolescents with a care role reported a greater degree of negative feelings about their family relationships and friendships. Taken together, negative views about *both* family and social environments were indicated. Drawing on existing literature, a number of explanations for the disparity between carers and teenagers without such family circumstances can be offered.

##### **4.2.1 Family Environment and Relationships**

Interdependent rather than detached relationships with parents are typically sought during adolescence (Youniss & Ketterlinus, 1987), where close ties are maintained yet the individuality of the young person is not threatened. According to the current study, poorer perceived family functioning amongst adolescent carers could be explained by a lack of ability to develop individuality on account of the care role. Where social relationships and interruptions to other areas of life prevail, as borne out by current research findings, developing a sense of oneself as different to other peers is likely to be more problematic. It could be suggested that carers' poorer views about the emotional atmosphere at home are consistent with the findings of Lefley (1996). She reported a higher prevalence of uncertainty and disruption of the home environment for some families living in the context of parental chronic mental health problems. Common to many young carers living in lone

parent families, absence of a second parent to help stabilize the environment and encourage outside activities might be a further reason for the perceived tension and poorer family relations. Additionally, the care role is often reluctantly inverted by parental illness, which may serve to reduce the sense of belonging and support available to the individual as a child in that family. This is consistent with the theory of role-reversal proposed by Zeanah, Mammen and Lieberman (1993), observed in children following sexual abuse (Levang, 1989) and parental divorce (Johnston, Gonzalez, & Campbell, 1985).

It is reasonable to hypothesise that carers had learned to internalise and repress negative feelings towards the ill or disabled parent as a consequence of the will to protect them and avoid feelings of guilt. This finding is consistent with expressed guilt about feeling critical of a parent amongst adolescents whose parent had a terminal illness (Christ, Siegel, & Sperber, 1994). Interview descriptions of the adolescent's role and relationship with the parent corroborated the conflict of positive and negative emotions felt by the teenagers. The experience of being a young carer was described by more than one respondent to invoke feelings of anger, frustration, and fatigue. If expression of these emotions, regarded as an integral part of adolescent adaptation towards adulthood (Coleman, 1980), was not possible with family or peers, this may be one potential reason for the increased depressed feelings amongst teenage carers (Hypothesis 2). Thus the protection against stressful events, offered through the availability of another person who is responsive to an individual's needs (Cohen & Wills, 1985) could be severely disrupted. Commitment to care tasks, striving to protect parents against a conflict of emotions, and poor peer relationships may be very strong indicators of the perceived unavailability of others and thus higher depression scores amongst adolescent carers in this study.

Drawing upon Hypothesis 2, poorer psychological health amongst adolescent carers could account for the perceived negative views of family and peer relationships. A reciprocal relationship, where poorer experiences with peers or family members lead to increased depression, and greater depression increases the likelihood of rejection by peers (Vernberg, 1990) or tension at home, could be inferred. This may be exacerbated amongst adolescents who report the care role to be intrusive to other areas of life (Hypothesis 4). It is beyond the scope of the current study to infer a causal relationship, yet the complexity of these factors indicates a need for further investigation.

An important finding for future research concerned greater levels of separation anxiety amongst carers (Hypothesis 2), during normative periods of schooling or social activities. This lends support to the findings of Kashani, Horowitz and Reid (1985) of children vulnerable to separation anxiety when their parent had unipolar depression. Anxieties caused by leaving the parent may be an important indicator of viewing relationships at home as less harmonious (Hypothesis 1). The need to recognize that the subjective, emotional aspects of the care role may often be more pervasive for carers than the physical input of time or task is substantiated by the current findings. The assumption that a care role is defined by tasks and level of responsibility, without recognising the emotional commitment to this position, is a fundamental oversight within existing clinical and theoretical carer literature.

#### 4.2.2 Peer Groups: Popularity and Belonging

It is conceivable that the tendency to also view friendships and social relationships less positively than peers is related to family circumstances of illness and disability. Developing a sense of belonging and popularity within an adolescent peer group relies, not least, on investing the time to participate. Confirmation of the predicted poorer social functioning amongst caregivers was not surprising given that opportunities to socialise or join in after school activities are cited as being frequently disrupted due to care responsibilities (Fox, 1995, 1998). Scores were indicative of adolescent carers feeling lonely and less popular relative to other teenagers in the study.

Performance in social situations is important during adolescence (Kirchler, 1991; Newman & Newman, 1976). Individuals with low expectations of being able to form relationships, perhaps through previous experiences of being excluded or bullied, expect others to lack understanding of their problems and may actually avoid potential sources of support (Brewin, 1988). Young carer literature corroborates this active avoidance by childhood carers of confiding in a friend or teacher, assuming that they will not understand or be supportive of their position (Aldridge & Becker, 1993b). The fear of professional intervention and potential breakdown of their family also often powerfully maintains secrecy of their role.

In addition to these explanations, preliminary evidence suggested that carers perceive themselves to be 'different' relative to age-related peers. Adolescents with a care role may well have less in common with teenagers who often have the practical advantage of time to enjoy popular media and leisure. It is conceivable that the *meaning* of friendships with peers who are not living in the context of parental illness may be fundamentally different and less intimate. The experience of a parental health problem, by the nature of its course, may reduce the sense of control and authority of a parent and place children in a position of needing to problem-solve or manage situations outside the experiences of a majority of young people. Barnett and Parker (1998) refer to this as 'pseudo-maturity', a concept that is not exclusive to childhood carers.

It is plausible that perceived difference to peers, in addition to fewer opportunities to socialize and to be aware of popular media, are contributory factors in setting carers apart from other teenagers. This is consistent with a number of descriptions given in interview. Moreover, a recent survey raising awareness about the prevalence rates of bullying and physical violence towards young people with a care role by other children (The Princess Royal Trust, 1999) may explain one of the ways in which this perceived difference is made manifest to others. Professionals who work with young people meeting care needs may find this attributional difference to age-related peers an important determinant of psychosocial health. The clinical implications of this finding will be discussed.

The final hypothesis, concerned with the degree to which care-giving was considered to intrude upon other areas of a teenager's life, offers further explanation of why relationships with friends and the emotional home atmosphere may be viewed negatively. Interference with relaxation, perhaps on account of intrusive worry during periods of separation from a parent, disruption to peer group identity and school work may lead some carers to feel more negative about these core relationships.

It should not be assumed that having a care role did not have some favorable outcomes. Evidence was found to validate the findings of Mahon and Higgins (1995) in acknowledging that many young carers feel closer to the parent for whom they offer care. This exemplifies evidence from parental descriptions of being closer to their child on account of an established care relationship (Aldridge & Becker, 1994). Descriptions of being closer to a parent, being able to empathize with others and rely upon oneself to

manage difficult situations were offered by a number of participants. Advocates of the child-centred perspective (Aldridge & Becker 1991; Meredith, 1992a) may refute that self-reliance is a positive outcome from meeting a care responsibility that places the child in a premature role. There remains a paucity of research into the favorable outcomes of having a care role beyond brief acknowledgement of its potential to bestow advantages as well as the more evident disadvantages.

#### 4.2.3 Gender Differences

The present research did not support a body of literature that identifies gender differences in relation to self-image. Female adolescents were not higher achievers according to interpersonal relationships or a more developed sense of self (Patterson, Sochting, & Marcia, 1992), and males showed no evidence of greater commitment to vocation and ideology (Josephs, Markus, & Tafarodi, 1992). Clearly, age is a central determinant of self-image development, with much of the work on achieving a sense of self proceeding from later adolescence into early adulthood (Adams, Gullotta, & Montemayor, 1992). The current study did not control for age-related differences.

Further research is needed into the effects, according to gender, of having a care role. Given that females commit to interpersonal relationships as a means of defining who they are, what implications ensue for adolescent girls, whose relationships are disrupted by the nature of a care role? Would the findings of raised levels of anxiety and social phobia within the current findings amongst female carers be corroborated within future studies? Moreover, if males conform to masculine expectations, how much more difficult is it for male carers to have positive masculine peer relationships in the event of providing intimate and personal care, such as bathing and dressing, for their mothers?

The above findings highlight at least three clinically important areas for further investigation. Firstly, chronic separation anxiety during adolescence may have important detrimental effects upon current and later adjustment in adulthood. Clinical services need to be adept at recognising and seeking to reduce, if not alleviate, excessive anxiety amongst young carers during normative separation from an ill or disabled parent. Implementing additional hours of voluntary care within the family home during these periods, negotiated with parent and adolescent, may work in conjunction with this.

Secondly, the potential to have to repress feelings of anger and frustration, as a protective mechanism for the parent, may have important clinical outcomes in terms of poor affect, guilt and withdrawal. Finally, perceived difference to peers, exacerbated by the responsibilities of a care role, have important implications for self-esteem, suicidal ideation (Adams, Overholser, & Lehnert, 1994) and future social relationships.

#### ***4.3 Impact of Care: Parental Physical illness or Disability/Mental Health Needs***

The findings support the concern that an adolescent care role can create risk to psychological health (Aldridge & Becker, 1995; Fallon, 1990). Care in the context of mental ill-health invoked significantly greater levels of depressive symptomatology amongst adolescents (Hypothesis 3). This discrepancy was not evident for reported anxiety. It is important to reiterate that a higher level of co-morbidity of parental condition is likely to have been reported, had the study not required the dichotomous differentiation between physical illness/disability or mental ill-health to be made. This potential co-morbidity needs to be borne in mind when considering the findings for adolescents whose parents had a physical illness or disability. Unfortunately, empirical studies have yet to address potential differences upon carers relative to mental health or physical health care needs. Thus, direct comparisons with other populations of young carers cannot be made.

The study offers some support for the assertion that the family environment can often be more erratic and unpredictable in the presence of parental mental ill-health (Lefley, 1996). This is particularly likely in the presence of violence within the home or the increased prevalence of parental suicide attempts. If the environment is experienced as more inconsistent for some families, how much more difficult is it for adolescent carers, for whom the possibility of minimizing this uncertainty through socializing or having a second adult in the home is often restricted?

In accordance with previous literature, albeit with a lack of emphasis on being a childhood carer, an important determinant of child mental health relates to associated parental mental health (Puzynska, Grzegorzczak, & Niedzielska, 1994; Rutter, 1966). Parental adjustment to their own illness or disability cannot be ignored as an important contributory factor to adaptation in other family members. Adolescent carers, drawn closer to their parent's

condition through their care role, may well experience parental fears, uncertainty of prognosis and fluctuations in mood that frequently accompany illness and disability. The current study lends some support to the notion that adolescents living and caring in the context of these family circumstances were vulnerable to their parent's higher levels of psychopathology. This intrinsic relationship between parental mental health and consequent negative emotions for the carer was supported by a number of interview respondents.

Heightened feelings of depression amongst carers of parents with a mental health problem may be explained in terms of the nature of the care responsibilities. Their role is likely to be characterised by uncertainties and transient periods of intensive involvement, followed by more stable periods of low intensity input. A qualitatively different care role can be assumed for these adolescents than when a parent has a more constant course illness, albeit often deteriorating, where responsibilities often predictably and gradually intensify over time. Interview responses were consistent with this presentation. Whilst many families experience frequent change and unpredictability in their relationships that are commonly associated with normative adolescent individuation, these changes are unlikely to be of the kind experienced by families affected by a chronic illness.

Differences in service delivery could be one important determinant of the disparate scores on depressive feelings by carers, according to parental condition. Resources and services for relapsing and unpredictable mental health problems may be less regular and consistent than those when a functional disability is implicated. This interpretation could account for the level of perceived intrusiveness expressed by carers (Hypothesis 4). Whilst many families were receiving some form of support from services (58%), there were a number of families where intervention was offered only at times of crisis, appeared dependent upon limited finances of the family, or was found to be completely absent.

Finally, there is evidence of the embarrassment and stigma of a parental mental health problem, such as schizophrenia or chronic depression, amongst children and adolescents (Lefley, 1996). This may serve to silence young carers further, who, through fear of ridicule, may resist seeking social support to preserve their own emotional health.

#### **4.4 *Illness and Disability in Families: Care Role Intrusiveness***

This study was the first to quantify how, within the family circumstances of illness or disability, the adolescent care-giver perceived the intrusiveness of having a care role. Theoretically, it is an important concept that requires further research. Being a carer introduced conflict for many adolescents who withheld or curtailed participation in activities, deemed important to quality of life, in order that priority could be given to other aspects of need in the family.

The notion of “silent curfew”, a concept developed by Aldridge and Becker (1993c) to refer to imposed restrictions, so that when young people do go out, they often have to return early, was supported by results and observations made by the researcher during the study. Activities were curtailed for some teenagers, whose recreation appeared to be regulated by parental needs. It is important to highlight however that intrusiveness was not excessive for a number of young people who enjoyed outside activities regardless of family circumstances. Thus, a significant minority of care-givers might be those most in need of recognition.

Semi-structured interviews provided a good indicator of how the adolescent regarded their position by requiring them to imagine how life would be without a care role. Interestingly, not every respondent could anticipate this lifestyle, nor did they wish to. However, others consistently reported that they would be involved in recreational and leisure activities with friends. This provides a further example of how heterogeneous young carers are in appraising their position. Clearly, carers can, and do, experience both losses and gains associated with their care-giving role.

##### **4.4.1 Impact upon Education**

A fundamental area of disruption to adolescent development and achievement concerned scholastic performance. Semi-structured interview responses were consistent with this finding, highlighting problematic periods of poor concentration or low attendance arising from meeting a care responsibility. Given that academic success and achievement has been consistently reported to be positively related to self-esteem (Miner, 1991), it could be

postulated that interruptions to school attendance and homework creates a sense of under-achievement and poor self-image (Hypothesis 1).

Disruption to academic attendance and performance validates the findings of Page (1988) and Fox (1995). Both authors have identified difficulties in school as one of the most salient outcomes for young carers. Punishment or ridicule for late attendance or poor quality work is likely to exacerbate attributions of difference to peers, as identified in Hypothesis 1. Moreover, once this difference has been publicly highlighted, this may well induce vulnerability to teasing and bullying amongst peers.

The prevalence of misunderstanding and neglecting the impact of a care role upon school life has begun to be addressed through awareness-raising initiatives by a number of Young Carer Organisations and a recent Government Green Paper “Teachers-Meeting the Challenge of Change!” (Department of Health, 1999). A number of issues within academic settings need to be prioritised if the young carer is to maximize on their school environment. Further work is needed in sensitively raising the profile of childhood carers amongst teaching staff as a prerequisite for offering discrete and appropriate support if required. Acknowledging their existence should not detract from maintaining an atmosphere that is as normative for carers and staff as possible. Collaboration with parents, who may be frequently unable to attend parent’s evenings due to ill-health or disabled access difficulties, is an integral aspect of offering full family support.

Whilst it cannot be elaborated upon from the current findings, recognition of the views of the parent in receipt of care needs to be highlighted in future studies. One study by Newsom and Schulz (1998) highlights the intrusiveness and discontent experienced by adults on account of having to be in the position of *receiving* care. It is likely that many parents will attempt to minimize the impact of the care role for their offspring in order that developmental tasks, such as friendships and school attendance can be prioritized for their children. It is all too easy to forget the position of the parent and this needs to be made explicit throughout future studies.

Regardless of gender or parental condition, relaxation was found to be the most affected area of life. This finding reiterates not only that practical, domestic tasks may prevent relaxation, but could also incorporate findings related to separation anxiety, as previously

highlighted in Hypothesis 2. An inability to relax may be exacerbated by intrusive worry during periods of separation from a parent. Several carers reported sleep disruption, an item not measured by the scale, on account of intrusive anxiety about their parent's health throughout the night. Moreover, care for siblings, as reported by 38% of the carer sample in the current study may restrict opportunities to relax, even once parental care needs have been met.

It cannot be assumed that levels of responsibility are directly related to how intrusive the care role is perceived to be. It may well be that involvement in more tasks invokes a higher sense of disruption to other life activities. However, how the role is appraised by the carer, even in the presence of minimal responsibility, is perhaps the most salient variable. Future research into the relationship between responsibility and intrusiveness, and the number of roles occupied in addition to 'carer', is an important priority.

Interestingly, no gender differences in relation to these activities were identified. It might be expected that, according to gender intensification theory (Biernat, 1991), males would perceive activities central to their identity, such as sports, as most disrupted: whilst female adolescents would attribute caring to be intrusive to maintaining close friendships. This was not corroborated in the current study.

A number of additional factors that could relate to perceived intrusiveness of the care role include: (1) The prevalence of mothers in need of care support. Without conforming to stereotype, it is likely that care tasks are more plentiful, particularly domestic responsibilities, if the mother endures a chronic illness or disability; (2) The duration and levels of care role responsibility (primary carer, co-carer with another adult, or minimal care role); and (3) Socio-economic status and family composition.

#### 4.4.2 Psychological Health and Caring Intrusiveness

Affirmation of a relationship between care role intrusiveness and feelings of depression and anxiety could have several different meanings. There may be a causal relationship between the two variables, such that both affect each other. It seems reasonable to propose that young people who do regard their role at home to hinder other aspects of their life

would be more likely to report associated low mood and anxiety. It is hypothesised from this finding that caring intrusiveness may compromise psychosocial well-being through a collaborative effect of reduced feelings of personal control, and restricted availability of positive support and social activity. This has important implications. Not least, it offers an advancement of our understanding of the views adolescents hold of their role and its impact on their own lifestyle as well as clinical implications for psychosocial support and co-ordination of services. Future research to determine whether perceived caring intrusiveness is a predictor of psychological morbidity amongst adolescents would equip professionals with knowledge of potential risk factors amongst this carer population. This could be a beneficial indicator during assessment of families, perhaps of lone parent households or large families, where intrusiveness of role for the adolescent is likely to be higher.

Finally, the possibility that the relationship is spurious, and that a third factor is related to role-intrusiveness and emotional health cannot be disregarded. For example, the stage of a parental disability or illness may influence the adolescent's psychological well-being and how intrusive a care role is perceived to be, without the latter being at all related.

The present study cannot reach a conclusion about causality nor which, if any, of the highlighted possibilities is correct. What is most central to how this finding informs current literature and practice is this initial consideration of a relationship between intrusiveness of role and psychological health. Obligatory assessment of the needs of young people, *as carers*, under The Carers Act (1995) needs to be sensitive to eliciting signs of psychological morbidity amongst children or adolescents with care responsibilities. This might be informed by assessment of perceived care role intrusiveness.

### 4.4.3 Perceived Future

Too little attention in current research has been paid to adolescents' views of the future. One of the most informative findings from the semi-structured interviews indicated a relationship between the adolescent's perception of their own future as intrinsically related to the health of their parent. This is in stark contrast to many adolescents without a care

role, with plans to leave home to progress through college or to secure a job. Several adolescents considered that they would be living at home in ten years, not necessarily for their own benefit, but on account of parental needs. All interviewees expected to have continuing care responsibilities for their parent into adulthood, given the chronic nature of their conditions.

#### **4.5 Further Theoretical Implications of Current Findings**

Three main implications for existing theory, according to adolescent development, families and illness literature and adolescent resilience factors emanate from the present study. These will be discussed briefly, in an attempt to reinforce the position of adolescents with a care role within these bodies of literature.

Some of the major theoretical contributions to an understanding of adolescent development have highlighted the importance of achieving “tasks”, such as mature, age-appropriate relationships; emotional independence of parents; achieving a set of socially desirable values; and preparation for adult relationships and vocation. It could be suggested that a number of adolescents committed to a care role for a family member experience difficulties in the development of these tasks and overall achievement of self-identity. Poorer self-image and negative appraisals of family and social relationships amongst carers in the current study has important implications for Erikson’s (1968) theory of identity development. Are a number of carers more vulnerable to what he refers to as identity foreclosure?

