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Clinical Psychology Doctorate

Children As Familial Care Givers: The psychological Implications.

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Declaration

The thesis was based on my own original idea. Dr. Tony Cassidy and Dr. Delia Cushway provided assistance in the development of ideas and formulation of the papers. Dr. Tony Cassidy gave substantial advice and support with the statistical analysis in the main paper. I carried out all data collection unless otherwise indicated in the paper. Authorship of any papers will be negotiated with the above. This thesis has not been submitted for a degree to any other university. Ethical approval was given by Coventry University Ethics Committee (see Appendix B for clearance).

Summary

This thesis is concerned with children as familial caregivers. To date 'young carers' have received limited attention from researchers, and the current body of literature has mainly developed from the social welfare field. This is in contrast to a vast body of research, which has established the psychological impact of care giving on adults. The first paper critically reviews the concept and research on 'parentification'. This is a systemic/dynamic perspective on the psychological and developmental implications of childrens' involvement in caring roles. It has been submitted to the Journal of Clinical Child Psychology and Psychiatry (see Appendix A for instructions to authors for all papers). The brief paper is a qualitative study employing focus groups and individual interviews to consider the views of twenty young carers. The aim was to gain an insight into their perceptions of the caring experience and to provide data which might be helpful in developing a measure of 'young carer stress' to be used in the main study. This paper has been prepared for the journal 'Qualitative Health Research'. The main research focused upon the application of a stress- coping model to a study of 108 adolescent young carers. It was found that those children who felt devalued in their caring role, overloaded, and used avoidant coping styles to manage their stress were most at risk of suffering from psychological distress. The results are considered in the context of the adolescent stress-coping literature and implications for prevention and intervention are discussed. Papers are prepared in accordance with the instructions to authors, although small changes to the formatting have been made to ensure consistency across all the papers. The whole thesis is less than 20,000 words (excluding references, and tables).

Literature Review

Parentification: a Conceptual and Methodological Review

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Parentification: A Conceptual and Methodological Review

Abstract

Young carers are children under the age of eighteen who provide care to a family member. Concern has been raised within the welfare services that these children are involved in levels and types of care that are developmentally inappropriate and that jeopardise their health and development. Despite a vast literature on the psychological impacts of care giving upon adult carers, there has been little investigation into the impacts upon children. This review focuses on one main area of research that has examined children as caregivers; research on the 'parentified child'. This literature derives from the traditions of systemic theory and is primarily concerned with establishing how care giving as a child impacts upon adult functioning. Studies suggest that identity development and personality, interpersonal relationships, and relationships with an individual's own children could be affected. How the literature conceptualises caring and the psychological theories that underpin the concept of parentification are discussed. The empirical studies are then summarised under four headings; precursors to parentification, impacts upon adult relationships, direct impacts upon the child and circumscribed research. Conceptual and methodological limitations are discussed. These include the lack of a clear definition of parentification, and problems with measurement, sampling and design. Finally, recommendations for improving and developing the parentification literature are presented that draw upon studies of resiliency, adult care giving and attachment.

Key words: care giving, parentification, role reversal, young carers, identity

Introduction: social context and scope of this review

Children as carers: the social context

It has been estimated that 50,000 children are involved in looking after an ill or disabled family member in the United Kingdom (Becker, Aldridge & Dreaden, 1998). These 'young carers' are defined as children under the age of eighteen, who provide 'substantial amounts of care on a regular basis' (Department of Health, 1996a). They are often involved in developmentally inappropriate tasks of a nature, or to an extent that the role restricts other opportunities and experiences that are crucial to their healthy development (Becker et al, 1998: p.13-14).

To date, the psychological impact upon children responding to care giving roles has received scant attention, with limited literature from a psychological perspective looking at 'young carers' per se. This is in spite of a vast body of both qualitative and quantitative research into the impact of family care giving upon adults (see Kahana, Biegel, & Wykle, 1994; Orbell, Hopkins,Gilles & Ungerson, 1993; Nolan, Grant & Keady, 1997).

Scope of this review.

The concept of children giving care is implicit within a number of bodies of literature. Chase (1999: p.3) suggests that studies relating to children of alcoholics, sexual abuse, and divorce all contain aspects of children providing care to another family member, usually a parent. The literatures on parental or sibling illness and disability are also associated with children as carers and have been reviewed elsewhere (Damiani, 1999;Kelley, Sikka & Venkatesan, 1997; Rolland, 1999). This review takes as its focus, research on the parentified child. This has been selected as it relates directly to care giving by children. It is an empirical literature with psychological foundations. The parentification literature places an emphasis on emotional care giving. However, other more practical aspects are also considered. 'Parentification', therefore has the potential to inform our understanding of the impacts of care giving upon children as it offers a broad conceptualisation of care giving within a familial context.

Reviews of the literature on parentification have taken place (see Barnett & Parker, 1998; Chase, 1999; Jurkovic, (1997). Barnett & Parker (1998) discuss

circumstances where parentification may be considered likely to occur including divorce, substance misuse and sexual abuse. They conclude that the impact of parentification is dependent upon a number of factors and can only be determined at the end of an individual's life-span. Jurkovic, (1997) takes a clinical perspective to the examination of the parentification construct, making suggestions as to how and why parentification arises within families, and introduces methods of assessment, treatment and prevention. Chase, (1999) describes the literature on parentification and suggests that there is a need to critically examine the empirical literature with respect to conceptualisation, design and methodology (Chase, 1999; p.26). These aspects are the focus in this review, which examines studies on parentification, role reversal with children (rather than role reversal between a parent and their adult child), and child-adult cross-generational boundaries. These terms are described in more detail below.