In the foreclosure status, young people adopt a convenient set of beliefs and life goals that present themselves early, without ever going through the process of considering other alternatives. Moreover, adolescents in this status typically remain strongly attached to their parents, committing themselves early to what is familiar (Erikson, 1968; Waterman, 1982). It is possible that having a care responsibility introduces premature commitment to early goals and beliefs, without having the scope to reject parental views and experiment with their own. This may manifest itself in poorer interpersonal relationships and a more negative view of the emotional home environment, as corroborated in the current study.

The implications for adjustment and maturity in adulthood remain an important longitudinal focus for future research.

Chronic parental illness or disability is likely to affect cohesion, negotiation of roles and potential confusion as to who is in the position of control and authority (Rolland, 1994). Developmental theories and family theory research within the context of illness (Brown, 1986; Rolland, 1987) are an interesting framework within which the position of the adolescent carer can, and must, continue to be considered. The most salient implications from the current study according to this systemic view is the difference in psychological health amongst teenagers according to predominant parental condition. Adolescents caring for a parent with a mental health condition reported higher levels of depression. This offers some support to Rolland's (1987) view that developmental transitions are made more difficult if the parental illness is relapsing and incapacitating, requiring the carer to oscillate between providing care and experiencing prolonged periods without needing to respond to care needs.

Finally, although it is not possible to infer from this study, the literature on resilience factors during adolescence (Groer, Thomas, & Schoffner, 1992) needs to be acknowledged in relation to young carers. The focus of research needs to be more balanced, exploring the factors that contribute to successful coping and adjustment to the challenge of chronic family illness or disability. Many of these studies remain anecdotal and subjective in their evaluation of the pathological experiences of care-giving. As the field has developed, further studies have arguably addressed some of these criticisms but there is scope for a more balanced approach.

Knowledge about resilience and protective factors in the context of parental illness or disability will invariably aid future research and clinical intervention, having implications for preventative services. Areas amenable to intervention, such as a sense of personal control and positive self-esteem have been previously highlighted as adaptive amongst adolescents without a care role during family illness (Adams-Greenly, Beldoch, & Moynihan, 1986). The role of individual coping styles, prior relationship between adolescent and parent(s) and perceived control and self-esteem are all potential mediators of care-giving outcomes (Schulz & Quittner, 1998). Resiliency against stressful situations

and emotional distress was likely to be prevalent for a number of carers in this study, although this level of individual analysis requires future investigation.

#### **4.6 Clinical and Service Implications**

A number of findings from the current study inform future clinical practice and service delivery. It is intended that these implications for practice will contribute to increasing demands from Government and local service initiatives to prioritise young carer issues.

It is important to highlight that the prevalence of care roles amongst offspring in the context of family ill-health or disability remains unknown. What is evident however is that no two young carers are the same. This heterogeneity clearly affects how individual families, and their unique service-based needs, will be addressed.

In acknowledging that there is diversity amongst children with a care responsibility, not simply on account of being a carer, but first and foremost being a child or adolescent, not all carers will require formal psychological help. The issue of how a minority of carers who do need this support can be accessed and encouraged to engage with a service are important clinical considerations. Improvements in legislation, to protect young carers' rights to needs assessment have introduced new dilemmas for local services. Not only are these young people hidden in the community, but this anonymity serves a function in concealing the family and keeping out services that are perceived by some as threatening to their family unit. The reality of social stigma, and fear of attending a Child and Adolescent Mental Health Service for their own needs, may substantiate fears many hold of being labelled with the same condition as their parent.

National Young Carer Organisations are now established. Given that the current study lends support to the fact that a minority of young carers may require direct clinical intervention for psychological distress or adjustment problems, it remains for services to know how best to negotiate multidisciplinary collaboration. In the short-term it is likely that Organisations will continue a separate, specialist service for people caring for a family member, but knowledge of where appropriate additional services can be sought remains essential to good practice.

The issue about whether young carers should be separated and protected as a unique population is currently being debated. Extreme positions taken by researchers such as Olsen (1996) and Parker (1995) imply that Young Carer Organisations distract from essential, yet currently lacking, assessment and support of the disabled or ill parent. Some professionals advocate for integration of carers into mainstream youth services, as has occurred within Nottinghamshire, whilst others prefer distinct Carer Groups. It is evident that rather than debate whether it is best to direct services entirely at young carers, or empower parents through adult-based services, the two extremes are beginning to see the efficacy of a more family-based perspective.

The fact that carers are reluctant to seek professional help has important implications for professionals. This may be even more pertinent an issue for adolescent carers from ethnic minority families, in view of general research on poorer help-seeking behaviour amongst individuals of ethnic origin (Beliappa, 1991). In the advent of the Carers (Recognition and Service) Act 1995, Clinical Psychology Services are more likely to come into contact with young care-givers through referrals made by local Social Services. Many psychologists may already be familiar with children who are in this role, without this necessarily being made explicit. It is conceivable that in future years, young carers will exist as an important clinical group who access Psychology Services.

In the present study, there are two means by which the clinical implications might best be met. Firstly, where necessary, through direct intervention with an individual and/or their family. Secondly, through consultation and advice to Project Managers regarding psychosocial issues, problems with friendships, social skills and anxiety management. Evidence from the findings that young carers experienced disruption at school, perceived themselves to be different to peers and endured a heightened sense of separation anxiety introduces a liaison remit for psychologists with educational services.

#### **4.6.1 Clinical Intervention**

The present study identified adolescents who expressed feelings of frustration, anger and fear, which were commonly inhibited by guilt and the strong desire to protect the parent. Initial recognition and normalisation of these feelings in addition to work centred around

loss of a parental ideal, changes to the pre-morbid parent-child relationship, and loss of social relationships and opportunities, is likely to be central.

Consideration of how professionals can offset some of the risk factors for isolation and poor peer group identity to enhance psychological health is essential to ongoing adolescent development. Carer's perceived difference to peers could best be incorporated into a cognitive behavioural model which allows experiences and anticipatory problems, such as future relationships or psychosexual anxieties, to be more constructively appraised. Emphasis on social performance, through help in acquiring skills in extracurricular activities and other areas of coping behaviour may enhance a sense of age-appropriate roles and integration.

The vulnerability of carers in delaying their interests and personal development could be identified through psychosocial assessment. A reduction of the anxiety provoked by normative separation from a parent relies on a collaborative approach with other agencies in minimising risk and enabling a young person to access a telephone on school or social premises.

Psychological outcomes in adolescent care-giving are not inevitably negative. The presence of this responsibility, for some adolescents, appeared to bring some closer to their parent. A greater sense of maturity and self-reliance was also expressed. Therapeutically, it would be important to work with each individual based on the strengths that they perceive to derive from their role, in order to address where potential difficulties occur. These are frequently overlooked in the assumption that a premature caring-role is detrimental to psychological well-being.

Gaining a sense of self in the context of a care role can become indistinguishable from what the family expectations may be. The use of a self-report inventory, such as the Offer Self-Image Questionnaire Revised (1989) enables the clinician to gain the views of an adolescent's world from their perspective. The present study also enables an understanding of potential psychological risk factors when an adolescent does perceive their role to be intrusive to other areas of their life. This may well alert professionals to associated poor affect amongst young people with a significant or primary level of responsibility.

Assessment clearly involves the need to listen to and prioritise the young person's emotional needs whilst being aware of their needs as a child within a larger family, whose system may be vulnerable in the event of change. Bringing the parent (s) into the therapeutic process may help to avoid demeaning their role and any feelings of guilt they hold regarding the position of their child as carer. Working with families in the context of illness and disability is becoming more of an academic and therapeutic concern (Altshuler, 1997). The use of family therapy techniques in working towards a renegotiation of an adolescent's connection to, and independence of, parents, without threatening the stability of the family and the adult's role as parent, is promising for future therapeutic intervention.

Transitions out of a care role have not been addressed within the literature. How a young person copes with the effects of bereavement after family care-giving, or through leaving the care role due to marriage or vocation are important considerations for research and future clinical intervention. Related to this, in the absence of longitudinal research into the longer-term implications of caring during childhood, tentative inferences are drawn from wider literature. These include evidence of (1) Physical problems, such as arthritis and back problems, from having lifted a parent at an early age (Aldridge & Becker, 1993a; Brittain, 1995). (2) Depersonalisation and difficulties in establishing relationships throughout life (Frank, 1995). (3) Longer-term characteristics of foreclosure in adolescence include limited capacity for change, remaining committed to activities adopted during the teenage years and (4) The potential to relate to others in adulthood with an attachment style that resembles compulsive care-giving (Bowlby, 1977; West & Keller, 1991). Interestingly, this is associated with the experience of a premature care role, leading in adulthood to rigid self-sufficiency and fear of weakness and lost control through expressing neediness. Young carers may be potentially vulnerable to patterns of exclusive care-giving in future relationships whilst suppressing a longing for care.

#### **4.6.2 Future Service Delivery**

The importance of health, education and social services in establishing ways of working to meet individual and family-based needs is beginning to be recognised. Reducing the need for children to care in the first place is an imperative future priority.

Young carers do not present an unrealistic challenge to services. Mostly, as shown during interviews in the current study, they require a degree of control over what services, voluntary or statutory, are made available to the family. Acknowledging carers' expertise and skill-base, and collaboratively exploring what cannot be managed repairs some of the previous failure by professionals to recognise their role (Aldridge & Becker, 1993b) and reinforce their silence.

Emphasis on raising awareness within local communities (see Appendix 10) and amongst educational staff has begun within a number of locations. The most recent Government Green Paper, 'Caring about Carers' (Department of Health, 1999) integrates a chapter on the needs of young carers. Particular emphasis on future work within schools so that more young carers feel that they are able to self-identify is discussed in this document. In addition, literature and briefing papers for professionals, regarding childhood care roles and children in a family affected by parental illness or disability, are becoming increasingly available (Dearden, Becker, & Aldridge, 1995; Segal & Simkins, 1996).

A lack of specific adolescent services, as reflected nationally, may leave a number of carers feeling that their needs are not met by child or adult services. Current revisions, such as Primary Care Groups and proposed Youth Mental Health Services (Department of Health, 1995) need to be alert to the existence of adolescents who meet a significant responsibility of care in the community. Moreover, professionals need to be aware of family care-giving demands when working within adult services. General Practitioners or psychologists working with disabled or chronically ill parents, particularly young parents with degenerative conditions such as multiple sclerosis, requires a holistic assessment of their role and particular needs as parents. Awareness of the dilemmas for some families in having care needs met by children is likely to be an important therapeutic and service issue over future years that the community can ill afford to ignore.

#### **4.7 Methodological Limitations and Strengths**

Whilst the present study attempted to address the methodological strengths and weaknesses of previous studies, there were inevitable restrictions of time and resources. There are a number of limitations to the current study that may have affected the results obtained.

## **Design**

The cross-sectional design of the current research provoked many questions that would have benefited from longitudinal research. The lack of longitudinal design in current young carer literature is of considerable importance as regards the uncertainties of the needs of future adult populations of childhood carers.

Emphasis on group differences was appropriate to the testing of the hypotheses. However, this did not allow for any individual adolescent differences to be identified. Thus, it was impossible to conclude that a significant minority of adolescents, rather than the total sample, were experiencing problems of self-image, and psychological morbidity.

Whilst beyond the scope of this study, it is important to acknowledge that parental views and participation were excluded. By the nature of the research area, omission of the parent involved in the care relationship can often be demeaning of their position and efficacy as a parent. Attempts were made to minimise this bias.

A future design would attempt to avoid the deterministic nature of research tools that tend to preclude the positive benefits of a care role being exposed. Employing a longitudinal study may also help to minimise the negligence of many studies of the temporal and changing nature of the care process over time.

## **Measures**

As the research field regarding childhood carers is relatively new, none of the measures implemented in the study had previously been standardised on populations of children or adolescents with a care role.

In addition, problems occurred in being able to identify an English Self-Image questionnaire for adolescents. The Offer Self-Image Questionnaire-Revised (Short Form, 1993) had a number of limitations. Amendments were made by the author in order that questions were accessible to an English population. None of these were considered to affect the validity of the measure. Of all the measures in the research packs, this was

considered by participants to be the most time-consuming to complete and the most difficult to understand and this may have affected the validity of the results.

It was not possible to make comparisons with the vast literature published on the use of the OSIQ-R with other populations of adolescents. This was due to a lack of empirical norms for the Short-Form of the questionnaire. However, this measure was able to provide an indication of how participants viewed themselves across a number of areas important to self-image and was thus preferable to alternative self-esteem questionnaires.

The research employed brief depression and anxiety measures, as an indicator of psychological well-being. Alternative questionnaires were considered that would have offered empirical norms for comparison but which would have compromised the scope of the research hypotheses. The current anxiety measure was the only identified questionnaire that enabled sub-types of anxiety problems to be assessed in accordance with the research hypotheses. There is a need for future research to address the lack of standardisation of the BDS and the SCAS on a teenage population with a larger age-criterion, and of different ethnic origin.

The wider debate concerning 'state or trait' symptoms is an important consideration for the current findings. The difference in scores may simply be due to a 'state' effect amongst carers, whose higher scores might have been a reflection of poorer parental mental health at the time of the study. Several participants expressed concern that the measure might not have been an accurate reflection of their overall mood, as it was so variable to change based on family circumstances. Longitudinal replication of this investigation would be of interest to highlight whether negative affect amongst carers was a more stable finding.

The concept of care role intrusiveness was an interesting modification of the illness intrusiveness measure used with chronically ill adults (Devins *et al.*, 1983). The questionnaire clearly restricted carers to a fixed choice of areas of their lives that they perceived as disrupted which may not have encapsulated those most important to them. However, it is an important concept that future research will hopefully aim to incorporate and extend within this population of care-givers.

Finally, the open-ended questionnaire, designed to elicit information from adolescents about the types of tasks they were involved in, was a creative attempt to understand their level of responsibility. The accuracy of this needs to be questioned, particularly as there was a discrepancy in how adolescents described their role, and what they chose to write down. It was deliberately designed as open-ended in order to avoid response bias. However, given that many carers do not identify themselves to be in a caring role and perceive their lifestyles as the “norm”, the reliability of this information needs to be questioned.

### **Participants and Data Collection**

Anticipated difficulties in being able to recruit adolescents with a care role, due to the nature of their lifestyles and appropriate protection by professionals in contact with them, led to the carer population being obtained through Carer Group Organisations. This immediately raised the question about the degree to which conclusions can be generalised, given that adolescents attending groups were established in a service, with access to support and opportunities to socialise. This population may not be representative of adolescent carers without contact with specialist services in the community.

Participants were likely to have been at different stages of developing self-image, according to age. The current research incorporated a wide age distribution that could have introduced bias. Future research could investigate age-related differences in relation to self-image, through employing a cross-sectional design.

Further confounding variables may have been introduced by the method of data collection. The lack of national consensus on service delivery across Carer Groups introduced a number of frustrations for maintaining a consistent method of sampling. Thus, both postal and group-based methods were employed; both of which introduced their own biases. Again, it could be suggested that the returned postal questionnaires were not representative of the carer population and therefore may have been unreliable. Carers who did not respond may well have had levels of psychological morbidity or poor self-image that differed from those that did respond. However, despite these weaknesses, the current study would not have been feasible had the design not been able to tolerate these limitations.

## *Discussion*

The diversity of the carer sample, in relation to socio-economic and care-related variables, meant that a comparison rather than control group, could only be matched for age and gender. Invariably, this weakened the degree to which findings could eliminate other background factors as influential in the current results. Recruiting comparison group participants from an academic setting, with pupils of mixed gender and of mixed ethnicity may have been a confounding factor in their encounter of different types of problems and experiences, perhaps with more of an emphasis on school-related problems.

The questionnaire pack relies on the participant's truthful responses. It may have been the case that adolescent carers disclosed less about their position of responsibility and associated feelings, based on perceived disloyalty to their parent or through fear of service input.

The current study made the assumption that all of the questionnaire measures would be appropriate for use with British Asian adolescents. Given that the degree of acculturation amongst participants from ethnic minorities was not known, their specific concerns or care responsibilities, such as having to translate sensitive health related information for their parent (Meredith & Yee, 1992b), may not have been addressed by the current measures. The limitations of this study in addressing whether there are distinct and important differences for Black and Asian young carers, that may have significant effects upon their self-image and psychological health, reflect limitations in the wider literature. Further cross-sectional research with young carers from ethnic minorities, according to potential cultural diversity in how depression or anxiety is expressed, or differences in the development of self-image, needs to be a future priority.

### **Strengths**

Whilst the present study is specific in its findings and cannot be generalised to all adolescents with a care role, it has enabled an important empirical exploration of issues that currently remain speculative within existing young carer literature. Adolescents recruited to the comparison group also had the opportunity to learn more about care-giving issues as they affect age-related peers. This awareness raising was also extended to the teachers in the specific schools.

Incorporating a limited number of semi-structured interviews into the overall design also enabled descriptions of carer experiences to be given, presenting opportunities for adolescents to elaborate on the positive benefits of a care role which would have been undetected by the questionnaire measures. Questions aimed at their perceptions of services and their future lifestyle do not appear to have been previously researched and offer practical implications for professionals.

Finally, adolescents' comments of their experience of participation within the current study (see Appendix 8b), whilst acknowledging some degree of response bias, supported assertions in the literature of enabling young carers to be actively involved in raising the profile of their position (Becker *et al.*, 1998).

#### **4.8 Future Directions**

The present study invokes a number of interesting questions for future research. It is important to consider whether the current findings would generalize to different types of parental condition. What are the effects of parental learning disability or alcohol addiction upon an adolescent's normative desire for individuation and separation from previous parent-child relationships? It would be of particular interest to examine psychological well-being and self-image development amongst teenagers in the context of a sudden onset care-role, such as for an acute illness, as compared with a more gradual extension of role in the presence of chronic ill-health (i.e. HIV, cancer) and other potentially fatal illnesses.

A minority of male and female adolescents in the current study were primary care-givers. Whilst no significant differences between them and adolescent co-carers were identified, future research could investigate whether this disparity is significant to adjustment. It would be expected that young people who share the role with another parent or sibling might be less vulnerable to psychopathology and over-involvement in assuming certain adult roles, however this assumption requires further investigation. It might also be an interesting addition to consider whether there are seasonal differences amongst carers in relation to greater feelings of depression and role interference. It may be that disruption to opportunities in the summer, during a school holiday, might exacerbate a sense of isolation and perceived difference to peers.

## *Discussion*

The current findings are addressed largely from the point of view of the adolescent carer, whilst acknowledging that the views of parents in receipt of support should not be minimized or ignored. Future research into the effects upon siblings is also required. More insight into family interactions and the changing nature of relationships through childhood into adulthood is needed. Additionally, parental views, and the reciprocal care relationships between child and adult deserve more recognition within future longitudinal research studies.

As already discussed, a longitudinal study would improve understanding of how problematic areas of self-image and friendships in adolescent carers manifest in adult relationships. Far too little is known of the effects of a childhood care role upon maturity into adulthood, and the stability of their future relationships and adjustment. Finally, as the development of Young Carer Services occurs over the next decade, it would be interesting to explore whether adolescent carers, integrated into generic youth and community services, experience greater peer group acceptance than those who are established within specialist Young Carer Groups. This is particularly important in light of new research into the prevalence of bullying towards young carers.

## **CONCLUSIONS**

The current study attempted to investigate a number of issues pertinent to adolescent development. Understanding this from the experience of a population of adolescents that are defined not only by their stage in development, their existence as a member of family, but also as individuals with responsibilities of care for a parent has led to a number of interesting findings.

The current study provides some support for young people in a care role being at risk of greater psychological vulnerabilities. Adolescent carers appear to be experiencing difficulties in the development of areas of self-image and psychological well-being, integral to the “tasks” of maturity into adulthood. It must be stated however, that this is only the beginning of being able to understand how the process of normative separation from, and conflict with, a parent may be problematic for adolescents helping to care for that parent.

Anxieties exacerbated by separation from the parent and potential differences in care role and psychological well-being on account of mental-health or physical illness conditions are two central areas for further investigation. What remains is the need to delineate how children or adolescents in a position of offering care differ to other young people involved in chores and duties at home, and what processes may prevent some children ever taking on a care role.

Factors contributing to coping and resilience in adolescent carers also need to be better understood. The care role is regarded positively by some young people and there is scope to be more balanced in our judgement of their position. Ideally, the means by which families solve problems successfully and adjust to the challenges of chronic illness and disability should be the place from which to proceed. Therefore, it is important that parental illness or disability, and thus, the care position of family members, are viewed as a process rather than a state.

Finally, the existence of children as young carers is not a new phenomenon. Moreover, many young people do not perceive their care position any differently to other individuals, given their involvement has been a long-standing part of ‘normal’ family life. Imposing a

## *Discussion*

label upon them as a unique population within contemporary society clearly has important financial and service benefits and aims to give international definition to their needs. However, there is no such thing as *a* young carer and the present findings reflect something of their diversity.

References

- Adams-Greenly, M., Beldoch, N., & Moynihan. (1986). Helping adolescents whose parents have cancer. *Seminars in Oncology Nursing*, 2 (2) (May), 133-138.
- Adams, G.R., Gullotta, T.P., & Montemayor, R. (1992). *Adolescent identity formation*. Newbury Park, CA: Sage.
- Adams, D.M., Overholser, J.C., & Lehnert, K.L. (1994). Perceived family functioning and adolescent suicidal behaviour. *Journal of American Academy of Child and Adolescent Psychiatry*, 33, 498-507.
- Aldridge, J., & Becker, S. (1993a). *Children who care: Inside the world of young carers*. Young Carers Research Group, Loughborough: Billingham Press.
- Aldridge, J., & Becker, S. (1993b). Punishing Children for caring: The hidden cost of young carers. *Children and Society*, 7, (4), 376-387.
- Aldridge, J., & Becker, S. (1993c). Children as carers. *Archives of Disease in Childhood*. 69, 459-462.
- Aldridge, J., & Becker, S. (1993d). Children who care. *Childright*, 97 (June), 13-14.
- Aldridge, J., & Becker, S. (1994). *My child, my carer: The parents' perspective*. Young Carer Research Group, Loughborough. Billingham Press.
- Aldridge, J., & Becker, S. (1995). *Young Carers: The facts*. Community Care. Young Carers Research Group. Reed Business Publishing.
- Allport, G.W. (1960). *Personality and social encounter*. Boston: Beacon Press.
- Altshuler, J. (1997). *Working with chronic illness*. London: MacMillan
- American Psychiatric Association (1994). *Diagnostic and statistical manual of mental disorders. Fourth Edition*. Washington DC: American Psychiatric Association.
- Bakken, L., & Romig, C. (1992). Interpersonal needs in middle adolescents: copanionship, leadership and intimacy. *Journal of Adolescence*, 15, 301-316.
- Baldwin, S. (1993). *The myth of community care: An alternative neighbourhood model of care*. London: Chapman and Hall.
- Barnett, B., & Parker, G. (1998). The parentified child: Early competence or childhood deprivation? *Child Psychology and Psychiatry Review*, 3, (4), 146-155.
- Beach, T. (1997). Family care-giving: The positive impact on adolescent relationships. *Gerontologist*, 37, (2), 233-238.
- Beardshaw, V. (1988). *Last on the list: Community Services for people with physical disabilities*. London: King's Fund Institute

## References

- Beardslee, W. R., & Podorefsky, D. (1989). Resilient adolescents whose parents have serious affective and other psychiatric disorders: Importance of self-understanding and relationships. *Annual Progress in Child Psychiatry and Child Development*, 485-498.
- Beck, A. T. (1967). *Depression: Clinical, experimental and theoretical aspects*. New York: Harper and Row.
- Beck, A.T. (1978). *The Beck Depression Inventory (BDI)*. New York: The Psychological Corporation, Harcourt Brace & Company.
- Becker, S. (1995). *Young carers in Europe: An exploratory cross-national study in Britain, France, Sweden and Germany*. Young Carers Research Centre: Loughborough University.
- Becker, S., Aldridge, J., & Dearden, C. (1998). *Young carers and their families*. London: Blackwell Science.
- Belliappa, J. (1991). *Illness or distress: Alternative models of mental health*. Confederation of Indian Organisations (UK). Newcastle-Upon-Tyne: Roger Booth Associates.
- Berndt, T. (1982). The features and effects of friendship in early adolescence. *Child Development*, 53, 1447-1460.
- Biernat, M. (1991). Gender stereotypes and the relationship between masculinity and femininity: A developmental analysis. *Journal of Personality and Social Psychology*, 61, 351-365.
- Bilsborrow, S. (1992). "You grow up fast as well...". Young carers on Merseyside. Carers National Association, Personal Services Society and Barnado's, Liverpool.
- Birleson, P. (1981). The validity of depressive disorder in childhood and the development of a self-rating scale: A research report. *Journal of Child Psychology and Psychiatry*, 22, 73-88.
- Birleson, P., Hudson, I., Buchanan, D.G., & Wolff, S. (1987). Clinical evaluation of a self-rating scale for depressive disorder in childhood (Depression Self-rating Scale). *Journal of Child Psychology and Psychiatry*, 28, 43-60.
- Blackford, K.A. (1988). The children of chronically ill parents. *Journal of Psychosocial Nursing*, 26, (3), 33-36.
- Blos, P. (1962). *On adolescence: A psychoanalytic interpretation*. New York: Free Press.
- Bowlby, J. (1973). *Attachment and loss, Volume 2: Separation: anxiety and anger*. London: Hogarth.
- Bowlby, J. (1977). The Making and Breaking of Affectional Bonds. *British Journal of Psychiatry*, 130, 201-210.
- Bradford, R. (1997). *Children, families and chronic disease: Psychological models and methods of care*. London: Routledge.

## References

- Brewin, C.R. (1988). *Cognitive Foundations of Clinical Psychology*. Sussex: Lawrence Erlbaum.
- Brittain, D. (1995). Young carers in France. In Becker.S (Ed). *Young carers in Europe: An exploratory cross-national study in Britain, France, Sweden and Germany*. Loughborough University: Loughborough.
- Brown, S.L. (1980). The developmental cycle of families: Clinical impressions. *Psychiatric Clinics of North America*, **3**, (3), 369-381.
- Bryman, A., & Cramer, D. (1997). *Quantitative data analysis with SPSS for windows. A guide for social scientists*. London: Routledge.
- Buck, R., & Hohmann, G. (1982). Child adjustment as related to severity of parental disability. *Archives of Physical Medicine and Rehabilitation*, **63**, 249-253.
- Busfield, J. (1986). *Managing madness*. London: Hutchinson.
- Byng-Hall, J. (1995). *Rewriting family scripts*. London: Guilford Press.
- Campbell, D. (1995). *Paradoxes in the system: Implications for working together*. Workshop paper presented at Social Services Inspectorate Workshops, May-July. Department of Health, London.
- Carter. B., & McGoldrick, M. (1988). *The changing family life cycle: A framework for family therapy*. New York: Gardner.
- Christ, G., Siegel, K., & Sperber, D. (1994). Impact of parental terminal cancer on adolescents. *American Journal of Orthopsychiatry*, **64**, (4), 604-613.
- Coffield, F., Borrill, C., & Marshall, S. (1986). *Growing up at the margins*. Milton Keynes: Open University Press.
- Cohen, S., & Wills, T. (1985). Stress, social support and the buffering hypothesis. *Psychological Bulletin*, **98**, 310-357.
- Coleman, J.C. (1974). *Relationships in adolescence*. London: Routledge & Kegan Paul.
- Coleman, J.C. (1980). *The nature of adolescence*. London, Methuen.
- Coleman, J.C., & Hendry, L. (1990). *The nature of adolescence. Second edition*. London and New York: Routledge.
- Coleman, J.C. (1993). Understanding adolescence today: A review. *Children and Society*, **7**, (2), 137-147.
- Combrinck-Graham, L. (1985). A developmental model for family systems. *Family Process*, **24**, (2), 139-150.

## References

- Cusinato, M. (1994). Parenting over the family life cycle. In L'Abate, L. (1994). Chapter 5. *Handbook of developmental family psychology and psychopathology*. New York, Wiley & Sons.
- Dearden, C., & Becker, S. (1995a). *The National Directory of Young Carer Projects and Initiatives. First Edition*. Loughborough: Young Carers Research Group & National Carers Association.
- Dearden, C., Becker, S., & Aldridge, J. (1995b). *Partners in caring: A briefing for professionals about young carers*. Loughborough: Loughborough Young Carers Research Group.
- Dearden, C., & Becker, S. (1998). *Young carers in the U.K.* London: Carers National Association.
- Dekovic, M., & Meeus, W. (1997). Peer relations in adolescence: effects of parenting and adolescent self-concept. *Journal of Adolescence*, **20**, 163-176.
- Department of Health and Social Security. (1981). *Growing older*. London: HMSO.
- Department of Health (1989). *Caring for People : Community Care in the Next Decade and Beyond*. HMSO. London.
- Department of Health (1995a). *Young carers. Something to think about. Report of four Social Services Inspectorate workshops. May-July 1995*. Department of Health. London.
- Department of Health (1995b). The NHS Health Advisory Service (HAS). *Child and adolescent mental health services. A Synopsis: Together we stand*. DoH: London
- Department of Health (1996a). *Carers (Recognition and Services) Act 1995: Policy guidance and practice guide*. Department of Health: London.
- Department of Health (1999a). *"Teachers-Meeting the Challenge of Change!"* London: HMSO.
- Department of Health (1999b). Green Paper (Feb): *Caring About Carers. A National Strategy*. London: Department of Health.
- Devins, G.M., Hutchinson, T.A., Hollomby, D.J., Barre, P.E., & Guttman, R.D. (1983). The emotional impact of end-stage renal disease: Importance of patients' perceptions of intrusiveness and control. *International Journal of Psychiatry and Medicine*, **13**, 327-343.
- Dunkel-Schetter, C. (1984). Social support and cancer: findings based on patient interviews and their implications, *Journal of Social Issues*, **40**, 77-98.
- Dusek, J.B., & Flaherty, J.F. (1981). The development of the self-concept during the adolescent years. *Monographs of the Society For Research in Child Development*. **46**, (4), 1-67.
- Eiser, C. (1990). *Chronic Childhood Disease: An introduction to psychological theory and research*. Cambridge: Cambridge University Press.

## References

- Elliott, A. (1992). *Hidden children: A study of ex-young carers of parents with mental health problems in Leeds*. Leeds City Council, Mental Health Development Section, Leeds.
- Erikson, E.H. (1968). *Identity: youth and crisis*. New York: Norton.
- Eurostat (1997). Unpublished tabulations provided by Eurostat from the 1994 European Community Household Panel, initial results. Cited in Becker, S., Aldridge, J., & Dearden, C. (1998). *Young carers and their families*. London: Blackwell Science.
- Fallon, K. (1990). An involuntary workforce. *Community Care*, 4 (Jan) 12-13.
- Feldman, S.S., & Elliott, G. (1990). *At the threshold: The developing adolescent*. London: Harvard University Press.
- Finch, J., & Groves, D. (1980). Community Care and the family: a case for equal opportunities? *Journal of Social Policy*, 9,4, 487-511.
- Firth, M.A., & Chaplin, L. (1987). Research Note: The use of the Birleson Depression Scale with a non-clinical sample of boys. *Journal of Child Psychology and Psychiatry* 28, (1), 79-85.
- Fitts, W.H. (1965). *Manual for the Tennessee Self-concept scale*. Nashville, TN: Counselor Recordings and Tests.
- Flannagan, J.C. (1978). A research approach to improving our quality of life. *American Psychologist* 33, 138-147.
- Fox, N.J. (1995). Professional models of school absence associated with home responsibilities. *British Journal of Sociology and Education*, 16, 221-242.
- Fox, N.J. (1998). The Contribution of children to informal care: A Delphi study. *Health and Social Care in the Community*, 6, (3), 204-213.
- Frank, J. (1995). *Couldn't care more: A study of young carers and their needs*. The Children's Society: London.
- Furstenberg, F.F., Brooks-Gunn, J., & Morgan, S.P. (1987). *Adolescent mothers in later life*. New York: Cambridge University Press.
- Galloway, D. (1985). *Schools and persistent absentees*. Oxford, Pergamon Press.
- Gilligan, C. (1982). *In a different voice: Psychological theory and women's development*. Cambridge: Harvard University Press.
- Groer, M.W., Thomas, S.P., & Schoffner, D. (1992). Adolescent stress and coping: A longitudinal study. *Research in Nursing and Health*, 15, 209-217.
- Hall, G.S. (1904). *Adolescence: Its psychology and its relation to physiology, anthropology, sociology, sex, crime, religion, and education*. In Kimmel, D.C., &

## References

- & Weiner, I.B. (1985). *Adolescence: A developmental transition. Second edition*. New York: John Wiley & Sons, Inc.
- Harter, S. (1983). Developmental perspectives on the self-system. In E.M. Hetherington (1985), *Handbook of Child Psychology, Vol 4. Socialization, Personality and Social Development*, 103-196. New York: Wiley.
- Hartup, W.W., & Rubin, Z. (1986). *Relationships and development*. Hillsdale, NJ: Erlbaum.
- Hauser, S.T., Vieyra, M.A., Jacobson, A.M., & Wertleib, D. (1985). Vulnerability and resilience in adolescence: Views from the family. *Journal of Early Adolescence* 5 (1), 81-100.
- Hetherington, E.M. (1985), *Handbook of Child Psychology, Vol 4. Socialization, Personality and Social Development*, 103-196. New York: Wiley.
- HMSO (1988). Sir R.Griffiths: *Community Care: Agenda for action*. HMSO, London.
- HMSO (1990). *Office of Population censuses and surveys. General Household Survey: Carers in 1990*. (OPCS 92/2). London: HMSO.
- HMSO (1990). *Community Care in the next decade and beyond*. London: HMSO.
- Howell, D.C. (1989). *Fundamental Statistics for the behavioral sciences: Second edition*. Boston: PWS-Kent.
- Johnston, J.R., Gonzalez, R., & Campbell, L.E.G. (1987). Ongoing postdivorce conflict and child disturbance. *Journal of Abnormal Child Psychology*, 15, 493-509.
- Josephs, R.A., Markus, H.R., & Tafarodi, R.W. (1992). Gender and self-esteem. *Journal of Personality and Social Psychology*, 63, 391-402.
- Judge, K. (1994). Serving children, siblings, and spouses: Understanding the needs of other family members. In Lefley, H.P., & Wasow, M. (Eds). *Helping families cope with mental illness* (pp. 161-194). Newark, NJ: Harwood Academic.
- Kahana, E., Biegel, D.E., & Wykle, M.L. (1994). *Family caregiving across the lifespan*. Thousand Oaks, CA: Sage.
- Kashani, J., Horowitz, B., & Reid, J. (1985). Differential effect on subtype of parental major affective disorder on children. *Psychiatry Research*. 15. 195-204.
- Kazdin, A.E., French, N.H., Unis, A.S., & Esveldt-Dawson, K. (1983). Assessment of childhood depression: Correspondence of child and parent ratings. *Journal of the American Academy of Child Psychiatry*, 22, 157-164.
- Keith, L., & Morris, J. (1995). Easy targets: a disability rights perspective on the 'children as carers' debate. *Critical Social Policy*, 45, 36-57.

## References

- Kelley, S.D.M., Sikka, A., & Venkatesan, S. (1997). A review of research on parental disability: Implications for research and counseling practice. *Rehabilitation Counseling Bulletin*. 41, (2), 105-121.
- Kimmel, D.C., & Weiner, I.B. (1985). *Adolescence: A developmental transition. Second edition*. New York: John Wiley & Sons, Inc.
- Kirchler, E., Pombeni, M.L., & Palmonari, A. (1991). Sweet sixteen... Adolescents' problems and the peer group as a source of support. *European Journal of Psychology of Education*. 6, (4), 393-410.
- Kovacs, M. (1982). *The Children's Depression Inventory (CDI)*. New York: Multi-Health Systems, Inc.
- L'Abate, L. (1994). *Handbook of developmental family psychology and psychopathology*. Canada: Wiley & Sons, Inc.
- Lee, C. (1999). Health, stress and coping among women caregivers. A review. *Journal of Health Psychology*. 4,(1), 27-40.
- Lefley, H. (1996). *Family caregiving in mental illness*. London: Sage.
- Levang, C.A. (1989). Interactional communication patterns in father/daughter incest families. In Barnett, B., & Parker, G. (1998). The parentified child: Early competence or childhood deprivation? *Child Psychology and Psychiatry Review*, 3, (4), 146-155.
- Lyons, R.F., Sullivan, M.J.L., & Ritvo, P.G. (1995). *Relationships in chronic illness and disability*. London: Sage Publications.
- Mahon, A., & Higgins, J. (1995). '...A life of our own'. *Young Carers: An evaluation of three RHA funded projects in Merseyside*. University of Manchester, Health Services Management Unit, Manchester.
- Marcia, J.E. (1980). Identity in adolescence. In J. Adelson (Ed). *Handbook of adolescent psychology*. pp 159-187. New York, John Wiley.
- Maslow, A. (1968). *Towards a psychology of being*. New York: Van Nostrand, Reinhold.
- McCalman, J. (1990). *The forgotten people: A study of carers in three minority ethnic communities*. London: King's Fund Centre.
- Meredith, H. (1991a). 'Young carers: The unacceptable face of community care. *Social Work and Social Sciences Review*, Supplement to Vol 3.
- Meredith, H. (1991b). Young Carers. *Contact*. Summer, 14-15.
- Meredith, H. (1992a). 'Supporting the young carer'. *Community Outlook*. May.
- Meredith, H., & Yee, L. (1992b). *Young carers in Black and minority ethnic communities. Workshop Day Report*. London: Kings Fund Centre Carers' Unit/ Carers National Association.

## References

- Miner, M.H. (1991). The self-concept of homeless adolescents. *Journal of Youth and Adolescence*, 20, 545-559.
- Minuchin, S., Baker, L., Rosman, B., Liebman, R., Milman, L., & Todd, T. (1975). A conceptual model of psychosomatic illness in children: Family organisation and family therapy. *Archives of General Psychiatry*, 32, 1031-1038.
- Morris, J. (1989). *Able lives: Women's experience of paralysis*. London: Women's Press.
- Morris, J. (1993). *Independent lives: community care and disabled people*. Basingstoke, MacMillan.
- Nada Raja, S., McGee, R., & Stanton, W. (1992). Perceived attachments to parents and peers and psychological well-being in adolescence. *Journal of Youth and Adolescence*, 21, (4), 471-485.
- National Health Service and Community Care Act (1990)*. HMSO, London.
- Newman, P.R., & Newman, B.M. (1976). Early adolescence and its conflict: Group identity vs alienation. *Adolescence*, 11, 261-274.
- Newsom, J.T., & Schulz, R. (1998). Caregiving from the recipient's perspective: Negative reactions to being helped. *Health Psychology*, 17, (2), 172-181.
- Nolan, M., Grant, G. & Keady, J.(1996). *Understanding family care*. Buckingham. Open University Press.
- Nouri, F.M., & Lincoln, N.B. (1987). An extended activities of daily living scale for stroke patients. *Clinical Rehabilitation*, 1, 301-305.
- Offer, D., Ostrov, E., & Howard, K.I. (1977). The self-image of adolescents: A study of four cultures. *Journal of Youth and Adolescence*, 6, (3), 265-280
- Offer, D., Ostrov, E., & Howard, K.I. (1981). *The adolescent: A psychological self-portrait*. New York: Basic Books.
- Offer, D., Ostrov, E., & Howard, K.I. (1984). *Patterns of self-image*. Chicago: Jossey-Bass.
- Offer, D., Ostrov, E., Howard, K., & Atkinson, R. (1989a). Normality and adolescence. In Rothenberg, A. (1990). Adolescence: Psychopathology, normality and creativity. *The Psychiatric Clinics of North America*, Sept, 430-455.
- Offer, D., Ostrov, E., Howard, K., & Dolan, S. (1989b). *A manual for the Offer self-image questionnaire for adolescents- (revised)*. 4<sup>th</sup> Edition. Special publication. Michael Reese Hospital, Chicago:IL.
- Offer, D., Ostrov, E., Howard, K.I., & Dolan, M.A. (1993). *Offer Self-Image Questionnaire-Revised: Short Form*. Special publication. Michael Reese Hospital, Chicago:IL.