Parentification – a Perspective on Care giving

Definitions

The term the *'parental child'* was coined by Minuchin and colleagues, (1967) to refer to children who assume parental responsibility in the home as a result of economic and social conditions. Later, Broszormenyi-Nagy and Spark, (1973) described a process of *'parentification'*, which broadly involves the self serving utilisation of children by a parental figure. This encompasses not only explicit care-taking roles, but also gratification of parental figure's sexual, aggressive or dependent needs. Broszormenyi-Nagy and Spark's, (1973) concept therefore focuses upon relationship patterns and family dynamics, as well as the more overt aspects of role assignment. Boszormenyi-Nagy and Spark emphasise ethical family relationships where parents enjoy their childrens' loyalty and concern but do not expect their children to look after their own emotional or physical needs. It is their process of parentification that is most frequently referred to in the empirical literature. Another term that is also used to describe the phenomenon of parentification is *'role reversal'*. This describes a child acting as parent to their parent, or a child acting as a 'mate' to their parent. Parental role reversal might include defending or nursing the parent, or acting as parent to siblings (see Kabat, 1996 for a clinical description of child as parent role reversal). Child- as- mate role reversal represents the child acting as confidant, friend or decision maker to the

in the literature and both 'child as parent' and 'child as mate' role reversal can be considered to be examples of cross-generational boundary transgressions. '*Boundaries*' represent the implicit and explicit rules and expectations that govern family relationships. Family theorists such as Minuchin and Boszormenyi-Nagy & Spark uphold that clear and defined boundaries are essential for the healthy functioning of the family and its individual members. Inappropriate alliances such as a child acting as a 'mate' to a parent are believed to upset the balance of the family system and compromise the individual members' growth and development.

Parentification-Theoretical Underpinnings.

Broszormenyi-Nagy & Spark's, original concept was considered to be a component of all relationships, including healthy ones. Care giving is viewed as a dynamic process, governed by the 'give and take' of family relationships. Conceptualised in this way, care giving by children is seen as an aspect of normal parent- child interactions. However, the pathological aspects result from excessive burden in an unsupportive environment. Jurkovic (1997) considers adaptive care taking as being dependent upon the recognition of the child's contribution, and the extent and duration of care giving. The result of overburdening the child is a shaping of the child's inter-personal style, in both the immediate and the long term. According to Broszormenyi-Nagy & Spark's theory, these patterns of relating are passed from generation to generation as the adult child seeks to compensate for their losses in childhood through their own children or adult relationships. Embedded in the theory are notions of reciprocity and balance within relationships. It is seen as healthy and appropriate that the child meets their parent's emotional needs to some degree. However this must be balanced by the care that the child receives from the parent.

The underpinning psychological concepts that are drawn upon to explain the impact of parentification are rooted in a number of theories including attachment theory (Alexander, 1992; Bowlby, 1980), social developmental theory (Erikson, 1968), object relations (Mahler, 1975) and self-development models (Kohut, 1971). Each of these models provides a framework for understanding how the developing child forms a sense of identity and an understanding of their relationship with others. For example Erickson's stage theory of psychosocial ego development (Erikson, 1959) requires the child to pass through various stages including, 'initiative versus guilt'

and 'industry versus inferiority'. The theory proposes that development is hampered if the demands upon the child are inappropriate and cannot be mastered, as consequently the child will be left with a view of themselves as inadequate (guilty and inferior). Mahler's (1975) stages of separation individuation and Kohut's self development model (1971) suggest that parentification prevents the child from developing the ability to contain and express their emotions as the parent is not responsive to the child's needs for containment. In effect, the child's developing sense of an autonomous self is compromised by the needs of the mother or the unstable family system.

Parentification –a Description of Research

Only a limited number of studies have examined parentification directly. Areas allied to this literature have attempted to examine the mother-child relationship in order to identify boundary distortions. This research examines family stressors as precursors to the parentification process. Studies examining parentification more directly focus on the long term developmental consequences of assuming care-giving responsibilities, by identifying links between parentification and adult personality processes. More circumscribed literature has investigated the effects of a parentified childhood upon academic and career choice. Few studies have examined the impact upon the child directly.

Precursors of Parentification.

A number of studies have examined circumstances where it is claimed parents may look to their children for emotional or logistical support to combat their own stresses and pressures. Schizophrenia (Bateson, Jaclson, Haley & Weakland, 1956; Karpel, 1976;Walsh, 1979), mothers with a history of sexual abuse (Burkett, 1991), mothers of low socio-economic status (Sroufe and Ward, 1980; Sroufe, Jacobvitz, Mangelsdorf, DeAngelo and Ward, 1985), divorce (Dawson, 1980), and 'intrusive' parenting styles (Jacobvitz & Sroufe, 1987) are some examples. The literature on addictions also includes concepts allied to parentification. It refers to the 'co-dependant' behaviours of children who adopt roles in their family such as 'scape-goat' or 'enabler' in order to support a family system that contains a substance abuser. Thus the literature on co-dependency implicitly and sometimes explicitly

incorporates descriptions of parentified functioning (see Olson & Gariti, 1993, Robinson, 1998b; Robinson and Post; 1995; Bekir, McLellan, Childress, and Gariti; 1993).

According to family systems theory the dynamic of the parent seeking care from their child represents a distortion of normal generational boundaries and leaves the child at risk of parentification. Parents whose own needs for nurturance were not met in childhood may attempt to satisfy their own emotional needs through their child (Karpel, 1976;Boszormenyi-Nagy & Krasner, 1986).