## References

- Office for National Statistics (ONS) (1996). *Young carers and their families*. The Stationary Office, London.
- Olsen, R. (1996). Young carers: Challenging the facts and politics of research into children and caring. *Disability and Society*, 11, (1), 41-54.
- Olsen, R. (In press). Families under the microscope: parallels between the young carer debate and the transformation of childhood in the late 19<sup>th</sup> century. *Children and Society* (Forthcoming, 1999).
- Olsen, R., & Parker, G. (1997). A response to Aldridge and Becker – ‘Disability rights and the denial of young carers: the dangers of zero-sum arguments’. *Critical Social Policy*, 17, 125-133.
- Ollson, G.I., Nordstrom, M., Arinell, H., & Von Knorring, A. (1999). Adolescent depression: Social network and family climate – A case control study. *Journal of Child Psychology and Psychiatry*, 40, (2), 227-237.
- O’Neill, A. (1988). *Young carers*. The Tameside research. Tameside Metropolitan Borough Council, Tameside.
- Orbell, S., & Gillies, B. (1993). What’s stressful about caring?. *Journal of Applied Social Psychology*, 23, (4), 272-290.
- Orbell, S. (1999). The role of social-cognitive research in informal care. *Journal of Health Psychology*, 4, (1), 41-44.
- Page, R. (1988). *Report on the initial survey investigating the number of young carers in Sandwell secondary schools*. Sandwell Metropolitan Borough Council. Sandwell.
- Parker, J.G., & Asher, S.R. (1987). Peer relations and later personal adjustment: Are low accepted children at risk? *Psychological Bulletin*, 102, 357-389.
- Parker, G., & Olsen, R. (1995). A sideways glance at young carers. In *Young Carers: Something to think about. Papers presented at four SSI workshops*. May-July 1995. pp 63-74. Department of Health. London.
- Patterson, S.J., Sochting, & Marcia, J.E. (1992). The inner space and beyond: Women and identity. In Adams, G.R., Gullotta, T.P., & Montemayor, R. (Eds). *Adolescent identity formation*. pp 9-24. Newbury Park, CA: Sage.
- Peters, L.C., & Esses, L.M. (1985). Family environment as perceived by children with a chronically ill parent. *Journal of Chronic Disease*, 38, 301-308.
- Petersen, A.C. (1981). The development of self-concept in adolescence. In Offer, D., Ostrov, E., & Howard, K.I. (1984). *Patterns of self-image*. Chicago: Jossey-Bass.
- Power, P. (1977). The adolescent’s reaction to chronic illness of a parent: some implications for family counselling. *International Journal of Family Counselling*, 5, 70-78.

## References

- Puzynska, E., Grzegorzcyk, J., Sredniawa, H., & Niedzielska, A. (1994). The mental health of offspring of patients suffering from endogenous affective disorder (Follow-up study). *Psychiatria Polska*, **28**, (3), 73-81.
- Raker, R. (1990). *Textbook of family practice*. Philadelphia: W.B. Saunders.
- Reisman, J.M. (1985). Friendship and its implications for mental health and social competence. *Journal of Early Adolescence*, **5**, 383-391.
- Reynolds, C.R., & Richmond, B. O. (1978). 'What I think and feel': A revised measure of children's manifest anxiety'. *Journal of Abnormal Child Psychology*, **6**, 271-280.
- Rolland, J.S. (1987a). Chronic illness and the life cycle: A conceptual framework. *Family Process*, **26**, (2), 203-221.
- Rolland, J.S. (1994). *Families, illness and disability*. Basic Books: Harper Collins.
- Rutter, M. (1966). *Children of sick parents: An environmental and psychiatric study*. Maudsley Monographs (16). London: Oxford University Press.
- Rutter, M., Graham, P., Chadwick, O.F.D., & Yule, W. (1976). Adolescent turmoil: Fact or fiction? *Journal of Child Psychology and Psychiatry*, **17**, 35-56.
- Rutter, M. (1989). Pathways from childhood to adult life. *Journal of Child Psychology and Psychiatry*, **30**, 23-51.
- Rutter, M., & Rutter, M. (1993). *Developing Minds: Challenge and continuity across the lifespan*. New York: Basic Books.
- Schulz, R., & Quittner, A.L (1998). Care-giving for children and adults with chronic conditions: Introduction to the special issue. *Health Psychology*, **17**, (2), 107-111.
- Segal, J., & Simkins, J. (1996). *Helping children with ill or disabled parents: A guide for parents and professionals*. London: Atheneum Press.
- Seiffge-Krenke, I. (1993). Coping behaviour in normal and clinical samples: more similarities than differences? *Journal of Adolescence*, **16**, 285-303.
- Spence, S.H. (1994). *The Spence Children's Anxiety Scale*. The Structure and assessment of anxiety in children. In Child Psychology Portfolio. NFER-Nelson.
- Spence, S.H. (1997a). The structure of anxiety symptoms amongst children: A confirmatory factor analytic study. *Journal of Abnormal Psychology*, **106**, (2), 280-297.
- Spence, S.H. (1997b, in submission). Psychometric characteristics and concurrent validity of a measure of anxiety disorder symptomatology amongst children. In *The Spence Children's Anxiety Scale*, Child Psychology Profile. NFER-Nelson.
- Siddall, R. (1994). Lost Childhood. *Community Care*, **9** (June) 14-15.

## References

- Steinberg, L. (1990). Interdependency in the family: Autonomy, conflict and harmony in the parent-adolescent relationship. In *Normal adolescent development*. Washington, DC: Carnegie Council on Adolescent Development.
- Symonds, A., & Kelly, A. (1998). *The Social Construction of Community Care*. London: MacMillan.
- The Children Act (1989). London, HMSO.
- The Journal of Young Carers Work (1998). Issue One. October 1998. Loughborough, Young Carers Research Group.
- The Princess Royal Trust (1999). *"Too much to take on". A report on young carers and bullying*. London: Princess Royal Trust, Crabtree.
- Thurman, S.K. (1985). *Children of handicapped parents: Research and clinical perspectives*. New York: Academic Press.
- Twigg, J. (1992). *Carers: Research and practice*. London: HMSO.
- Vernberg, E.M. (1990). Psychological adjustment and experiences with peers during early adolescence: Reciprocal, incidental or unidirectional relationships? *Journal of Abnormal Child Psychology*, **18**, (2) 187-198.
- Wallston, B.S., DeVellis, B.M., & DeVellis, R.F. (1983). Social support and physical health. *Health Psychology*, **2**, 367-391.
- Walmsley, J. (1993). Contradictions in caring: reciprocity and interdependence. *Disability, Handicap & Society*, **8**, (2), 129-141.
- Waterman, A.L. (1982). Identity development from adolescence to adulthood: An extension of theory and review of research. *Developmental Psychology*, **18**, 341-358.
- Weiner, I.B. (1985). *Adolescence: A developmental transition. Second edition*. New York: John Wiley & Sons, Inc.
- Wellisch, D. (1979). Adolescent acting out when a parent has cancer. *International Journal of Family Therapy*, **7**, 164-175.
- West, M., & Keller, A.E. (1991). Parentification of the child: A case study of Bowlby's compulsive care-giving attachment pattern. *American Journal of Psychotherapy*, **45**, (3), 425-431.
- Woods, B. (1994). One articulation of the structural family therapy model: a biobehavioural family model of chronic illness in children. *Journal of Family Therapy*, **16**, 53-71.
- Wright, S., Stein, A., Boyle, H., Lewis, S., Moorhouse, J., & Walls, T. (1995). Negative affectivity, uraemic symptoms and quality of life in end-stage renal disease. In J. Rodriguez-Marín (Ed.). *Health psychology and quality of life research*. pp 498-509. Alicante: University of Alicante.

## References

- Youniss, J., & Ketterlinus, R.D. (1987). Communication and connectedness in mother and father-adolescent relationships. *Journal of Youth and Adolescence*, 16, 265-280.
- Youniss, J., & Smollar, J. (1985). *Adolescent relations with mothers, fathers and friends*. Chicago: University of Chicago Press.
- Yule, W., Ollendick, T., & Blagg, N. (1992). Fears in British secondary school children. In Birleson, P. *The Birleson Depression Scale: Child Psychology Portfolio*. NFER: Nelson.
- Zeanah, C. H., Mammen, O., & Lieberman, A.F. (1993). Disorders of attachment. In Zeanah, C.H. (Ed.). *Handbook of infant mental health*. pp 332-349. New York: Guilford Press.
- Zigler, E., Kagan, S., & Klugman, E. (1983). *Children, families and government*. Cambridge: Cambridge University Press.
- Zung, W.W.K. (1965). A self-rating depression scale. *Archives of General Psychiatry*, 12, 63-70.

## **APPENDIX 1**

### **Confirmation of Research Indemnity**

Health Trust Headquarters  
Lane  
Humberstone, Leicester LE5 0TD  
0116) 246 0100  
0116) 246 1222



Ref: \_\_\_\_\_ My Ref: \_\_\_\_\_

Our Ref: MAE/jdw/KBindem

13 October 1998

Ms Kate Broadbent  
Clinical Psychologist in Training  
Leicester University  
Flat 1, 96 a Clarendon Park Road  
Leicester LE2 3AE

Dear Kate

**INDEMNITY: RESEARCH PROJECT - ADOLESCENTS/DISABLED PARENTS**

Thank you for meeting with me this morning.

I write to confirm that, given that you are employed by Fosse Health and that your project has been approved by the Ethical Committee, the Trust will indemnify you for this research project.

Good luck.

Kind regards

Yours sincerely

Dr M A Edgar  
Medical Director

cc: Ms A Cooper  
Mrs C Stebbings

## **APPENDIX 2**

**Initial Letter to Young Carer Organisation Managers/ School Headmasters**

Information Sheet Provided to Carer Group Managers/Research Committees  
(accompanied by a written letter to each Manager)

Developing Research with Young Carers

Why?

This project plans to:

- Understand more about how teenagers who provide a caring role feel about areas of their life, such as friends, home, school etc ( adolescent self-image).
- Ask the question about whether there are differences for young carers in their psychological well-being and self-image from their peers who do not having a caring responsibility
- Allow carers who wish to with an opportunity to talk as much or as little about the benefits and the disadvantages for them of their role
- Respect these views by seeing whether any service implications, suggested by the carer, can be acted on.
- Educate other adolescents who know relatively little about the implications of caring.
- To dispel myths and assumptions about a relatively hidden population with reliable findings
- Add to an important and growing amount of knowledge about young carers that will hopefully have direct benefits for individuals, families, statutory and voluntary agencies. National Carer Organisations are very likely to be interested in the project and its implications. Research is an important avenue by which individual Young Carer Group needs can be understood and shared at a national level.

How?

It is intended that the project will include:

- 35-40 adolescents between the ages of 12-18 years (and another group of non-carers from a school in Leicester)
- Carers whose parents have a chronic illness and/or physical disability/ mental health difficulties and live at home
- Adolescents who have had a caring role for longer than 3 months

(excluding parents with a learning disability and carers in paid/voluntary employment in addition to the caring role)

- Times to complete five brief questionnaires will be arranged together
- These include two general well-being (anxiety/depression) questionnaires, one is on self-image, and two relate to the amount of caring they do and how much it interferes/does not interfere with their daily activities.
- This should take about 30-40 minutes to complete and I will be present to offer any help/explain anything that is not understood.
- Interested carers will be asked if they can spare an extra ten minutes to answer some very short questions about their caring role.

Full written consent will be gathered (parental consent for those under sixteen years old) before the questionnaires are filled in. None of the questions are likely to cause any distress and have been fully assessed and agreed by the Leicestershire ethics committee. All information will be treated confidentially and adolescents will be fully informed that they can stop their involvement at any time. None of them will be able to be identified by name and individual data will not be used in any NHS or clinical capacity.

When?

The project will start in December 1998.

What then?

Once the research is finished (May 1999), a time to present a talk on the findings will be arranged if this is something people would like. A time to write a short article together could also be decided upon.

## **APPENDIX 3**

### **Letter to participants (Carer/ Comparison Sample)**

Carer cohort

Participant Information Leaflet



COULD YOU SPARE FORTY MINUTES?.

WOULD YOU LIKE TO HELP OTHERS WHO DON'T KNOW ABOUT THE  
GROUP FIND OUT MORE ABOUT IT? ☺☺☺

I'll soon be doing a project and I am very interested in finding out about you and others in your Group and listen to your experiences of being a carer. I'll ask you to fill out a few short questionnaires designed to find out how teenagers like yourself feel about areas of your life such as friends, home, school (nothing scary!).

I will visit the Group to set up times to meet with you for forty minutes. I'll be able to then check how many of you would also be happy to answer a few further questions that aren't included on the questionnaire a few weeks later.

Anything that we talk about will not be repeated to anybody else (parents, friends, Carer Group Leader) and there will hopefully not be anything too difficult for you to answer. If you wanted to stop at any time you would be able to do so and you will not be judged by the things you talk about.

I hope to come back to a Group so that I can give you a talk on the project when I have finished meeting with everyone. I have read a few copies of your newsletter and wondered if we might be able to write something in there to let other people know about what we find out?.

Thank you for thinking about the project and maybe talk about it with your friends at the Group to decide whether you want to be involved. It will be great to come along and meet you.



Kate Broadbent  
Leicester University

## **APPENDIX 4**

**Letter to parents (Carer Group Sample)**

## Research letter/Consent form sent to parents (Carer Group Sample)

Dear Parent or Guardian,

I am writing to inform you that a researcher, Kate Broadbent, from Leicester will be joining me at \*\* for one or two of the evenings planned for the forthcoming Carer Programme. She is currently completing a project on adolescent development and their general well-being. Kate is particularly interested in adolescents involved in helping at home, perhaps with domestic or personal tasks or general care and support. We have met and discussed the project and it is planned that she will ask young people in this group to complete a short booklet of questionnaires.

Kate intends to involve about sixty adolescents between the ages of 12 and 18 years from different Carer Groups. There will be some questions about their experiences of helping out at home which will be handled sensitively and confidentially.

The questionnaires will be part of the Programme that we have planned so it will not compromise the arranged activities. Whilst the questions are unlikely to raise anything that will be too upsetting, your son/daughter (name) will be told that they can stop at any time. If they wish they can also talk to one of the Group leaders who will be helping out.

One of the aims of the project is to help inform the Group whether there are suggestions made by the young people that we can act upon to improve the services we offer. The research will also contribute to information and literature available to the general public. Naturally, all names will be erased so that your child will not be identifiable.

I would be very grateful if you would consider Kate's intended visit and complete the following consent slip. This needs to be completed and returned if you wish (name) to be included. If you would like to know more about the questionnaires, please contact me as usual on the above number. Kate is also very happy to talk to you about the project. She can be contacted on (0116) 2252900.

Thank you.

---

I give my consent for my son/daughter to be involved.

Name of son/daughter: (please print) .....

Age of son/daughter: .....

Name of parent/guardian (please print) .....

Parental/guardian signature .....

Date: .....

---

## **APPENDIX 5**

**Letter and consent form – School Sample/Postal Participants (Nottingham Group)**

**Research letter/Consent form sent to parents (Comparison School population)**

Dear Parent or Guardian,

I am writing to inform you that a study is being conducted within the School by Kate Broadbent, a researcher from Leicester University and an employee of Fosse NHS Trust. She is currently interested in understanding more about the self-image and psychological health of adolescents. She has a particular interest in adolescents who have a significant responsibility of care for an ill or disabled parent at home and several 'carer' organisations are currently involved in the study.

In order to evaluate the research, Kate wishes to involve a number of students at \*\* School who do not have this role at home. She intends to visit the School on one occasion and ask students to complete three brief questionnaires based on their general feelings about themselves. The questions take approximately ten to fifteen minutes to complete and will be part of a PSE lesson. All answers will remain confidential and anonymous so that your child cannot be identified. None of the questions are likely to cause any distress.

I would be very grateful if you would consider whether your son/daughter could be involved in the study during Kate's visit in February 1999. If you would not like them to participate, for any reason, please would you complete the slip below and return it to us as soon as possible. If we do not receive anything from you we will assume that you are happy for your child to support this work. It is important to say that whatever decision you make, this will **not** affect your son/daughter's usual academic timetable or School activities.

If you would like more information, Kate Broadbent would be very happy to talk to you further and she can be contacted directly on Leicester (2586929).

Thank you for considering the study.

Yours sincerely,

\*\*

---

Parent/Guardian Form

**Only to be completed if you would not like your child to be included in the study.**

I would prefer my son/daughter (delete as appropriate) to **not** complete the questions in the study on adolescent self-image, being conducted by Kate Broadbent.

Name(please print):..... Date:.....

Name (please sign):.....

---

Please send this back to Fullhurst College, addressed to Mrs P, Head of Year 11.

**" What do you call a deer  
with no eyes? "**

**No idea**

 **(no eye deer)**



HA, ha, ha, ha, ha, ha...

**Hi , I'm Kate.**

**I'm doing a project on young people and their feelings about  
different things in their life. Some of them are young carers  
like yourself.**

**I really hope you can help me to learn a bit more**

**about you too!**

I've sent you a pack of questions (nothing *scary!*) to fill in  
for me. They take about 25 minutes  to finish and there are  
no right or wrong answers. Other young carers have done them and  
found it interesting. Why not make a start now?

**THIS BOX IS IMPORTANT. PLEASE MAKE SURE THIS BOX IS SIGNED!!!!**

**\* If you are over 16, please sign your name below to say you agree to fill it  
in.**

**\* If you are younger than 16, please ask your Mum or Dad to sign it before  
you begin.**

**I agree to take part in the project. I know that the answers I give will only  
be used in this project and my name will not be put on anything.**

**Signed: \_\_\_\_\_**

**Age: \_\_\_\_\_**

**(Your Mum or Dad needs to  
sign it if you are younger  
than 16 yrs old)**

**I've put in an envelope so all you have to do is post it back to  
me at C's office, Action For Young Carers, no later than **\*\*23rd  
Feb 99\*\*****

**THANKS  
THANKS**

for your help and I promise not to tell any more  
unfunny jokes!

## **APPENDIX 6**

### **Self-consent form**

**Form for self-consenting participants (Carers/Comparison Sample)**

**Consent Form**

- The project has been explained to me.
- I agree to be involved and I understand that it will take about thirty minutes.
- I understand that my name will not be put on any information. If the results are given in a talk to the Group/School after the project is finished, I know that my name will not be mentioned.
- I have been told that the general results will be written into a report for other people to read.
- I know that I can stop at any time. This will not make any difference to the things at the Group/School that I normally take part in.
- All the answers I give will be used in this project only.

-----  
I agree to be involved in the project.

I am over 16 yrs old:      Y                      N

Name (please print) \_\_\_\_\_

Name (please sign) \_\_\_\_\_

Age: \_\_\_\_\_

Date: \_\_\_\_\_

Signature of researcher \_\_\_\_\_  
-----

Please ask the Project Leader/teacher to get in touch with me if you want to ask anymore about the project.