Studies have used a variety of methods to investigate this phenomenon including passive observational, retrospective, controlled and longitudinal designs. The observational studies (for examples see Burkett, 1991; Fish, Belsky, & Youngblade 1991; Jacobvitz & Sroufe, 1987; Sroufe and Ward, 1980, Sroufe, Jacobvitz, Mangelsdorf, DeAngelo and Ward, 1985) focus on the parenting behaviour rather than the direct impact upon the child. They attempt to capture parental behaviours that are identified through theory and observation as 'parentifying'. They then attempt to define and validate their observations through examining inter-rater reliability and by making links with other psychological variables.

For example Sroufe and Ward (1980) observed the maternal behaviour of mothers with sons. They were interested in noting the occurrence of 'seductive behaviour'; defined as manipulation of the child using promises of affection, sensuality or teasing. This type of behaviour is described as 'parentifying' as the child is drawn into meeting the needs of the mother.

Observational ratings were made of 173 mothers and their sons and sixteen mothers were identified as engaging in seductive behaviour by three independent raters. Family history interviews were also conducted with a sub-sample of mothers that included eight of the sixteen mothers classified as 'seductive'. Seven of these eight mothers had histories suggestive of parentification ranging from incest to aspects of role reversal. This was compared with four of the remaining twenty mothers not classified as 'seductive'. Sroufe and Ward attempted in this study to identify and validate a behavioural category of 'seductive behaviour'. On the basis of

Boszormenyi-Nagy and Spark's theory this may be developmentally damaging to the child. They claim support for Boszormenyi-Nagy and Spark's, (1973) theory of intergenerational patterns of relationships on the basis of the high incidence of 'parentified' histories of the 'seductive' mothers. A follow up study (Sroufe *et al*, 1985) examining the mother-daughter relationship of these mothers suggested that seductiveness was not a characteristic of the mother but an aspect of their relational history found only with their sons.

Jacobvitz *et al* (1991) investigated the transmission of role reversal across generations. They found that grandmothers' memories of over protection were related to observational ratings of high boundary distortions between the mothers and their children. Fish *et al* (1991) in a rare longitudinal study attempted to identify family characteristics as antecedents to boundary violation behaviours by parents. A number of measures were taken in infancy including parental personality, dyadic interaction between spouses, and between themselves and their child, and parental perception of the child's difficulty in infancy. Observational follow up studies at aged three indicated that husbands and wives in the boundary violation group were more likely to be over controlling and intrusive with each other than those classified as non boundary violating. These families were also characterised by low support and decline in their relationship.

Studies have also compared 'high risk' groups with controls on parentification measures. For example Goglia, Jurkovic, Burt, and Burge-Callaway, (1992) compared adult children of alcoholics with adults of non-alcoholics. Using a projective measure of boundary distortion (Walsh, 1979), which yields scores for 'child as parent' or 'child as mate'; and a self report measure of parentifiation (Sessions & Jurkovic, 1986). Goglia *et al* (1992) reported that significantly more adult children of alcoholics showed distortions in generational boundaries when compared with adult children of non-alcoholics. Child-as-parent cross-generational boundaries on the Walsh measure are described as themes of the younger generation providing for, nurturing, or defending the parent. Child-as-mate cross-generational boundaries are evidenced by sexual themes between generations, or conflicts in family loyalty.

The observational studies have been valuable for mapping the behaviours of mothers with their children in relation to their own parenting history. However with this design it is not possible to infer a causal relationship between mothers' parentified history and their behaviour with their child. A longitudinal study examining mothers' behaviours and their impact upon the developing child would be a more appropriate design for establishing antecedent-consequent relations. Studies, which do examine more specifically the impact of parentification upon long-term development, have tended to focus on the adults' adaptation to their childhood roles, the main focus has been the impact on adults' inter-relational style.

Impacts of Parentification on Adult Relationships.

These studies have attempted to investigate how care giving responsibilities as a child might affect an individual's functioning in adult relationships. Key areas are the roles that individuals assume in relation to others, and one's ability to manage rejection and disappointment in relationships. The studies are generally retrospective and rely on the use of self-report measures and student samples. Regression analysis is employed to determine to what extent parentification accounts for the variance in the psychological variable of interest.

Wells, Glickaf-Hughes and Jones, (1999) found parentification to be linked to 'co-dependency'(described by Beatttie, 1989 as a tendency to be over controlling of another). Similarly, Valleau, Raymond & Horton (1995) suggested that adults who fulfilled a parental role as a child, continue to adopt care-taking roles with other adults in later life as they develop a self concept that is adapted to the caring task. They termed this the 'care-taking' syndrome. Analysis showed that subjects who fell within the high parentification group on a self-report measure of parentification (Mika et al 1987) scored significantly higher on the Caretaker Syndrome Survey (Valleau et al, 1995) compared with those in the low parentification group. The survey aimed to measure characteristics of the 'caretaker syndrome' described by Peek and Trezona (1984) (cited in Valleau et al; 1995) as behaviours that are heavily care taking in nature (e.g. fixer, rescuer or advisor).

Wells and Jones, (1998) have examined a number of personality variables including

'splitting'. This is defined as the separation or keeping apart of opposing psychological representations. These representations may take the form of positive or negative feelings towards oneself and others. It is considered a primitive defence mechanism that diminishes once separation-individuation is negotiated (Kernberg, 1989). Wells and Jones, (1998) proposed that the separation-individuation process is interrupted by parentification and therefore individuals may continue to use 'splitting' as a defence mechanism at times of interpersonal stress. They found that parentification accounted for 10% of the variance in splitting (measured by the Gerson Splitting Scale, Gerson, 1984). A similar study by the same authors (Wells and Jones, 2000) found that parentification contributed significantly to the variance in shame-proneness (measured by the TOSCA Shame Scale, Tangney, 1989). It was hypothesised that shame results from the child's inability to meet the unrealistic expectations of parents.