**APPENDIX 7 (a and b)**

**7a: Table 14: Summary information – 15 questionnaire responses (Job Description)**  
**7b: Summary of descriptive data from questionnaires**

Appendix 7a

**Table 14 Care-related Information for the Participants whose Care Task Questionnaires were Randomly Selected.**

<b>Participant 1:</b> (Northants)	<u>Male</u> , 15 yrs.	Cares for mother – <b>multiple sclerosis</b>
<b>Participant 2:</b> (Lincoln)	<u>Female</u> , 12 yrs.	Cares for mother - <b>chronic depression</b>
<b>Participant 3:</b> (Nottingham)	<u>Female</u> , 16yrs.	Cares for father - <b>physical disability</b>
<b>Participant 4:</b> (Lincoln)	<u>Female</u> , 13 yrs.	Cares for mother - <b>chronic depression</b> [elder brother involved as primary care-giver]
<b>Participant 5:</b> (Stafford)	<u>Female</u> , 12 yrs.	Cares for mother, <b>M.E and mental health problems</b>
<b>Participant 6:</b> (Nottingham)	<u>Male</u> , 17 yrs.	Cares for mother - <b>physical disability (unspecified)</b>
<b>Participant 7:</b> (Nottingham)	<u>Female</u> , 13 yrs.	Cares for mother with <b>multiple sclerosis (severe)</b>
<b>Participant 8:</b> (Stafford)	<u>Female</u> , 16 yrs.	Cares for mother with significant <b>mental health problems</b>
<b>Participant 9:</b> (Lincoln)	<u>Male</u> , 14 yrs.	Cares for mother with <b>multiple sclerosis</b>
<b>Participant 10:</b> (Nottingham)	<u>Female</u> , 15 yrs.	Cares for mother with <b>Crohns Disease and chronic mental health problems</b>
<b>Participant 11:</b> (Kettering)	<u>Male</u> , 13 yrs.	Cares for mother with chronic <b>depression/anxiety</b>
<b>Participant 12:</b> (Stafford)	<u>Female</u> , 12 yrs.	Cares for mother with chronic <b>depression</b>
<b>Participant 13:</b> (Northants)	<u>Male</u> , 12 yrs.	Cares for mother with <b>anxiety</b> (also blind)
<b>Participant 14:</b> (Kettering)	<u>Female</u> , 12 yrs.	Caring for mother with <b>physical disability</b> (back problems)
<b>Participant 15:</b> (Nottingham)	<u>Male</u> , 15 yrs.	Cares for mother with chronic <b>mental health problems</b>

## **Appendix 7b**

### **Care Tasks 'Job Description' Questionnaire**

#### **Examples taken from returned questionnaires**

A summary of the descriptive data gleaned from the questionnaire is provided as it was written. A number of these measures (n=15) were selected at random. This was to ensure that a reasonably representative summary of the types of care tasks perceived to be performed by participants was presented. The material described below was not selected on the basis of the most severe or potentially demanding tasks but aimed to demonstrate a cross section of care roles.

#### **Domestic Tasks**

“ I need to help her get around, do housework, cook and clean. General chores really”.  
(Participant 1, 15 years old)

“ Make dinner, clean, keep everywhere tidy”.  
(Participant 2, 12 years old)

“ The things I do are washing, cleaning, ironing, some cooking, sewing, shopping. I sort out problems with bills and other things”.  
(Participant 3, 16 years old)

“ Make cups of tea, cook meals, do the shopping, clean the kitchen, wash the clothes, wash-up, tidy all the bedrooms and living room, iron, do the garden”.  
(Participant 4, 13 years old)

“ Fetch things. Take the dog out, help with the shopping and the dishes. Hoover up and clean up other stuff ”.  
(Participant 5, 12 years old)

“ Job details: wash pots, hoover, dust, mop, cook, iron, hang out washing, make drinks”.  
(Participant 6, 17 years old)

“ I have to clean, do the shopping, do the washing, make drinks and on the odd occasion make dinner”.  
(Participant 7, 13 years old)

“ I often help Mum with cooking tea”.  
(Participant 8, 16 years old)

“ Washing up, shopping, make meals, gardening”.  
(Participant 9, 14 years old)

“ I cook tea, set the table, do washing, feed the dog and cat, help with the shopping if I’m there. If my Mum or Dad is ill then I have to help more”.

(Participant 10, 15 years old)

“ Loading the dishwasher, clean up, look after myself, make my own breakfast and get ready for school”.

(Participant 11, 13 years old)

“ Clean, walk the dog, make tea”.

(Participant 12, 12 years old)

“ Help cook, housework, e.g. hovering, washing up, sort colours of clothes, take Mum out shopping, tidy up”.

(Participant 13, 12 years old)

“ Make my sister’s breakfast, washing up, shopping, help around the house, get my Mum’s clothes”.

(Participant 14, 12 years old)

“ Sort out bills, washing the dishes, help to make meals, then I have to generally help around the house”.

(Participant 15, 15 years old)

### **Personal/Intimate Tasks**

“ Often need to help her get dressed, take her to the toilet”.

(Participant 1, 15 years old)

“ Remind her to take her tablets everyday”.

(Participant 2, 12 years old)

“ Help Mum up and down stairs. Lift her off seats. My sisters helps with baths and that ”.

(Participant 6, 17 years old)

“ Help bath and shower my Mum, wash her, change her, wash her clothes”.

(Participant 7, 13 years old)

“ My Mum can wash herself and dress herself. I help to make sure she’s dry ”.

(Participant 8, 16 years old)

“ Carers do all that”.

(Participant 9, 14 years old)

“ Doing my Mum’s hair and sometimes massaging her to relax her”.

(Participant 10, 15 years old)

“ Remind Mum a lot to take her tablets”.

(Participant 12, 12 years old)

“ Test Mum’s blood, check her injections (medication)”.  
(Participant 13, 12 years old)

“ Put Mum to bed”.  
(Participant 14, 12 years old)

### **Additional Tasks (Emotional/Social/Siblings)**

“ I look after my brother”.  
(Participant 1, 15 years old)

“ Stay at home. Stay with her when there’s an emergency. If me and (brother) were not there Mum would get stressed out and run away”.  
(Participant 2, 12 years old)

“ Cash her money books. I have to bath my brothers”.  
(Participant 4, 13 years old)

“ Stay quiet and wake her up in the afternoon when she goes to bed for an hour. Go places with her”.  
(Participant 5, 12 years old)

“ I look after my three sisters because I am the eldest. My youngest sister has special needs so she needs lots of love and attention like Mum. I take the kids to school and the park at weekends”.  
(Participant 8, 16 years old)

“ Make Mum feel safe. i.e. look out for her. Introduce new carers to my Mum and my autistic brother. I get my brothers and sisters ready for school and remind him to take his medication”.  
(Participant 9, 14 years old)

“ When my Mum’s going out I help her choose her clothes and shoes. Being a companion, being a friend, socialising and talking with my Mum. Being there for my Mum”.  
(Participant 10, 15 years old)

“ I don’t really do much because she is O.K a lot of the time but when she is bad I just can’t make her come and help me or anything”.  
(Participant 11, 13 years old)

**APPENDIX 8 (a and b)**

**8a: Table 15: Summary information for Semi-structured Interview participants**  
**8b: Semi-structured Interview Protocol/ Transcripts**

**Appendix 8a.**

**Table 15 Demographic and Care-Related Information for Participants in the Semi-structured Interviews (n=7)**

CARER GROUP	PARTICIPANT	PARENT CARED FOR	CONDITION	PERCEIVED LEVEL OF SUPPORT
Lincoln*	Male, 16 yrs	Mother	Chronic depression/suicidal	Primary Carer
Kettering	Male, 14 yrs	Mother	Muscle fatigue/ Disability (FMS)	Primary Carer
Kettering	Female, 12yrs	Father	Multiple Sclerosis Secondary mental health problems	Moderate support
Staffordshire	Female, 13 yrs	Mother	Multiple Sclerosis	Primary Carer (Father deceased 1998)
Lincoln	Male, 13yrs	Mother	Chronic mental health problems	Significant support
Lincoln*	Female 12yrs	Mother	Chronic depression/suicidal	Significant support
Lincoln	Male 15yrs	Mother	Physical disability/ Wheelchair dependent	Primary carer

\* Siblings

**Appendix 8b: Interview Protocol**

**INTERVIEW SCHEDULE**

**INDIVIDUAL**

1. Do you help to look after someone in your family?
  
2. How did you become a carer?  
When did you start to look after your Mum/Dad?  
(look for unexpected onset)  
Have you been helping for a long time? (continuous/broken)
  
3. So, you have been a carer now for \_\_ months/years.
  - i) Can you tell me 3 things that you think of when you are asked what it is like to be a young carer?
  - ii) Do you think there are any benefits/advantages to caring for your (ill/disabled parent)?
  - iii) What sorts of things do you think they are?
  
4. What do you like the *most* about it?
  
5. Is life different at the moment from other young people your age who aren't carers?  
  
[ Prompt if necessary: Some people who have important responsibilities find that their own lives are changed. (Emotional, Practical, Social, Financial, Educational)]
  
6. How do you think your life would be different if someone else took over your role as a carer for your (ill/disabled parent)?

The next question asks about how caring affects you during the day- if at all.

7. Have you had to take much time off school?

**When you are at school or away from home, do you find yourself thinking about things at home?**

**Y            N**

- i) What is the most difficult part of not being with them?**
- ii) Would you say you worry about how things are? (what worries you the most about caring for your Mum/Dad?)**

**Do you manage to enjoy the break for a while? (elicit what helps)**

**Are there things that you enjoy when you aren't helping at home?**

**8i) Imagine we had a fast forward button: where do you see yourself in ten years time?**

**ii) What would your dream future be like?**

## **FAMILY**

**Choose five words to describe what your relationship with your (ill/disabled parent) is like.**

## **SERVICES**

- 1. Do you get any help in caring for your (Mum/Dad)?  
How do you decide who does what?**
- 2. Has this been helpful for *you*? How?**
- 3. Could it be better? How? (what should we do about it to make it better?)**

4. **How long have you been coming to the Group?**
  
5. **Name one good thing and one bad thing, no matter how small, about the group.  
[would you like to change it in any way?]**
  
6. **Imagine you could have any kind of help at all, what would you find the most helpful?  
[what would be the most important?]**
  
7. **Who would you most like to offer this help?.**

Have we missed anything?

Is there anything else you would like to say about being a carer or being a member of the \_\_\_ Carers Group that we have not had chance to mention?.

I really appreciate you taking part and wonder if there are any positive or negative things about how you found the project that you could tell us about. Please do include anything negative or hard about answering these questions as it will help me to think about how I talk to other young people helping to care for their parent.

Can you come up with two words to describe how you found the project (ie questions etc), either by telling me or writing them down and putting them in this envelope.

## **8b: SEMI-STRUCTURED INTERVIEW TRANSCRIPTS**

### **Participant 1**

**Male: Aged 16 yrs. Caring for mother with chronic mental health problems (depression/numerous suicide attempts).**

[Brief introduction to interview process provided]

KB: So you help look after your Mum?

P1: Yeah

KB: Have you done this for a long time?

P1: Ever since I can remember really.

KB: Really. A long time? If I asked you to roughly give me an age, when would you say?

P1: Seven or eight I should say really.

KB: OK. So you've been caring for about....

P1: About eight years

KB: Right. Do you have any memories of how this began?

P1: Mum was just really down and wanted us to do things. My sister was young then so I did lots of things, jobs and stuff. She's done more as she's got older.

KB: So, until your sister was old enough you helped your Mum with things a lot more. More to do at first and less now?

P1: Probably. It gradually built up and now its just the stuff that we do really.

KB: Sure. Can you tell me three things that you think about when you are asked what it is like to be a young carer? Do you like that word, 'carer'?

P1: I suppose its a word to describe it but ..er..yeah...its a term I suppose.

KB: It's a term, right.

P1: Frustrating

KB: You find it frustrating.

P1: Upsetting

KB: Upsetting

P1: It makes me feel angry as well.

KB: OK. You've described some that seem quite difficult. Do you think that there are any advantages to being a carer? Do you think there are benefits that.....?

P1: You learn a lot.

KB: Can you describe a bit more about this?.

P1: You learn a lot earlier in life that you might have to call on later on I suppose.

KB: Right.

P1: Learn how to be responsible, more mature really.

KB: Learning things before you might have done otherwise?

P1: I've definitely found that. Its about being responsible really, how to deal with different things in different situations

KB: Right.

P1: That you might find difficult when you come across.. the first time but haven't had experience before.

KB: Could you give me an example of this kind of thing ?

[Participant 1 continued]

P1: Er..like if Mum goes into hospital and I've got to visit her and visit my sister who stays with a relative.

KB: So, if this comes up again you feel you'll know how to deal with it a bit more easily?

P1: Yeah. And you get an understanding as well. Like of people with the same problems and that. So when you are caring you get some people you see in the street who are having people ..erm laugh at them or avoiding them. You can sort of understand how they are...

KB: You find that a lot outside don't you, people just laugh because they don't see what its like...

P1: Yes. Yeah.. that's right.

KB: And you feel you've got an understanding of what that's like so you are less likely to laugh?

P1: Yeah.

KB: Right, that's really interesting. What do you like the most about being a young carer do you think?

P1: Erm.. I think that's it really, just having that understanding.

KB: That's great. Do you think that life at the moment is different because you help to look after your Mum? *Your* life is different?

P1: Yeah. Yeah you have to sacrifice a lot.

KB: Right. Can you give me some examples?.

P1: Em..like my school work and stuff. There's a lot of ..er..stuff that you can't do sometimes 'cos you are too busy helping or too tired.

KB: So, would that be homework that maybe you don't get time to finish?.

P1: Yeah. And there've been some nights now I've experienced that so I've had to be awake all night helping Mum and then not be able to go to school the next morning 'cos I'm so tired.

KB: So you think in sacrificing a lot, is that a lot about things that if you weren't caring for your Mum you'd just be doing normally like..you'd....

P1: Yeah.

KB: Like you'd be at school and..

P1: Yeah, and friends as well. A lot of friends don't really understand about it and you feel awkward having to explain...especially with mental health 'cos if anyone is in a wheelchair or something its a lot easier to understand. There's something there that you can see. You can't explain you know "Sorry you can't come round tonight 'cos Mum's not well" and not being able to explain *how* she's not well.

KB: Mmm. So do you tend not to explain?

P1: Yeah... you keep it to yourself.

KB: I think that the example of something needing to be visible before people seem to understand is very important.

P1: Yeah..

KB: How do you think that your life would be different if someone else took over your role?

P1: I think I'd have a lot more freedom. I wouldn't feel as responsible. When I'd go I'd always be looking over my shoulder to just see if Mum was O.K..or.. but I wouldn't always have to be there.

[Participant 1 continued]

KB: So you'd feel a bit more like you had choices to..to do what you wanted to do?.

P1: Yeah.

KB: The next question is asking about how caring affects you during the day, if it *does* affect you during the day because I know you are at school X. Have you had to take much time off school?

P1: There've been days in the past where I've had to go in late and stuff... if I've been up in the night or just getting things sorted out for Mum like if she's been in hospital.

KB: Right, and that comes back again to what you said earlier about sacrificing things.

P1: Yeah.

KB: When you are at school or if you are just away from home, for whatever reason, do you find yourself thinking about home a lot,.. think about your Mum?.

P1: I don't really. I seem to find school a sort of escape really. Just to get away and not think about it all.

KB: OK So it gives you a bit of a break does it?.

P1: That's right.

KB: What are the sorts of things that help you switch off, you know, 'cos school seems as if it helps?

P1: Just not really being in the house, not really being there.

KB: Right. That helps you switch off?

P1: Yeah.

KB: Is there anything that helps you X when you are in the house, at home..like could you just sit and watch a programme..?

P1: Not really no.

KB: No. O.K, just a few more questions. Are there things that you enjoy when you are not helping at home?

P1: Erm...not really no. Just having the time out to have that freedom, not to be worrying.

KB: Feels like a bit of a relief does it?.

P1: Yeah. [physically relaxed shoulders as he answered].

KB: Imagine that we had a fast forward button and we could fast forward time to ..I don't know..ten years time. Where do you see yourself in ten years time? What do you think it will be like?

P1: Its difficult to say really 'cos its changed so much in the past and you can never really see ahead 'cos you don't know what's gonna happen the next day, you know. Like I don't know now whether Mum will be fine in the future or whether she will be ill again. Its very sudden.

KB: So almost.. that's a very difficult question to actually think about?

P1: Yeah it is.

KB: I think its really important that you said that.

P1: Yeah

KB: ..for someone who isn't a carer that might seem like quite a straightforward question but ...

P1: Yeah.. to plan a future, but you can't because you don't know.

KB: I see. Can you imagine for me then for a minute that you could have a dream future? What would you like that to be like? What would you like for yourself X?

P1: I don't think I'd like really to have to be responsible anymore. And maybe not have to live with Mum.

[Participant 1 continued]

KB: O.K, not to be responsible and not live with Mum. Is there anything else that dream future would look like?

P1: Erm..so I could forget about it all really 'cos I know it sounds quite nasty and everything but just to not have... to not have to be responsible for her and for her to be responsible for me.

KB: Right, so take care of you a bit?

P1: Yeah.

KB: Is there anything in terms of like....a big house, flash car,...do you think about any of these things?.

P1: I wouldn't mind being rich.

KB: So that would be part of your dream future... to be rich.

KB: Now this question asks you to choose five words to describe what your relationship is like with your Mum O.K? Those can be just immediate words that come into your head, and it doesn't have to be five.

P1: Its very stormy, up and down like, changes a lot.

KB: Stormy.

P1: There's a lot of anger in it and a lot of sadness as well.

KB: There's a mixture of feelings there then.

P1: Yeah.

KB: Do you get any help from...anybody coming in from any services?

P1: We have done before, like only after Mum's come out of hospital for the first week. But after that she'd have had to pay for it herself and she couldn't manage so..

KB: So then its yourself and your sister?

P1: Yeah.

KB: So is nobody currently helping out, coming in to help with anything?

P1: No.

KB: So, could it be improved for you? Would it be something that you would like to see happen or do you feel that help from services would intrude on what you do?

P1: I think it would be good sometimes but I don't think it would be good to get dependent on it.

KB: OK And could you describe what type of help would be good?

P1: Erm.. just a cleaner or something like that to give us a break...to wash up or clean the house.

KB: Who would you most like to offer this help?

P1: A woman probably, possibly from social services.

KB: Social services you think.

P1: Mmm.

KB: How long have you been coming to the Group?

P1: Not that long actually. Only about three months.

KB: Oh, can you name one good thing and one bad thing, no matter how small, about the group? Are you in a group with the youth?

P1: Yeah.

P1: Er, a good thing is finding that there are other people in the same situation, like before you just didn't think. Actually there are quite a few children from our school as well who you wouldn't think to look at them. Yeah, its quite surprising.

KB: Can you think of anything bad about it?.

[Participant 1 continued]

P1: Not really no.

KB: Oh that's good. I should come back and ask you the same question in another three months!.

KB: I've asked you this already. Imagine you could have any kind of help at all. What would you find the most helpful?

P1: Erm...just before as I said, just someone who would be able to come in and give Mum a break.

KB: From what? What would you like to give your Mum a break from?

P1: From erm...cleaning really and stuff like that. I think she finds that hard.

KB: So, somebody like a cleaner who she could chat to and she....

P1: Yeah, and she'd be doing something for her too.

KB: Do you think we've missed anything?. Is there anything else that you'd really like to talk about or that you haven't had the chance to comment on?.

P1: Erm....not really no.

KB: So its covered quite a lot?

P1: Yes [laughs].

**[End of formal interview]**

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Additional feedback from P1 regarding the **process** of being involved in the research/interview.