Jones and Wells (1996) have examined personality styles and defence mechanisms used by individuals who are 'parentified'. They examined parentification as a predictor of masochistic, narcissistic, and compulsive personality styles. These styles represent defence mechanisms that protect the individual from feelings of inferiority, or fears of loss and develop in response to inappropriate parental expectations placed upon the child. Narcissistic parentification, for example, is said to result from the parents' expectations that the child will fulfil the parent's own ideals and dreams for success. Jones & Wells (1996) used the Parentification Questionnaire (Sessions & Jurkovic, 1986) and the MCMI-11 (Millon, 1987) that assesses personality styles. Regression analysis provided empirical support for parentification as a predictor of both narcissistic and masochistic personality styles but not compulsive characteristics.

Jacobvitz and Bush, (1996) explored how womens' reconstructions of their family patterns during childhood related to anxious and depressed symptoms as adults. They proposed that relationships with parental figures where parents sought intimacy with their child as opposed to their spouse would interrupt the child's developing independence. This, it was hypothesised, would result in childrens' lowered self-esteem. Results indicated that mother-daughter alliances were related to adult

childrens' anxiety, while father-daughter alliances were related to adult childrens' depression.

Parentification-Direct Impacts upon the Child.

Few empirical studies have examined the effects on young people directly. Stein, Riedel, and Rotheram-Boras, (1999) assessed the predictors and psychological outcomes of parentification among adolescents whose parents have AIDs. They employed three indicators of parentification, spousal (e.g. sharing problems and secrets), parental (includes items on a parent asking for decisions or advice) and adult role taking (includes chores in the home). They hypothesised that the more severe the parental illness the greater the involvement in spousal and parental role taking. A relationship was found between the severity of the parent's illness and these two aspects but results did not support a link between these parentification indicators (spousal and parental) and the child's emotional distress. Contrary to their hypothesis, findings indicated that 'adult role taking' was significantly and positively correlated with emotional distress.

Johnston, (1990) examined role reversal in divorced families. She hypothesised, primarily on the basis of clinical observations, that role reversal following divorce would predict responsible, controlling styles and emotionally restricted behaviour in the child. On the basis of clinical ratings by six independent clinicians blind to the hypothesis, scores were calculated for aspects of the parent-child relationship and child outcomes. Role reversal and parental boundary problems were found to predict controlling interpersonal style and emotional and somatic problems in children.

In a study of identity development in young adolescent women, Fullinwinder–Bush and Jacobvitz (1993) explored the relationship between parent-child role reversal patterns in families and the identity development of daughters. They found that role reversal with either parent was related to less identity exploration in the domain of dating relationships. They suggest that this is accounted for by the womens' inability to explore their own needs because of attunment to meeting the needs of their parents.

Circumscribed Parentification studies.

Finally, more circumscribed studies have looked at the relationship between parentification and academic and career choice. Chase, Deming and Wells, (1998) examined the childhood perceptions of 360 students in relation to parentified roles. They found that 'low academic status' participants reported greater care taking responsibilities, and scored more highly on parentification measures than students classified as having higher scholastic aptitude. Sessions, (1986) compared graduate psychology and engineering students, and found that the psychology students had higher scores on parentification measures than the engineering group. In terms of career choice, Lackie, (1983) examined the histories of 1,577 social workers and found that two thirds had histories of 'care-taking' roles. Although he emphasises the positive aspects of their histories in the cultivation of care-giving skills and sensitivity to others, he proposes that this legacy can also hamper the professional in their role as objective helper. Similarly, Glickauf-Hughes and Mehlman, (1995) proposed in a theoretical paper that, as a result of a parentified childhood, therapists are likely to struggle with maintaining their parents' expectations and suffer perfectionist tendencies. They suggest that the parentified therapist's ability to attune themselves to the needs of others can result in burn out if their own needs are not recognised. Examining the relationship between measures of parentification and burnout in therapists could test this hypothesis and provide an opportunity to explore the relationship between an individual's up bringing and their functioning as a therapist. Important variables to consider might include the mediating role of supervision or the potential influences of personal therapy.

Summary.

This overview of the parentification literature illustrates the impact that care giving *may* have on beliefs about the self and others. Studies suggest that identity development and personality, interpersonal relationships, and relationships with an individual's own children could be affected. Another theme in the literature is loss and grief and the intergenerational nature of parentification, as each individual redresses their losses through the next generation. Whilst the parentification studies have attempted to answer major questions about the long-term impact of caring, the

findings must be considered in the light of conceptual and methodological limitations.

Parentification- Conceptual and Methodological critiques

Conceptual considerations.

Boszormenyi-Nagy and Spark's (1973) original concept viewed the impact of care giving as existing on a continuum, with adaptive and maladaptive poles. A number of psychological theories are referred to in support of the parentification process (e.g. psychosocial developmental theory, theories of identity development). Although there are similarities in the theories and dynamics that various authors ascribe to when commenting on the phenomenon of parentification, there are problems with integrating theories based on differing assumptions. This limits the comparisons that can be made across studies and ultimately the conclusions that can be drawn from the literature.