KB: I wonder whether there are positive and negative things that you have felt about being involved in this project?

P1: I think it was good to.. erm.. give you the facts really so that people might be able to understand more and they can appreciate it more.

KB: So do you feel that if people know more about young people helping at home then that would be good?

P1: Yeah, if there was just some more understanding.

KB: I know I have already said quite a bit about the project to you but when its all done, I do intend to be able to go into a few schools where there are young people who don't help care for their parents. It should really help in schools for people to be aware, because there seems to be a lot of bullying and...

P1: Yeah, that's right, there is. Especially if erm...even if they don't know you are a young carer, the teachers don't know and you find it awkward explaining why you were late or why you haven't done this or that.

KB: Do you find that hard?

P1: Yeah.

KB: Do you tend to explain, do you say I'm helping...?

P1: No, not really.

KB: You don't explain. Can you think of two words to describe how you have found the project? You don't have to tell me directly, you can just write them down for me and put them in here if you want.

P1: I've found it very helpful really.

KB: Mmm. What's been helpful about it?

P1: Just to be able to answer some questions really and to hope that some people might benefit from what's been said.

[Participant 1 continued]

KB: Has there been anything that you haven't liked?

P1: I've found some of the questions quite awkward.

KB: Awkward?

P1: In the way they were said.

KB: Is that in the interview here or in the questionnaires you did?

P1: In the questionnaires.

KB: Have you mentioned those to me?

P1: Yeah.

KB: When you say awkward, has that been because they have been upsetting, or intrusive, erm...or maybe they've not really been...

P1: Not that they've been upsetting or interfering no, just that they haven't really, I don't know, been set very well.

KB: Right. Thank you for telling me this. Are they the one's we've looked over together?

P1: Yeah. There aren't any others I don't think.

KB: Thank you.

[Interviewee was debriefed and thanked for his participation.]

## **Participant 2**

**Male: Aged 13yrs** Caring for mother (**mental health problems**, exacerbated by paranoid symptoms). Brother with chronic illness.

KB: S, how long have you been looking after your Mum and your brother?

P2: Mum, erm eight years. My brother, probably about three.

KB: How did you become a carer?

P2: Erm, Mum just kept getting upset and stuff really, so I helped with things.

KB: So, you've gradually built up to doing more and more things to help?

P2: Yeah.

KB: Can you tell me three things that you think of when you are asked what it is like to be a carer?

P2: Yes, weird, hard, scary. Also, not knowing what to do and getting in trouble for being in the way is hard.

KB: Do you think there are any benefits to being a carer?

P2: No, I can't think of anything really- there isn't anything nice about feeling worried a lot.

KB: Do you feel life is different to other people your age because you help look after people at home?

P2: Yes. I don't get to see my friends and I can't give my phone number out because my Mum doesn't like people to phone and disturb us. People take the mickey out of you too and say "your brother's really ill".

KB: So you find that there are a lot of people who don't really understand what it is like for you and appear quite cruel?

P2: Yes they are but you just try to ignore it.

KB: Names can really hurt can't they, our feelings can really be hurt when people don't think through what they are saying. Can you talk to someone at home about this?

P2: Yeah, Mum.

KB: Good. How do you think your life would be different if someone else took over your role as a carer?

P2: I'd have more time for myself.

KB: Yeah. What would you do with that time?

P2: I'd go out and see friends and play football.

KB: Do you do this now very often?

P2: No, I miss playing football really- I try and play at school.

KB: So, you get some chance at school to play, have you had to take much time off school?

P2: No.

KB: When you are at school or away from home, do you find yourself thinking about things at home?

P2: Yeah, a lot.

KB: What's the most difficult thing about not being with them?

P2: Erm, I worry that my brother might die and that Mum might not cope. She cries a lot.

KB: There seems to be a lot that you find yourself thinking about X when you aren't there. Can you ever enjoy the break for a while?

P2: Yes, sometimes but not very often really. You find yourself soon thinking about them again.

[Participant 2 continued]

KB: Are there things you enjoy doing in the brief times that you can switch off a bit?.

P2: Football.

KB: Imagine that we had a fast forward button to move time on ten years, where do you see yourself in ten years time?

P2: Erm. [remained silent]

KB: Is this a hard question to think about?

P2: Yeah.

KB: We can come back to it if you would like more time to think about it?

P2: Mmm.

KB: How about thinking about your dream future?

P2: I would just really like my Mum to be OK and my brother.

KB: So your future wish is for your family to be better, is there anything you would like to think you might be doing or might have?

P2: No not really- just that.

KB: Can you choose five words for me to describe what your relationship with your Mum is like?

P2: We fight a lot. She gets angry with me and then upset.

KB: So, you argue and things are heated and then calm down, usually with your Mum crying?

P2: Yeah, I can't think of anymore words really.

KB: That's fine. X do you get any help in caring for your Mum?

P2: No. What do you mean?

KB: I suppose I wondered whether anyone comes in to help, a friend, someone else in the family, services like home care?

P2: Oh, a bit. My step-dad sometimes, but we don't get on, I don't like him. He helps with my brother but he hardly helps really. Mum sometimes helps me with my school work- its too hard.

KB: So all the help comes from within the family?

P2: Well, this woman comes in school holidays from a volunteer's thing.., erm, and talks to Mum. Sometimes we get to go out together. A nurse used to visit my brother but she hasn't been for ages.

KB: So, someone comes a few times a year to help your Mum and a nurse for your brother.

P2: Yeah. None of them are coming at the moment though.

KB: Did these women help with any of the work you do?

P2: Sort of- not with the cleaning and stuff, but they talked to Mum so I did more.

KB: Was it helpful for *you* to have this help?

P2: Yeah.

KB: It sounds like you did find it was of some help X, could things be made better for you as far as help goes?

P2: Yes. I'd like someone to look after my brother sometimes so that me and Mum can go out.

KB: What sorts of places would you go to?

P2: Not sure- the shops

KB: How often would you like to get out, just you and your Mum?

P2: Once a week.

KB: How often do you manage that now?

[Participant 2 continued]

P2: Hardly ever!

KB: Who would you most want to come in and look after your brother so that you could do this?

P2: Someone we knew really but everyone we know wants money for it- like we've asked Nana.....

KB: What about someone you didn't know?

P2: I suppose so- but they would have to be a nurse and know what to do.

KB: Right. How long have you been coming to the Group?

P2: A few weeks.

KB: So you are still getting to know all about it then?. Can you name one good thing and one bad thing about the Group so far?

P2: You get time to yourself to do what you want. There isn't anything bad.

KB: That's good. You enjoy the chance to think about what you would like to do for a short time then?

P2: Yeah.

KB: Good. Have we missed anything? Is there anything else you'd like to say?

P2: Can't think of anything.

KB: Well, I wonder if you could just think of a few words to say how you have found the project, either by telling me or writing them on here if you want to do that?

P2: Hard, I suppose. You've got to talk about your feelings and that.

KB: You've found that difficult. Do you tend to keep things to yourself ?

P2: Yeah. I don't tell anyone at school that I'm a young carer, I just keep it to myself...because its my family, not because I don't know you or anything.

KB: Right, so you find talking about your family hard, whoever it might be with rather than the questions being too difficult or upsetting. Have I got that right?

P2: Yeah, it didn't upset me, just made you think a bit I suppose.

KB: Is there anything that you might want to ask about the interview or the research that I didn't cover with you before we started?

P2: No.

[participant was thanked for answering the questions and debriefed]

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### Participant 3

**Female. Aged 12 years Significant care responsibility for mother with chronic mental health problems/suicide attempts. Regular hospital admissions. Brother, aged 16 yrs, primary carer. Gender-divided roles.**

KB: R, Do you help look after someone in your family?

P3: Yeah, my Mum.

KB: How did you become a carer?

P3: A social worker was involved to start with when Mum was first ill and then we just started to do more really.

KB: So, it was quite gradual?

P3: Erm

KB: What I mean is you have done more to care, like jobs and things, as time has gone by.

P3: Yeah.

KB: How long have you been looking after your Mum?

P3: About two years.

KB: Can you tell me three things that you think of when you are asked what it is like to be a young carer?

P3: Hard, you've got to put a lot of effort and thought into it.

KB: Do you think there are any benefits to caring for your Mum?

P3: Yeah, coming here.

KB: So, you really like the Group then?

P3: Yeah, its really good, you get to see everyone.

KB: What do you like the most about looking after your Mum?

P3: Nothing.

KB: O.K. Do you think that your life is different from other young people your age who aren't carers because you help to look after your Mum?

P3: Yes. Friends go out a lot more and you miss a lot. I can't go out with Mum like I used to as well.

KB: So, you feel like maybe you are missing out on things?

P3: Yeah, they are always talking about stuff on Monday at school.

KB: How do you think your life would be different if someone else took over your role as a carer?

P3: It would be a change for me. I'd be going out a lot more and I wouldn't feel stuck. I suppose I'd be independent. I'd feel guilty, a bit.

KB: Guilty? Can you help me understand a bit more about that?

P3: Yeah, about leaving Mum.

KB: Right, for going out and being with friends?

P3: Yeah, when she would be at home.

KB: I see. The next question asks about how caring affects you during the day, if at all. Have you had to take much time off school?

P3: No.

KB: So, when you are at school, or away from home, do you find yourself thinking about things at home?

P3: [nods]. A lot. I can't stop really.

KB: Can you concentrate?

P3: No. If I put the effort in I can sometimes. I can't if Mum is in hospital. I used to be taught at home so it was better then, I was there.

[Participant 3 continued]

KB: You didn't worry if you were in the house with your Mum.

P3: You still do a bit but it was just...er...better.

KB: Do you get chance to do homework?

P3: Yeah.

KB: Whats the most difficult part of not being with her?

P3: Erm.. thinking how Mum is feeling really. I miss her and I'm used to caring for her.

KB: So you wonder how she is, if she's safe?

P3: Not really safe, just how she feels.

KB: Right. Can you manage to enjoy the break at all?

P3: Yeah.

KB: What helps you to switch off?

P3: Other excitement, TV, music, homework sometimes helps.

KB: So you do find you can have a bit of a rest. Imagine we had a fast forward button: where do you see yourself in ten years time?

P3: Er..

KB: What might you be doing, where might you be?

P3: Worrying about Mum. I'd still be at home but I might go to college.

KB: What would your dream future look like?

P3: I want to work with animals.

KB: Oh, so you already know what career you want then?

P3: Yeah.

KB: Anything else this dream future might have?

P3: Erm....I don't know really.

KB: O.K, it involves animals though. Can you choose five words to describe what your relationship is like with your Mum?

P3: We have a good relationship, sometimes argue, she gets stressed and angry.

KB: Do you get any help in looking after Mum?

P3: Yeah, S [brother] helps.

KB: How do you decide who does what?

P3: Mum tells us. S does the heavy things like shopping bags and rubbish bins.

KB: And you?

P3: Er, washing up, cleaning up. We both do the same things sometimes.

KB: Could the help be better for you in any way?

P3: No not really, I can't see how. You can't just click your fingers. The Group has been helpful.

KB: That's really good. How long have you been coming?

P3: About ....a year now.

KB: Can you name one good thing and one bad thing about the Group?

P3: Going out. We went to Pleasure Island last time. Did you see the photos?

KB: X showed them to me. It looked like it was really good fun.

P3: It was.

KB: Can you think of anything bad about the Group? Anything you would want to change?

P3: No.

KB: O.K. Nearly finished. Imagine you could have any kind of help X, What would you find the most helpful?

P3: Someone to help Mum and S [brother] to get on a bit better- they argue a lot.

KB: They argue? When they do argue, what do you do?

[Participant 3 continued]

P3: I'm in the middle. I just stay out of it.

KB: Who might be able to offer that help?

P3: Don't know.

KB: Mmm. Someone you all knew?

P3: No, someone we didn't know would be better.

KB: What about other help?

P3: I don't want a cleaner or anything, we do it.

KB: You wouldn't like that. Any other things that might be helpful?

P3: No.

KB: Have we missed anything X? . Is there anything else you would like to say?

P3: Er...just that its very hard really, its difficult but I don't want to give up being a young carer.

KB: So some days are really tough but you wouldn't like to stop being a carer. Thanks for telling me that. Can you think of two words to describe how you have found the project, good or bad, by telling me or writing them down and putting them in here?

P3: Its been good, someone understands you.

[the participant was debriefed and thanked for her involvement in the interview]

## Participant 4

**Male: Aged 14 years** Shares role with father/Care responsibility for mother with FMS (fibromyalgia)- muscle fatigue. Carer for 4 year old sister.

KB: Do you help look after someone in your family?

P4: Yeah, my Mum.

KB: Can I ask what condition your Mum has?

P4: FMS.

KB: I'm not familiar with that. Can you say a bit more about it?

P4: Yeah, its called fibromyalgia.. its nerve fibres...muscle fatigue.

KB: Oh, does she experience pain?

P4: Yeah, a lot.

KB: Hmm. And gets easily tired?

P4: Yeah.

KB: When did you start to help look after her?

P4: About three years ago.

KB: From the age of 11?

P4: Yeah.

KB: How did it begin?

P4: She's got worse so I've helped more really. I started off just doing a few things to help dad out. I do lots for my sister too. She's four next week.

KB: So, its been gradual really. You've done more as time as gone on and as your Mum has needed more support? With a young sister too, I should imagine there are lots of things to be done?

P4: Yeah, she runs around all the time!

KB: Can you tell me three things that you think of when you are asked what it is like to be a young carer?

P4: Er... frightening sometimes. Its hard really, you miss out on friends and school stuff.

KB: Do you think there are any advantages to caring for your Mum?

P4: Yeah, you get a lot closer to her. I've really got to know Mum a lot more.

KB: That is a really positive thing.

P4: Yeah it is.

KB: What do you like the most about it?

P4: That really, you get to know your parent more. There is more responsibility too.

KB: Is that a good thing?

P4: Yeah, it is for me. I'm usually lazy!

KB: Do you feel that your life is different from other people your age who aren't carers?

P4: Yeah, definitely.

KB: Could you say in what type of way?

P4: Friends. You can't go out. Can't do after school activities. You grow up quickly too, more mature like. Mum has carers coming in from services because Dad works as a teacher.

KB: So, you feel that you miss out on friendships and you've found that you are different from them because you are more mature as a result of having a care responsibility?

P4: Yeah

KB: You also mentioned that carers help support your Mum and relieve some of the tasks that you and your Dad do. Where are these carers from?

[Participant 4 continued]

P4: Social Services

KB: Right. I'm going to come on to ask you a bit about services in a minute if that's OK. How do you think your life would be different if someone took over your role as a carer?

P4: I'd have more time to go out. I wouldn't want someone to totally take over though.

KB: So you'd like to go out a bit more but still have a role in helping to look after your mum?

P4: Yeah.

KB: Have you had to take much time off school?

P4: Yeah, loads. Mum had a bad spell last year for ages so I had about half a year off to look after her.

KB: So, you missed school for six months. Have you had a hard job catching up?

P4: No not really. It was Year 8. Dad couldn't miss many days really 'cos he's a teacher but he didn't want me to miss much either.

KB: A teacher. It sounds like that was quite a hard time to work out a balance really.

P4: Yeah it was, Mum was quite bad then but she's better than she was then.

KB: So, you are now back in school. Do you find yourself thinking about your Mum when you are there?

P4: Yeah. Quite a bit. It's mainly if I think she might be there on her own. That doesn't happen much now.

KB: Can you concentrate?

P4: Yeah, most of the time. I do worry whose going to be there. If I leave to come here I know that my Dad arrives home five minutes after we've left so I know she'll be O.K.

KB: Do you find yourself having to work out things like this in your head to bring your worries down?

P4: Yeah, you look at your watch a lot.

KB: So, would you say that most of the distraction is about wondering whose going to be there with your Mum, and when.

P4: Yeah.

KB: What's the most difficult thing about not being with her?

P4: If she's had a bad week. I worry then. She sometimes goes into a trance, and has been kind of knocked out. I worry that she might hurt herself. She got stuck at the top of the stairs a few weeks ago and couldn't get down. I wouldn't be able to lift her, she's quite a large lady really.

KB: So you worry she might not be safe or might come to harm?

P4: Yeah.

KB: What about enjoying the break for a while if you are at school or out elsewhere?

P4: Yeah, that's good. I like playing on the computer or playing football.

KB: From what you've said it sounds like football is a big thing for you that you really enjoy.

P4: It is yeah.

KB: Right, imagine we've got a fast forward button and we're going to whiz forward ten years. You are now 24. Where do you see yourself?

P4: 24. Er... I'd be popping in, no I'd probably still live at home because Mum's is a long-term illness. I'd like to join the fire service.

KB: You think you'll be caring then too, living at home but possibly be trained as a fire fighter. You are definitely tall enough! OK, so that's how you imagine it, what would your dream future be like if you could be doing anything.

[Participant 4 continued]

P4: I'd like Mum to be better, that would be the best future.

KB: So you would like that to be your dream, about your Mum, not just what you would like.

P4: [Nodded]

KB: Can you choose five words for me that describe what your relationship is like with your Mum? You have already given me some idea.

P4: I'm closer to her, I talk to her a bit more, it distresses me a bit when I see her when she's down.

KB: Mmm, sure. You mentioned X that services help out too. What do they do?

P4: There are a few carers that visit and help Mum get washed and dressed and stuff. Cath comes on Mondays, Louise..

KB: Do they visit every day?

P4: Yeah.

KB: Does your Mum have any time on her own?

P4: Not really no. They help her shop and stuff too.

KB: Does that help then mean that there is less for you to do?

P4: Yeah, things like housework and stuff but I do it at weekends.

KB: Has it been helpful to have them come in for *you*?

P4: It does take my mind of it and lets me concentrate on my school work and stuff.

KB: So, less housework and more homework?

P4: [laughs] Yeah.

KB: Could it be better X?

P4: No, that's the most help we could get I think. They don't tuck her in at night or anything.

KB: Do you do that?

P4: Dad tends to but I'm around.

KB: How long have you been coming to the Group?

P4: Since September.

KB: What is it like?

P4: Alright. You have a laugh.

KB: Can you name one good thing and one bad thing about it?

P4: You get to meet lots of people. There isn't a bad one really.

KB: That's good. So imagine you could have any kind of help at all, what would you find the most helpful?

P4: Probably help to look after my sister. We do that after the carers have gone.

KB: Can your Mum look after her?

P4: She can't do a lot really, it makes her worse. Its been worse since she couldn't drive anymore.

KB: That has been very hard for your Mum?

P4: Yeah, she misses driving I think.

KB: So, help would involve supporting the care your sister needs.

P4: Yeah. She's really energetic.

KB: Who would you most like to do this?

P4: Someone we knew already, a friend. A friend, Chris does do this sometimes, comes to take her out and stuff.

KB: That sounds like it helps your Mum.

P4: Yeah.

[Participant 4 continued]

KB: Well, do you think we've missed anything. Have you thought of anything as we've been talking that we haven't covered?

P4: Er, I don't think so no.

KB: OK. I'm very grateful for the time you've spent with me on this. Before we end, could you come up with two words to describe how you found this interview part of the project?

P4: Alright. It wasn't hard. I think it made me think what I've had to do for Mum.

It wasn't upsetting or anything. The other questionnaires were a bit long and the first questionnaire was a bit confusing.

KB: I'm glad you didn't find that it upset you, and it seemed to allow you to think about things at home a bit. The pack was quite long. The first questions were from an American form that isn't the easiest one to fill in so thank you for persevering and for being honest now in saying what was confusing and long.

[Interviewee was debriefed and thanked for his participation.]

## Participant 5

**Female: Aged 12 years** Caring for her father who has MS and depression. Lives at home with her Mother and younger sister (aged 8).

KB: Do you help to look after someone in your family X?

P5: Yeah, my Dad's got MS.

KB: MS. Has he had MS for a long time?