Inherent in the theories is the developing child's capacity to contribute to their relationships with others. Parentified roles could therefore function as precursors to the development of appropriate adult responsibility taking. It is feasible on this basis that a continuum of parentification exists from appropriate to inappropriate care taking. Erickson's stages, for example suggest that, for a time, the child's role as caregiver may compliment the capacity for the child to be helpful and competent (the industry versus inferiority stage). However the theory also requires that the child must be able to master the demands placed upon them.

The focus for research has been the pathologising effects of parentification, with limited attention paid to the factors that delineate adaptive and maladaptive parentification. We therefore know little about the risk factors for parentification or how much care is too much care? Instead the research conceptualises caring by young people as a predominately pathological process, in which the child forsakes their own emotional needs to care practically or emotionally for another family member. Some authors have pointed to the benefits of a parentified childhood including increased sensitivity and greater capacity for intimate relationships (Barnard & Spoentgen, 1987). Walker and Lee, (1998) cite evidence for role reversals in alcoholic families as accelerating the individuation process (rather than

inhibiting it) and for an increase in childrens' self esteem as opposed to an inherently pathological process.

Jurkovic, Jessee, and Goglia, (1991) have suggested two factors that may determine maladaptive parentification; these are the age at which the child assumes the parental duties and the developmental appropriateness of the role demands. They propose, on the basis of clinical observations, that children suffer more from expressive, i.e. emotional care giving rather than instrumental care taking roles. The study by Riedel, and Rotheram-Boras, (1999) did not support this view and it remains to be established as to how these factors influence the parentification process.

Another conceptual gap relates to the notion of reciprocity and the recognition of care giving within the family of origin. Empirical studies have not examined how this interaction may affect the parentification process and instead have considered parentification as a linear rather than a systemic phenomenon. Walker and Lee, (1998) in examining the strengths of children of alcoholics, emphasise the concept of relational resilience, in which the family is considered to be a source of resilience rather than pathology. They propose that role taking functions carried out by children can be considered to be an example of a family system capable of adapting to the stress of an addicted parent. They are careful to emphasise however, the importance of tasks being within a child's developmental capabilities, and the importance of support and respite provided by other family members.

Another area for consideration is the importance of sociocultural context when making judgements about 'appropriate role taking'. Jurkovic (1997; p.43) gives examples of different cultural expectations placed upon children in relation to care giving tasks. Similarly, Goglia *et al*, (1992) highlight the importance of gender in a study of children of alcoholics, and suggest that males may be less inclined to admit to care giving behaviours because of societal gender role expectations. How socialisation processes influence the process of parentification has yet to be considered.

Methodological considerations.

The empirical literature, which attempts to examine the impact of parentification upon adults, relies predominately on retrospective designs using parentification questionnaires although occasionally projective techniques (Walsh, 1979) have also been used. The retrospective approach requires respondents to recall events that occurred in childhood. This is problematic because forgetting, defensiveness, and social desirability affect the recall of child and family functioning. It has been suggested that parentified individuals may be particularly prone to employing defensive strategies to manage anxieties associated with disappointment in others (Burt, 1992). If this is so, there may be particular problems with using retrospective methods to investigate the phenomenon of parentification as parentified individuals may have particular difficulties with recalling their childhoods accurately.

The two main parentification questionnaires (Mika, Bergner and Baum, 1987; Sessions & Jurkovic, 1997), ask questions about the extent of care giving in childhood (for a full description of the psychometric properties of tools, which measure concepts allied to parentification, see Chase, 1999). This assessment method can have drawbacks, as measures do not always recognise other issues pertinent in the assessment of parentification, such as the age at which tasks were carried out, the degree of responsibility for those tasks, and the duration of responsibilities.
The measure by Mika *et al,* (1987) claims to be based on a conceptual analysis of parentification, however the authors do not refer to any firm conceptual foundations for the development of items. It does however attempt to take account of the age that caring tasks were carried out. The items are weighted according to the age at which the adult recalls carrying out the role, with younger ages carrying higher scores. Further items are weighted according to the physical and/or emotional burden the item is believed to entail (based on three authors judgments). Clearly, there are a number of difficulties with the accuracy of adults' subjective ratings of childrens' emotional burden. This factor calls into question the validity of the measure. The authors quote a Spearman correlation of $r = 0.98$ based on a comparison of qualitative coded data from interviews with participants and individuals' scores on the measure.

Sessions and Jurkovic's (1997) measure (which is also available in youth form) attempts to account for notions of reciprocity in the family system. Items were developed from clinical observation and theory. The psychometric properties have been more extensively tested than Mika's measure. Spearman-Brown coefficients of 0.85 and a coefficient alpha of 0.83 were reported and a test-retest reliability of 0.86 is quoted for the adult version. Studies suggest that the measure can distinguish between children who grew up in alcoholic and non-alcoholic homes (Chase, Deming & Wells, 1998; Goglia, Jurkovic, Burt & Burge - Callaway, 1992).

Both of these measures, however, rely on an assessment of the extent of care taking behaviours in childhood and tend to neglect the socio-cultural or family context in which care occurred. Newberger, (1980) has developed a semi-structured interview to assess parental attitudes that might mediate the parentification process. It employs direct questions and hypothetical scenarios. Responses are classified according to levels of parental awareness of their child's needs. This has the advantage of considering underlying beliefs about the child-parent relationship, but as before cannot assess the actual extent of parentification directly.

Obtaining clinical ratings of parentification through observational studies circumvents the difficulties of retrospective self-report measures. They are however, particularly prone to measurement reactivity which can compromise the validity of the data, particularly if they are not carried out in a naturalistic setting. The use of projective techniques, which rely on the researcher coding themes reflected in stories that the participant describes in response to pictures, has the advantage of over coming socially desirable responding, or cultural expectations, but is limited with respect to reliability.

In selecting participants, researchers have predominately relied on student samples which may limit the generalisability of findings with respect to age, and socio-economic status. Furthermore, the student population represents individuals who have achieved a degree of independent functioning and might therefore be construed as 'survivors of the parentification process', regardless of the scores obtained on retrospective parentification measures. Possible confounds within the literature also need to be addressed. Parentification is unlikely to occur in isolation. Other familial

difficulties such as parental conflict, family illness, abuse, and poverty have been cited as just some of the factors influencing the development of parentified roles within a family (see Jurkovic, 1997; p28-40). Similarly, there is evidence that many of these factors are linked with poor outcomes for children. For example on- going parental conflict has been associated with poorer school performance, less social competence with peers and poor self- perceptions (see Barber & Eccles, 1992). Therefore the relationship between parentification and adult outcomes could be accounted for by other variables.

Discussion

The parentification literature raises more questions than answers. Problems with a clear definition of parentification, the diversity of conceptual foundations, measurement difficulties, limited samples and the use of retrospective accounts make it difficult to accurately assess the impact of care giving upon a child's development. Currently the knowledge base and theoretical formulations are limited and could lead to unwarranted assumptions about the meaning of care giving in families' lives. Most of the available studies have sample, design, and measurement problems that could invalidate their findings.

Whilst the parentification literature has many limitations it does serve to highlight the familial and developmental context of care giving and the *potential* for pervasive effects on an individual's identity and relationships. It raises the importance of a systemic approach to children as care givers, and emphasises the role of reciprocity, that is parents as providers and givers of support as well as recipients. Parents have been receiving more recognition in the young carer debate (Department of Health, 2000a, 2000b) and research may need to take more account of their role in supporting their child with their responsibilities.

There are numerous clinical and anecdotal reports of the phenomenon of parentification (see Miller 1981; Jurkovic, 1997 for case examples). The social literature has highlighted the extent and nature of childrens' care giving roles in our society. It is feasible that care giving responsibilities may effect the individuation process that is necessary for the development of a sense of identity, separate and independent from one's care-giving role. These factors would suggest that further

research into the long-term effects of care giving on adjustment and maturity is an important and necessary undertaking.

Methodological Recommendations and Future Directions

Methodological Recommendations. New studies should aim to expand the diversity of their samples to reduce the potential for bias. The current reliance upon American college student samples to investigate the effects of parentification upon an adult's functioning ignores cohort effects. Samples should be selected that represent age, gender and cultural differences to increase the generalisability of findings to other populations.

The issue of confounding between parentification and other variables may be addressed through path analysis or structural equation modelling that controls for the influence of the potential confound of interest. If the presence of a variable e.g. abuse, adversely affects the adult outcome measure of interest, controlling for this variable would remove the variance attributable to parentification that is mediated through abuse. This is an appropriate analytic strategy to determine the impact of confounding variables upon measures of adult outcome. It is recognised that there are numerous confounds which cannot all be measured and controlled for. Analysis, however of key factors which may influence both the presence of familial parentification and the outcome variable of interest would aid in the interpretation of findings and the delineation of the parentification construct.

The measurement of parentification has presented difficulties in the research. The two key parentification questionnaires both have flaws (Sessions and Jurkovic, 1986; Mika et al, 1987) and are unable to capture the complexities of the parentification construct as outlined by Boszormenyi-Nagy & Spark (1973). There is however a developing base of literature that attempts to observe the parentifying behaviours of mothers and link this with retrospective accounts of their own childhood upbringing. Studies examining adult outcomes of parentification and the observational studies, which focus on precursors to the parentification process, have represented separate although related literatures. To date there has been limited cross fertilisation of these two aspects of the parentification literature.

The adult attachment literature (see Ainsworth, 1978; Bowlby, 1973,1979,1980) like the parentification studies represents a retrospective literature that examines unconscious processes and relates them to adult behaviour. This literature provides a useful example of how observational studies can be employed to develop and validate measurement tools.

The parentification literature has examples of observational studies that attempt to categorise and validate the parentifying behaviours of parents with their infants (for example Sroufe & Ward, 1980). Future observational studies may provide a basis for validating the parentification questionnaires (Sessions & Jurkovic, 1986; Mika *et al*, 1987) against observations of the parents' behaviour with their children. According to theory those parents who are classed as high on parentifying measures will attempt to address their loss of emotional nurturing as a child through their own children. It can be hypothesised that this group will display significantly more parentifying behaviours with their children than the non-parentified group.

Ultimately the development of a more qualitative approach to the measurement of a parentified history may be necessary to capture the nuances of parentification that are absent from current measures. For example notions of reciprocity, the duration of care and an individual's perception of their childhood role.

Directions for Future Research.

The refinement of measures of parentification is an important methodological undertaking and future studies might aim to explore a semi-structured interview format in the assessment of parentification. The Adult Attachment Interview (AAI) (Main & Kaplan, 1985) is an example of a semi-structured interview designed to measure an individual's attachment style based on their retrospective accounts of family and childhood. Similarly, an interview aimed at examining the key aspects of parentification such as household responsibilities, familial roles and relationships, as well as age and duration of responsibilities, may be a fruitful development. The AAI already includes an assessment of role reversal, which may be usefully employed in the development of a parentification interview. The interview method has an advantage in that it provides an opportunity for the assessment of 'unconscious'

processes. The individual themselves may be unaware, for example of a tendency to respond to others in a caretaker role in adult life, however this may come to light during the interview process. The exploration of such dynamics is unfeasible in a self-report format, although interviews also have drawbacks with respect to ease of administration.