P5: About four years now.. er..yeh.

KB: So, have you been helping to look after him for four years?

P5: Mmm. More now really, but yeah, since he started getting bad really.

KB: So over time, you've found your Dad has needed more help from you. Can you remember how you began to help look after him?

P5: Not really. It just started and he was quite bad for a bit really- He's in a wheelchair now 'cos his legs ache a lot and stuff.

KB: So again, as time has gone by things have changed for him and now that his legs are bad he perhaps needs more help than he did, say, a year ago.

P5: Yeah he does.

KB: Can you tell me three things that you think of when you are asked what it is like to be a young carer?

P5: Tiring, worrying, important.

KB: Those are three good words. Are there any advantages to caring for your Dad?

P5: Yeah, you get to learn things quickly. You talk a lot more too.

KB: What sorts of things do you learn?

P5: Er.. just like things Dad might need, whether his wheelchair will fit in places and things.

KB: I see. So maybe if you go to the shops and things you have to learn how to get around the best way?

P5: Yeah.

KB: What do you like the most about it?

P5: Just being with him really. It makes you feel special too.

KB: Special because you help him with things that he needs an extra set of hands for?.

P5: Yeah.

KB: Right. Do you think that your life is different from other people your age who perhaps don't help to look after someone?

P5: Yeah. You're inside a lot more. Don't really go out.

KB: So you spend time indoors when perhaps you might have been going out with friends or playing sport or something?

P5: Yeah but I don't mind. Dad used to teach at a College.

KB: I see.

P5: I think he's finished now.

KB: Does he help with your work?

P5: Maths he does yeah.

KB: I heard you say that you don't mind, do you miss your friends?

P5: Yeah.

KB: Mmm. So do you think your life might be different if someone took over your role as a carer?

P5: Yeah a bit. I wouldn't have to look after my sister as much.

KB: Do you do a lot for her?

P5: Its more when Mum's on nights and I've got to get her in bed so Dad can be quiet downstairs.

[Participant 5 continued]

KB: So looking after your sister would be something that would change, especially when your Mum isn't there to help. Does your sister go off to bed with your help?

P5: Yeah. She's quite good really.

KB: And you like to keep things quiet for your Dad too?

P5: Yeah. He doesn't like too much noise and stuff.

KB: I see. I just want to spend a bit of time asking about school. Have you had to miss much school because of helping out at home?

P5: No.

KB: That's good. How easy is it to concentrate at school?

P5: Its alright. I do think about home but I can do stuff.

KB: Good, so it doesn't disrupt too much. What is the most difficult thing about not being there with your Dad.

P5: I know my Mum is there so its OK, she works nights a lot so she's there in the daytime.

KB: Having your Mum there in the day means you can concentrate on school more then.

Do you enjoy the break?

P5: Yeah. Except for lessons being boring sometimes.

KB: Mmm, I remember those! It sounds like you can switch off a bit then. Do you do other things that let you switch off?

P5: What like?

KB: Er.. hobbies, TV?

P5: Oh, my homework and listening to my CD's.

KB: Great. Imagine we had a fast forward button and I whiz you forward in time by ten years. You are now 24 years old. Where do you see yourself?

P5: 24. (laughs). I want to work in a home or something, helping people with MS like my Dad's got.

KB: You'd like to work with other people like your Dad, getting to know others with MS.

P5: In a home or something.

KB: So your intended future looks like that, what would your dream future look like?

P5: I don't know.

KB: If you could have anything.

P5: [long pause]

KB: Is that a tough one to think over?

P5: A bit. Like money or something?

KB: It could be anything really. What I'm trying to get at is sometimes people really wish that their future will be spent travelling a lot, having a family of their own, maybe owning a flash car, things like that and I just wondered whether your ideal future had things in it that you really wished for?

P5: Er, to be rich probably, I'm not sure.

KB: OK, that's fine. Could you give me five words to describe what your relationship is like with your Dad. I've already got a fair idea.

P5: Fun, close, scary sometimes, er...

KB: OK, its fine if five don't come into your head. Thank you for those. Do you get any help in looking after your Dad?

P5: My mum and my sister.

KB: Right, good. How old is your sister?

[Participant 5 continued]

P5: She's nine.

KB: So its a bit of team work is it? Does anyone from services visit to help?

P5: Yeah, they haven't been for a bit. Dad goes out with this nurse sometimes.

KB: Its not that regular then?

P5: No. He's really nice though.

KB: Good. Your Dad gets on with him?

P5: Yeah.

KB: Have we missed anyone else who visits or goes out with your Dad?

P5: No. Family come quite a bit.

KB: Right. Could the help be better for you in any way?

P5: Er.. sometimes when Mum's on nights it might help then.

KB: Any particular things in mind that they could help with?

P5: My sister. Drinks for Dad.

KB: Right. Who would be the best person to do that?

P5: Dad's friends or someone we know.

KB: A friend or family member rather than someone in a service then?

P5: I think so.

KB: How often do you come to the Young Carers Group?

P5: Not very often. It's a bit different at the moment, different stuff to do.

KB: Oh, how do things normally happen then?

P5: J or S usually visit at home. We go out then to the park or cinema or something. Its good, I don't know everyone but we're all carers. I know V and J.

KB: So, how long have you been part of the Group then?

P5: About 2 years I think.

KB: That's quite a while. Can you name one good thing and one bad thing about it?

P5: No. You get to go out, that's good.

KB: So, that's one thing- you like it because you go out places. Anything you don't like?

P5: No.

KB: Good. How about more group things like tonight?

P5: Yeah, that would be good sometimes too.

KB: Just sometimes then. If you could have any kind of help what would you find the most helpful do you think?

P5: Not sure. Just when my Mum's out sometimes- someone to look after my sister.

KB: Yes. We've come nearly to the end now, have we missed anything? Is there anything you'd like to say?

P5: No, don't think so.

KB: No other thoughts, OK, you've been thinking quite hard through this. Last two thoughts for tonight then- can you give me two words to describe how you have found the project, good or bad, by telling me or writing them down and putting them in here?

P5: Its been good, coming in and being together and the questions were good really. There were quite a lot on the first one.

KB: The first one in the pack?

P5: That number thing. I didn't get some of them.

KB: Mmm. Its not the easiest one to work out really. Thank you for telling me that. Anything bad about it, it can be absolutely anything?

P5: No.

[The participant was debriefed and thanked for her involvement in the interview and research]

## Participant 6

**Male: Aged 15 years** Primary carer for Mum (neurological problems/wheelchair dependent) Mum's new partner is supportive but works shifts. Two brothers-both with learning disabilities (eldest- 17 yrs:autism). Organises their preparation for school-washing, dressing, breakfast.

KB: So D, you help to look after your Mum?

P6: Yeah and my two brothers.

KB: How old are your brothers?

P6: Twelve and seventeen.

KB: Right. How did you become a carer?

P6: It started from Mum feeling ill one day really. There's less she can do now.

KB: So, as she's found things more difficult, do you think you've taken them on?

P6: Yeah.

KB: When did you start to look after your Mum?

P6: When I was ten.

KB: So you've been a carer now for five years. Can you tell me three things that you think of when you are asked what it is like to be a young carer?

P6: Erm, sad, sometimes happy and angry.

KB: Do you think there are any benefits to caring for your Mum?

P6: Yeah. It makes me feel good if I know I'm doing it. Mum tells me too.

KB: So when you feel like you have got something done and your Mum tells you perhaps that you've done it well, that makes you feel good?

P6: Yeah.

KB: What do you like the most about it?

P6: That really.

KB: Do you feel that your life at the moment is different from other people your age who aren't carers because you help at home?

P6: Yeah. You can't go out, can't watch TV and I can't really spend much time with Mum on her own because of my brothers.

KB: How do you think your life would be different if someone else took over your role as a carer?

P6: I wouldn't like that much. I like what I do. I know I'm doing it right and someone else wouldn't.

KB: That's important. You wouldn't like anyone else to take over in case they didn't do it right?

P6: No.

KB: What do you think of the term 'young carer' then?

P6: It doesn't bother me really- I suppose it helps other people know what you are and what you do. I feel angry if people say its not good to be a young carer though.

KB: So, if people suggest that it might be a burden then you don't like this?

P6: No, it is hard sometimes but I wouldn't want anyone else to take over what I do.

KB: Thank you for telling me that X. Have you had to take much time off school?

P6: Yes, in the past. I took a full week off recently when Mum went into hospital. I caught up eventually.

KB: Does it feel like "catch up" very often?

[Participant 6 continued]

P6: Yeah, loads. The teachers understand though.

KB: That's good. When you are at school or away from home, do you find yourself thinking about things at home?

P6: Yeah. I can't really settle down.

KB: In what way? Can you tell me a little bit more about that?

P6: I can't concentrate very much and I don't always really listen to what's going on.

KB: Right, there are times you get distracted as well. What's the most difficult bit about not being with them?

P6: Just in case she turns ill or my brothers are ill.

KB: Do you ever manage to enjoy the break?

P6: No.

KB: Are there any things that you enjoy doing when you aren't helping at home?

P6: I like coming here. I went on holiday with school last year but I didn't enjoy it much. I wanted to be back really. I sometimes go into town to get things for Mum.

KB: Do you ever get out into town and look forward to buying things for you?

P6: No. Its like that question on that sheet- I can't think of any times when I feel happy.

KB: Most of the time you find you are unhappy then and don't look forward to doing things?

P6: Mmm.

KB: What about thinking about what the future might be like X? Imagine we had a fast forward button. Where do you see yourself in ten years time?

P6: Being on an air base, as a fighter pilot. I'm in the ATC.

KB: So you already know what you want to do- how often do you go there?

P6: Once a week.

KB: Right. What about that?. Does that help you to switch off?

P6: No. I'm not there that long and I still think about them really.

KB: OK, so "X of the future" would like to be a fighter pilot. A career of your own, leaving home and everything.

P6: Oh, I don't think I'll leave the caring behind. You can stay at home all the time and get calls out so I might do that.

KB: Right. Can you choose five words for me to describe what your relationship with your Mum is like?

P6: Happy, upset, angry...with my brothers, and stressed.

KB: Stressed. You or your Mum?

P6: Me and Mum.

KB: Do you get any help in caring?

P6: No, just me.

KB: So, could the help situation be made better for you in any way?

P6: No, I wouldn't want that. If they did something wrong, I'd get really angry.

KB: So generally you'd like the control for it really and then you feel things are being done properly? Imagine you could have any kind of help you wanted though, just for a minute, what would you find the most helpful?

P6: Someone to help in the mornings with my brothers, getting them ready for school and stuff.

KB: So, although you wouldn't really like it, someone to help your brothers in the morning might help you a bit? Who would be the best person to do that do you think?

P6: Erm, just someone I know, ..trusted. I don't trust services, especially social services, we've fallen out with them loads of times.

[Participant 6 continued]

KB: Right, so that someone would have to be reliable and trustworthy. Family?.

P6: There isn't anyone really.

KB: A trustworthy volunteer that you might have to get to know?

P6: Suppose if they were nice with my brothers.

KB: Right. Have we missed anything? Is there anything else you'd like to say or ask me about?

P6: No.

KB: Could we end by asking you to think of a few words to describe how you have found this project, you can write them down and put them in here if you wanted.

P6: Its been fun but hard.

KB: Hard questions?

P6: Yeah.

KB: Could you describe in what way?

P6: I could understand them, er..it sometimes made you think about things that you don't always like to but its important to.

KB: I'm wondering whether it might have felt intrusive for you?

P6: No, its like someone understands really, talking about it and that. It just gets you thinking really.

KB: Were there any particular areas that made you think more than others?

P6: Yeah- stuff about me in the first lot of questions and what I want in the future.

KB: Is that hard for you to think about, the future?

P6: Er, I just don't do it really.

KB: Are there any other areas you want to mention, maybe that we haven't touched on but might have made you think of a question to ask?

P6: No.

[participant was thanked and debriefed]

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## Participant 7

**Female: Aged 13 years**      Caring for Mum with multiple sclerosis. Older sister (aged 17) and older brother (aged 20). Brother no longer living at home. Father died last year.

KB: Thank you for being involved in the research X. You help to look after your Mum?

P7: Yes.

KB: How did this start?

P7: Probably about two years ago now, I can't remember. She couldn't get around and kept dropping things.

KB: So you began to notice that maybe she wasn't as strong as she had been before?

P7: Yeah. She still does loads for herself, she doesn't like us taking over.

KB: Keeping her independence is important to her then? Have you helped out for about two years then?

P7: Yeah. My brother left last year so, yeah.

KB: How did you decide who did what?

P7: Me and my sister did more really- David had to work and stuff.

KB: So you supported things that your Mum wanted particular help with, trying not to take over?

P7: Yes.

KB: Can you tell me three things that you think of when you think of when you are asked what it is like to be a young carer?

P7: Its sometimes lonely, not too bad, and ...irritating, sometimes.

KB: That's quite a mixture really, lonely at times and irritating, generally OK?

P7: I get irritated if I want to do something else or now Mum can't drive long distances so we can't go out to places as much.

KB: I see. Do you think there are any benefits to being a carer?

P7: Yes. Spending time together mainly.

KB: Right. What do you like the most about it?

P7: That really, doing things with Mum.

KB: Do you feel that your life is different from other young people your age who aren't carers because you help to look after your Mum?

P7: I suppose so but not that much.

KB: Can you think how it is different? What things might you be doing if you weren't helping your Mum?

P7: I can't see friends cos I haven't got much transport -er, its not that different.

KB: OK. How about if someone took over your role, can you think of any things being different then?

P7: I might go out a bit more, I wouldn't be in the Group then either.

KB: That's true. No major differences though?

P7: No.

KB: Have you had to take much time off school to help look after your Mum X?

P7: No.

KB: How is it at school? Do you find yourself thinking about things at home?

P7: Not really. I don't worry.

KB: So you are able to concentrate on your work and things?

P7: Yes, I can.

KB: Is there anything difficult about being away from your Mum during the day?

[Participant 7 continued]

P7: She's usually alright so I know she can do most things. A friend visits quite a lot too.

KB: That's good. So, switching off a bit happens because you know your Mum manages quite well, and someone visits quite often in the daytime too. Are there other things you enjoy that help you to switch off a bit?

P7: Playing my play station and listening to my CD's.

KB: Great. Dare I ask what your favourite game is?

P7: Overboard.

KB: I've seen that –it looks quite complicated.

P7: Its easy.

KB: With lots of practice!. OK, imagine I could fast forward you in time to ten years from now. Where do you see yourself?

P7: I want to be a vet. I hope to go to University.

KB: Wow. Lots of hard work in the ten years then!. So, will you leave home for University?

P7: Yes, probably.

KB: OK. What would your dream future look like?

P7: That really, being a vet and having lots of animals.

KB: Sounds interesting. Can you choose five words to describe what your relationship with your Mum is like X?

P7: Its good, we get on well.

KB: Right. Do you get any help for the things you've described on the questionnaire that you do for your Mum? Apart from your sister and brother.

P7: No, friends of Mum really.

KB: No services then?

P7: We did have a social worker about a year ago but she hasn't been for ages. She came to do some forms with Mum.

KB: What did she help with?

P7: I don't know, money and stuff I think.

KB: Imagine you could have any kind of help at all, what would you find the most useful?

P7: [long pause]. Someone to take Mum out probably. She can do lots of things though so I don't know what help she would want.

KB: OK. Would anything help your role?

P7: Not really.

KB: OK. How long have you been coming to the Group?

P7: Since August 1997

KB: So, about 7 months. Do you like it?

P7: Yeah, you make friends and get away from your family. I don't see Sarah often so its good. We only meet as a Group in the holidays.

KB: That's right. Would you like it to be more than that?

P7: I don't know really, maybe more often.

KB: Does Sarah come during the holidays too?

P7: Yeah, you were talking to her before.

KB: Yes. So people have friends here. What might be a bad thing about the Group?

P7: There isn't anything really.

KB: Well that's good!. Have we missed anything? Is there anything else that you'd like to say that we haven't covered?

[Participant 7 continued]

P7: Don't think so. Have you got to ask everyone these?

KB: Only a few people like yourself who volunteered. Are you worried about the interview answers?

P7: No, I just wondered if everyone answered this bit too. How many people have filled in the packs for you?

KB: So far, about thirty. They are all unnamed though so I don't know who has answered what. Is there anything else that I covered this morning about the project that you want to know more about or any questions you want to ask me?

P7: No, I can't think of any.

[X was fully debriefed and thanked for her participation in the research]

## **APPENDIX 9**

### **Questionnaire Pack Measures a – g**

- a) Participant information sheet**
- b) Offer Self-Image Questionnaire –Revised (short-form)**
- c) Birleson Depression Scale (BDS)**
- d) The Spence Children’s Anxiety Scale**
- e) The Care-Giving Intrusiveness Rating Scale (CIRS)**
- f) Care Task Information (Job description)**
- g) Amended Activities of Daily Living measure (omitted following pilot study)**

**(All measures were reproduced in colour for the research study)**

Carer source:  
Grouping variable:

**Demographics**

**Section 1**

- i) Gender:
- ii) Age:
- iii) Locality: town/rural
- iv) Current education:
- v) Does the young carer live primarily with their parents/ Grandparents?
- vi) Any brothers/sisters also living at home?
- vii) Any unusual circumstances?

**Section 2**

- i) Parent cared for:
- ii) Perceived level of care provided by this young carer:  

1	2	3	4
Minimal	Moderate	Significant amount	Primary carer
- iii) Predominantly  
Physical disability  
Mental health needs  
Or both
- iv) Known others cared for within the household
- v) Is anyone else in the family also regarded as a carer for this parent?.
- v) Length of time as a carer
- vi) Age started caring
- vii) Length of time attending Carer Group

**Section 3**

- i) Known status of family (employed, unemployed, benefits)
- ii) Known services the family receives (source, frequency if known)

**A  
f  
e  
w  
q  
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i  
c  
k  
p  
e  
r  
s  
o  
n  
s**

Are you male or female?

M  F

How old are you?

\_\_\_\_\_

What area do you live in?

\_\_\_\_\_

Please tick the following boxes to show who lives at home:

- Mum
- Step-Mum/partner
- Dad
- Step-Dad/partner
- Brother (s)  How many? \_\_\_\_\_
- Sister (s)  How many? \_\_\_\_\_
- Grandparents
- Anyone else? \_\_\_\_\_

Does anyone in your house have a paid job?  
(please state who)

\_\_\_\_\_

Do you help look after your Mum or Dad due to a long term illness or disability?  
(if yes, can you state what the condition is?)

Yes  No

\_\_\_\_\_

Does either your Mum or Dad receive benefits  
(ie money because they have a long term illness/disability)

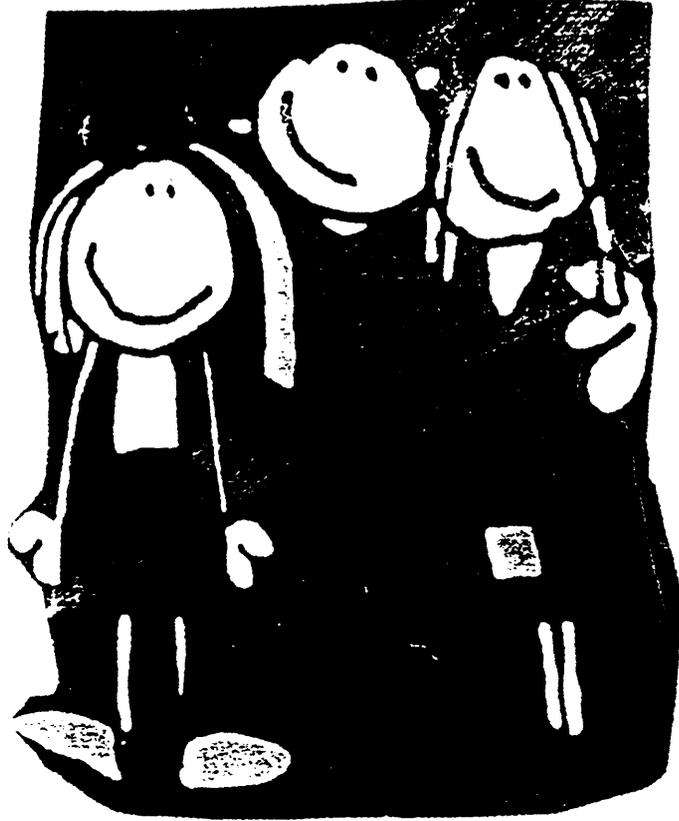
Yes  No

Do you have any jobs at home to help out?