Of clinical interest are the questions; when is parentification harmful to children, and how can families be supported? The research to date has done little to answer this question and instead has focused on the pathologising impact of parentification. Investigations into factors that help to delineate adaptive and mal-adaptive care giving represents an important area for research. The concept of resilience has been operationalised as successful adaptation despite experiencing adversity (Cicchetti & Garmezy, 1993). Research on the processes leading to successful outcomes is an important avenue for facilitating intervention and prevention strategies. The parentification literature would benefit from greater recognition of factors that result in adaptive outcomes for individuals *in spite* of a history of care giving.

Resilience and Protective Factors.

Future research is needed to determine possible mediating and protective factors. One may have undertaken extensive care taking roles as a child but because of protective factors, or maturation and development throughout the life span, have remained "unparentified" as an adult. Investigations into the influence of demographic factors such as age, gender and ordinal position within the family may help to identify children who may be " at risk". The influence of the coping style of both children and parents, as well as the role of reciprocal behaviours and support are areas that require consideration. The nature of the caring task and the impact of the duration and extent of care giving responsibilities also warrant further attention.

Direct Impacts Upon the Child.

Little attention has been paid to the effects upon the child. The focus on the long-term implications represents an "adulto-centric" bias. Developmentally specific effects may occur that do not persist into adulthood, or that assume a different form as an individual matures. Examining the impacts of involvement in care giving for

defined age groupings may be a useful area for exploration. Goodnow, (1988) in a review of the literature on childrens' house - hold work emphasises the importance of the child's perceptions of their work role in relation to the impact upon them. She found that when children are expected to perform expanded duties the experience is more positive if they perceive their jobs as necessary and feel supported. Understanding the child's appraisal of their role and how this influences the parentification process is another issue for future consideration.

Conclusion

Currently we have a limited understanding of the effects of growing up with caring giving responsibilities. Yet the social literature illustrates that this is not an uncommon phenomenon. The parentification studies represent a first step in a generally uncharted area and though there are a number of inherent problems both in the design and conceptualisation of investigations, the phenomenon of parentification is beginning to be mapped and observed in the behaviour of parents. Better methods and tighter conceptualisations of psychological constructs must however be developed before we can begin to understand the impact of caring as a child. Key areas for future development include the measurement of parentification in adulthood, the development of links between the retrospective studies and observational research, and expansion of our understanding of the impacts and protective factors that influence outcomes for the child. Ultimately prospective longitudinal studies are required to shed light on the developmental course of children who care.

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Brief Research Paper

An Exploration Of Childrens' Perceptions And Experiences Of Care Giving: A Focus Group Study.

Prepared for submission to the Journal of Qualitative Healthcare Research

An Exploration Of Childrens' Perceptions And Experiences Of Care Giving: A Focus Group Study.

Abstract

The stress of care giving for spouses and adult children has been extensively documented in the empirical literature. More recently, attention has been paid to childrens' involvement in family care giving. Qualitative studies in the social welfare field have highlighted the social restrictions that caring places upon children. There remains a need however to understand what children are thinking and feeling in an effort to cope with their care giving demands. This study used focus group methodology and individual interviews to explore the experiences of twenty young carers aged between ten and sixteen. Thematic analysis was employed to identify themes relating to the nature of the stressors, childrens' appraisal of them, and the coping strategies they used to manage the task of caring.

Introduction

An extensive literature has emphasised the deleterious consequences of familial care giving roles for adults (for example see Nolan, Grant & Keady, 1996). Childrens' involvement in care giving has been slow to come to the attention of academics, researchers and policy makers. Researchers in the social sector have attempted to redress this imbalance by examining the extent and impact of childrens' care giving involvement in families with an ill or disabled family member (for example Aldridge & Becker 1993, Tatum & Tucker, 1998). These qualitative studies have raised the profile of 'young carers'. They have, however, been criticised as not adhering to sound qualitative principles, as well as for lacking theoretical foundations and a developmental framework with which to explain their findings (Olsen, 1996).

Research allied to young caring is broad and draws upon literatures pertaining to parental disability and illness (for reviews see Roy, 1990; Rolland, 1999; Aldridge & Becker, 1999) roles and responsibilities of siblings of children with a learning disability (see Damiani, 1999) and the systemically orientated 'parentification' literature, which focuses on the long term developmental consequences of a child's involvement in caring. The theories underpinning the concept of 'parentification' suggest that young carers are at risk of developing an identity constructed around their caring responsibilities (Boszormenyi-Nagy & Spark, 1973). Despite these areas of study our understanding of the impacts of caring on young people is limited.

One draw back of the studies mentioned above is that they have relied upon retrospective accounts (for example Wells & Jones, 2000; Jones & Wells, 1996) self report questionnaires (for example McHale & Gamble, 1987; Stoneman, Brody, Davis, Crapps, & Malone, 1991) or parental report (for example Gath & Gumley, 1987; Gold, 1993). They have therefore neglected to take account of childrens' appraisals; that is their perceptions, thoughts and beliefs about their care giving experiences. From a stress-coping perspective (see Lazarus & Folkman, 1984) an individual's appraisal of stressful experiences has been shown to be crucial in influencing psychological outcome. It is therefore important to understand how young carers view their care giving experience and to listen to their understanding of the stresses encountered in their lives.