Yes  No

If yes, what sorts of things do you do?  
(please write below if you need more space)

\_\_\_\_\_



Well Folks....

Its time to find  
that pen and  
get scribbling!





Please ask if you need help or you don't understand a question



Take as much time as you need- its not a race



Your answers will be *private* so please be as *honest* as you can



Please check that you've filled it all in!

 Thanks

# All about you

Here are some important questions that ask you for your views on different things. Please choose a response that you think fits you best and write in a NUMBER on the blank line. Ask if you aren't sure!.

\_\_\_\_\_

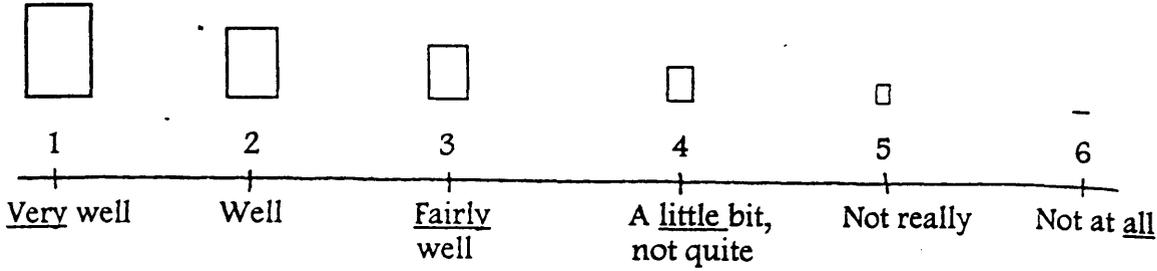
Each question describes me:

<input type="checkbox"/>					
1	2	3	4	5	6
Very well	Well	Fairly well	A little bit, not quite	Not really	Not at all



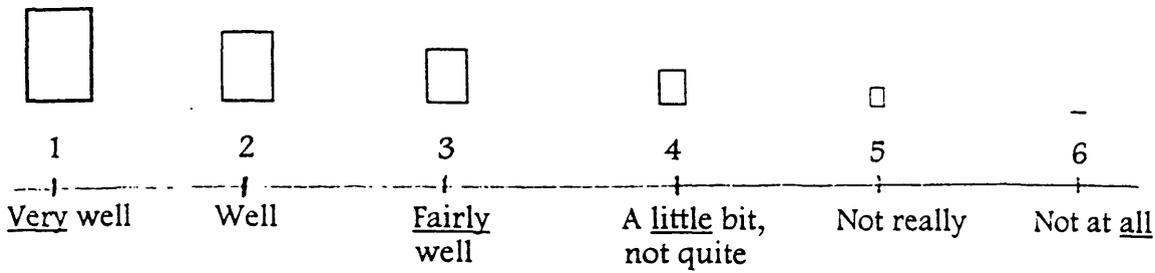
- |  |                            |
|--|----------------------------|
| 1. I find it easy to laugh and have fun.                                       | <i>Describes me:</i> _____ |
| 2. I carry a lot of grudges.   | <i>Describes me:</i> _____ |
| 3. When I am with people, I am afraid someone will make fun of me.             | <i>Describes me:</i> _____ |
| 4. Most of the time, I think the world is an exciting place to live in.        | <i>Describes me:</i> _____ |
| 5. I easily lose my temper.  | <i>Describes me:</i> _____ |
| 6. I feel tense most of the time.  | <i>Describes me:</i> _____ |
| 7. I feel that any kind of work is too much responsibility for me.             | <i>Describes me:</i> _____ |
| 8. If I put my mind to it, I can learn almost anything.                        | <i>Describes me:</i> _____ |
| 9. Very often I feel like my Dad is no good.                                   | <i>Describes me:</i> _____ |
| 10. I am confused most of the time.  | <i>Describes me:</i> _____ |
| 11. I don't feel as good as most of the people I know.                         | <i>Describes me:</i> _____ |
| 12. I can count on my parents most of the time.                                | <i>Describes me:</i> _____ |
| 13. I am happy most of the time.   | <i>Describes me:</i> _____ |
| 14. I am going to devote myself to making the world a better place to live in. | <i>Describes me:</i> _____ |
| 15. Sometimes, I feel so ashamed of myself.                                    | <i>Describes me:</i> _____ |
| 16. I am sure that I will be proud of the job I do in the future.              | <i>Describes me:</i> _____ |
| 17. When I want something, I just sit around wishing I could have it.          | <i>Describes me:</i> _____ |
| 18. I am one of the better students in school.                                 | <i>Describes me:</i> _____ |

Each question describes me:



- 19. I feel emotionally empty most of the time. *Describes me:* \_\_\_\_\_
- 20. I would rather sit around than work. *Describes me:* \_\_\_\_\_
- 21. Even if it were dangerous, I would help someone if they were in trouble. *Describes me:* \_\_\_\_\_
- 22. Our world is competitive, but I am not afraid of it. *Describes me:* \_\_\_\_\_
- 23. I get violent if I don't get my own way. *Describes me:* \_\_\_\_\_
- 24. I think that other people just do not like me. *Describes me:* \_\_\_\_\_
- 25. I am proud of my body. *Describes me:* \_\_\_\_\_
- 26. I manage to stay calm, even under pressure. *Describes me:* \_\_\_\_\_
- 27. I often feel that I would rather die than go on living. *Describes me:* \_\_\_\_\_
- 28. When I grow up and have a family, it will be similar to my own family in at least a few ways. *Describes me:* \_\_\_\_\_
- 29. I find it very hard to make friends. *Describes me:* \_\_\_\_\_
- 30. I would rather be supported for the rest of my life than have to work. *Describes me:* \_\_\_\_\_
- 31. I feel that I have a part in making family decisions. *Describes me:* \_\_\_\_\_
- 32. I feel very lonely. *Describes me:* \_\_\_\_\_
- 33. I feel pleased when a job is done well. *Describes me:* \_\_\_\_\_
- 34. My parents are usually patient with me. *Describes me:* \_\_\_\_\_
- 35. I prefer being alone than with people my age. *Describes me:* \_\_\_\_\_
- 36. Very often, I think that I am not the person I would like to be at all. *Describes me:* \_\_\_\_\_
- 37. If I know that I have to face a new situation, I will try before to find out as much as possible about it. *Describes me:* \_\_\_\_\_
- 38. Usually I feel like I am a trouble to people at home. *Describes me:* \_\_\_\_\_
- 39. Being with other people makes me feel good. *Describes me:* \_\_\_\_\_

Each question describes me:



- 40. I often feel ugly and unattractive. *Describes me:* \_\_\_\_\_
- 41. My parents are ashamed of me. *Describes me:* \_\_\_\_\_
- 42. I feel strong and healthy. *Describes me:* \_\_\_\_\_
- 43. There is nothing wrong with putting yourself before other people. *Describes me:* \_\_\_\_\_
- 44. I try to stay away from home most of the time. *Describes me:* \_\_\_\_\_
- 45. I find life is an endless string of problems, without any solutions in sight. *Describes me:* \_\_\_\_\_
- 46. I feel that I am able to make decisions. *Describes me:* \_\_\_\_\_
- 47. Most of the time my parents are satisfied with me. *Describes me:* \_\_\_\_\_
- 48. I do not have a particularly difficult time making friends. *Describes me:* \_\_\_\_\_
- 49. I do not enjoy solving difficult problems. *Describes me:* \_\_\_\_\_
- 50. Very often I feel like my Mum is no good. *Describes me:* \_\_\_\_\_
- 51. Usually I can control myself. *Describes me:* \_\_\_\_\_
- 52. I enjoy most parties I go to. *Describes me:* \_\_\_\_\_
- 53. I often feel sad. *Describes me:* \_\_\_\_\_
- 54. I think I am a nice person. *Describes me:* \_\_\_\_\_



# How are you feeling?



The sentences below ask about how you have been feeling over the past week. It is important to say how you have felt so please answer them as honestly as you can. There are no right answers so put a tick in the box that you think is right for you.

	Most of the Time	Sometimes	Never		Most of the Time	Sometimes	Never
1. I look forward to things as much as I used to	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	10. I think life isn't worth living	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. I sleep very well	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	11. I am good at the things I do	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. I feel like crying	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	12. I enjoy the things I do as much as I used to	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. I like to go out	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	13. I like talking with my family	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. I feel like running away	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	14. I have horrible dreams	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. I get tummy aches	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	15. I feel very lonely	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. I have lots of energy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	16. I am easily cheered up	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. I enjoy my food	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	17. I feel so sad I can hardly stand it	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. I can stick up for myself	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	18. I feel very bored	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>



Please tick the box under the word that shows how often each of these things happen to you.  
There are no right or wrong answers.

	Never	Sometimes	Often	Always
1. I worry about things	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. I am scared of the dark	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. When I have a problem, I get a funny feeling in my stomach	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. I feel afraid	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. I would feel afraid of being on my own at home	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. I feel scared when I have to take a test	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. I feel afraid if I have to use public toilets or bathrooms	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. I worry about being away from my parents	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. I feel afraid that I will make a fool of myself in front of people	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. I worry that I will do badly at my school work	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11. I am popular amongst other kids of my own age	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12. I worry that something awful will happen to someone in my family	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13. I suddenly feel as if I can't breathe when there is no reason for this	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14. I have to keep checking that I have done things right (like the switch is off, or the door is locked)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15. I feel scared if I have to sleep on my own	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
16. I have trouble going to school in the mornings because I feel nervous or afraid	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
17. I am good at sports	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
18. I am scared of dogs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
19. I can't seem to get bad or silly thoughts out of my head	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
20. When I have a problem, my heart beats really fast	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
21. I suddenly start to tremble or shake when there is no reason for this	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
22. I worry that something bad will happen to me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
23. I am scared of going to the doctor or dentist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>



# These questions ask about how much caring for your Mum or Dad affects different things in your life.

**INSTRUCTIONS** Please put a circle round which one shows how much being a carer affects the things you do. If you think a question doesn't fit, circle number 1 (very little) to show this isn't really an area that is affected. Please be as honest as you can and answer ALL the questions. Ask if you aren't sure.

**How much does caring for your Mum or Dad *interfere* with your:**

## 1. HEALTH

*Very little* 1 2 3 4 5 6 7 *Very much*

## 2. DIET (the things you eat and drink)

*Very little* 1 2 3 4 5 6 7 *Very much*

## 3. SCHOOL/COLLEGE WORK

*Very little* 1 2 3 4 5 6 7 *Very much*

## 4. SPORTS/HOBBIES

*Very little* 1 2 3 4 5 6 7 *Very much*

## 5. RELAXING (e.g. reading, listening to music)

*Very little* 1 2 3 4 5 6 7 *Very much*

## 6. MONEY

*Very little* 1 2 3 4 5 6 7 *Very much*

## 7. RELATIONSHIPS WITH FRIENDS/PEOPLE YOUR AGE

*Very little* 1 2 3 4 5 6 7 *Very much*

## 8. DEVELOPING YOUR OWN INDEPENDENCE

*Very little* 1 2 3 4 5 6 7 *Very much*

## 9. RELATIONSHIPS WITH YOUR FAMILY

*Very little* 1 2 3 4 5 6 7 *Very much*

## 10. MAKING PLANS FOR THE FUTURE

*Very little* 1 2 3 4 5 6 7 *Very much*

**Last One**

Here's something different



**Imagine** you are writing a short job description for someone you trusted to take over the caring you do for your Mum or Dad for one month.

**What would they need to be able to do?**

**What do YOU do now that THEY would have to also do?.**

Think about what you do to help from when you get up to when you go to bed.

1) What sorts of things do you need to do (i.e. around the house, outside of home) for your Mum/Dad?.

2) What things do you do to help your Mum/Dad look after themselves, their health and their appearance/hygiene?

3) Have we missed anything-anything else you can think of that you do to help (ie look after sisters/brothers etc)?

...Phew.....

Made it!!

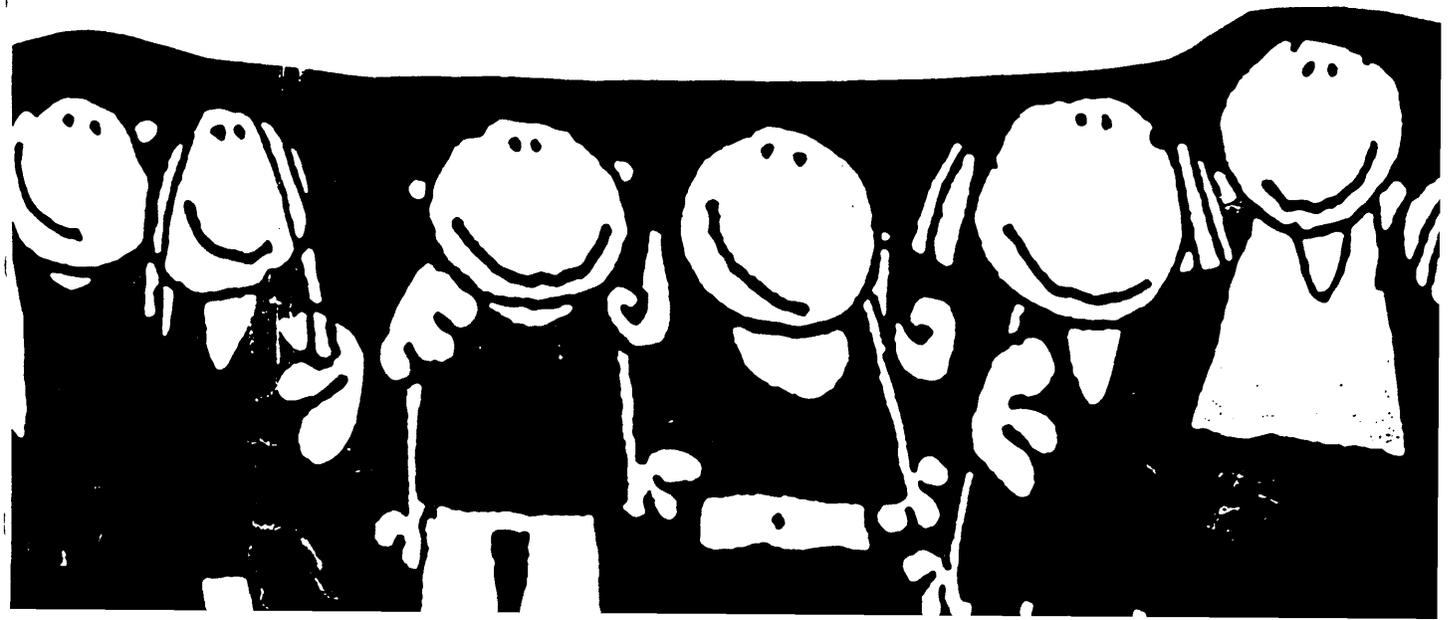
THANKS FOR YOUR HELP!

Please check that you've filled everything in for us.



*Bye,*

*Kate*



## Activities of Daily Living Questionnaire (ADL)

**INSTRUCTIONS:** Below you will find a list of activities. Think about your \_\_\_\_\_ and how s/he manages each one. Choose which one it is from the top line and circle the number below it to show whether they need help or can do things easily. Please could you also tick whether you help with this or not?. Ask for help if you aren't sure.

**For example:**

Sally's Mum does make her own drinks but she finds this task very difficult/tiring. Sally helps her do this. Sally would circle this column:

	Not at all	With help	Alone with difficulty	Alone easily	Do you help with this?
She manages to make a hot drink	1	2	3	4	

	Not at all	With help	Alone with difficulty	Alone easily	Do you help with this?	
<b>Mobility</b>						
Does your _____:						
Can walk around outside?	1	2	3	4	Y	N
Can climb stairs?	1	2	3	4	Y	N
Can get in and out of bed?	1	2	3	4	Y	N
Can get in and out of a car?	1	2	3	4	Y	N
Can cross roads?	1	2	3	4	Y	N
Can travel on public transport?	1	2	3	4	Y	N
<b>In the kitchen</b>						
Can manage to feed themselves?	1	2	3	4	Y	N
Can manage to make themselves a hot drink	1	2	3	4	Y	N
Can do the washing up?	1	2	3	4	Y	N
Can make themselves a hot meal?	1	2	3	4	Y	N
<b>Domestic tasks</b>						
Can manage their own money when out?	1	2	3	4	Y	N
Can wash small items of clothing?	1	2	3	4	Y	N

please turn over.....

	<b>Not at all</b>	<b>With help</b>	<b>Alone with difficulty</b>	<b>Alone easily</b>	<b>Do you help with this?</b>	
<input type="radio"/> do their own shopping?	1	2	3	4	Y	N
<input type="radio"/> do a full clothes wash?	1	2	3	4	Y	N
<b>Self-care</b>						
<input type="radio"/> manage to dress themselves?	1	2	3	4	Y	N
<input type="radio"/> manage to bath themselves?	1	2	3	4	Y	N
<input type="radio"/> manage to use the toilet?	1	2	3	4	Y	N
<b>Leisure activities</b>						
<input type="radio"/> read newspapers or books?	1	2	3	4	Y	N
<input type="radio"/> use the telephone?	1	2	3	4	Y	N
<input type="radio"/> write letters?	1	2	3	4	Y	N
<input type="radio"/> go out socially?	1	2	3	4	Y	N
<input type="radio"/> manage the garden?	1	2	3	4	Y	N
<input type="radio"/> drive a car?	1	2	3	4	Y	N

Thank you for completing this. Please check that you have answered ALL of the questions

## **APPENDIX 10**

**Newspaper Article: 'Who Cares For Young Carers?' (May 20<sup>th</sup> 1999)**

KNIGHTON & HUMBERSTONE

# Mail

PART OF THE LEICESTER MAIL SERIES

THURSDAY, MAY 21, 1993

## WHO CARES FOR YOUNG CARERS?

MORE than 100 city children, many as young as 10, are known to be looking after mentally and physically ill parents - and the number not registered is thought to be far bigger.

Leicester Social Services has identified 108 children, aged on average just 11, who take care of disabled and sick relatives at home.

The department's children's and family's service is responsible for working alongside voluntary groups such as the city-based Carefree Young Carers Project in a bid to reduce the burden on these youngsters.

Even though more than 100 children are registered - receiving all the help available - social workers have no way of knowing how many

By **TOM PEGDEN**

young carers there are who rely solely on family and friends for help.

Mr Chris Batty is assistant director of the children's and family's service, looking after the most vulnerable children in the city including the disabled, youngsters in homeless families, those in trouble with the law, young carers and children in care.

### Identified

Mr Batty said: "It's difficult to say exactly how many young carers there are in Leicester, but our recent management action plan identified 108 in 78 families who we referred to the Carefree Young Carers Project.

"The project provides them with practical help and gives them somebody to talk to.

"As a department we

provide home care and other help to free the young children up so that they can have all the other opportunities children their age pursue."

He added: "It's very difficult to say if they all get the support they need, but each individual child has to be assessed.

"One of the real diffi-

culties is that many young people in this situation aren't known to us because their families deal with the problem themselves."

For details on support available for young carers, contact Leicester City Council's children's and family's access service on 0116 253 1191.