The aim of this study was to explore young carers' appraisals of the impacts of care giving and the ways they cope with these demands. Lazarus and Folkman's (1984) model of stress and coping is used to guide this research. This is the model most frequently used with child populations (Boekaerts & Roder, 1999) and upholds that the outcome of a stressful encounter is influenced by the individual's perception of its threat, and their resources to cope. It was hoped that by exploring the child's views of their experience within a psychological framework and guided by an appropriate model, information could be identified that might shed light on the potential developmental consequences of assuming care giving roles in childhood. In addition it could guide future quantitative work into the stresses of young carers. A qualitative approach was adopted as these methods place an emphasis upon description rather than explanation, and on the meaning of the experience to the participants themselves (Creswell, 1998; p17).

Method

The design was a non-experimental qualitative study. Thematic analysis (see Dey,1993) was used to identify and describe young carers' experiences of caring for a relative, their perceptions of the stresses and satisfactions encountered and the ways that they cope.

Participants

The participants were contacted through two voluntary agencies that support young carers in the community. The two groups were selected on the basis of proximity and geographical location. One group was situated in an inner city and another in a market town. Once the agreement of the group managers was secured, a leaflet explaining the study was given to the young person inviting them to participate (see appendix C for all correspondence). If they were in agreement then a parental consent form was posted to the child's home to be returned to the carer group (Appendix D).

The criteria used were that children must be between the ages of 10 and 16 to ensure that they understood the questions asked and that they cared for a relative with a chronic illness or disability. To reduce the extent of the diversity within the group, an effort

was made to screen out children caring for someone with HIV and AIDS, mental health or drug and alcohol problems.

Thirty-eight children were consulted of which twenty-four expressed an interest in participating. Consent letters were then sent to their parents and, in-total, seventeen were returned. Table One describes the demographic profile of participants for each of the two focus groups. The mean age of participants in focus group one was 13.1 years and in focus group two was 11.4 years. All were described by care staff as involved in some form of care giving, ranging from occasional to extensive care duties. Unfortunately it was not possible to have an equal distribution of age and gender across both of the groups. Only three of the participants were female and they participated in focus group one. This issue is addressed further in the triangulation of the data (see below). Four children cared for a brother, four cared for a sister, five for a mother, one for a grandparent and three children cared for more than one family member. Four of the participants were Asian and the remainder were Caucasian. When determining the number of years spent caring the starting point for assuming caring responsibilities was taken as the time when the child was first exposed to their relatives illness or disabilility. This was chosen because of the difficulties in pin pointing the precise time when the child began assuming caring tasks.

Table 1. Demographics for participants in each focus group.

Focus Group 1.					Focus Group 2.				
Age	Sex	Recipient	illness/ disability	Years Caring	Age	Sex	Recipient	illness/ disability	Years Caring
13	M	Grandmother	PD	6	11	M	Brother	LD	10
12	M	Sister	LD	8	10	M	Brother	LD	6
12	M	Sister	LD	4	13	M	Mother	CI	5
12	M	Sister	LD	7	11	M	Brother	CI	3
16	F	Mother	PD	8	10	M	Both Parents	CI/PD	10
14	F	Mother	CI/MH	7	12	M	Mother/brother	CI/LD	missing data
15	F	Brother	LD	3	14	M	Mother	CI	4
12	M	Mother	CI	4	10	M	Brother/Father	CI/LD	4
12	M	Sister	PD	9					
Mean				Mean	Mean				Mean
13.11				7	11.39				6.14

M, male — PD, physical disability
CI, chronic illness — F, female
LD, learning disability — MH, mental health

Triangulation.

Additional methods of data collection were used in order to triangulate the data and provide corroborating evidence for the emergent themes (Stiles, 1993).

1. Individual semi-structured interviews. Three females participated aged 10, 12 and 14. One cared for their mother, one for a father and one for a brother. It was hoped that using female participants would increase the representiveness of the sample.

2. A postal survey of young carer support group workers was carried out. A short questionnaire enquired about *their perception* of the stresses, satisfactions and coping strategies of the young carers they were involved with. This was sent to seventy support group workers with a letter of explanation. Forty were returned (57 % response rate).

3. Young carers' coping strategies were also assessed as part of a larger related survey of 108 young carers. One questionnaire item in this survey asked children to list any of their coping strategies that were not included on a standard checklist (The Adolescent Coping Scale, Frydenberg & Lewis, 1990). This qualitative question therefore provided additional information on strategies unique to young carers (see appendix F for a list of strategies).

Procedure

A questioning route was devised in order to elicit childrens' descriptions and appraisal of the stressors and satisfactions they encountered in caring for a relative and the coping strategies they used (Appendix E).

Each group lasted approximately 50 minutes. The length and structure of the group was designed to ensure that all participants had time to contribute to the discussion without

experiencing fatigue. The first author moderated the groups. A member of the young carers' group staff sat in to act as a scribe. As well as a group debrief each child was also offered individual time with the moderator and/or scribe (who was known to them). One child in each group took that opportunity. The groups were taped recorded for later transcription (see appendix E for transcriptions).

Coding Process

Thematic analysis was used to encode the data (Dey, 1993). Both focus groups were crudely coded for major categories of stressors, satisfactions, coping strategies, and appraisals (Appendix F). Categories were selected if they emerged across both of the focus groups or if they were emphasised as important. These preliminary categories were then refined following more detailed exploration of the focus group data transcripts, and a definition of each category was written. Thus a codebook of categories was developed that enabled the transcripts to be annotated (Appendix F).

Findings

Each of the following categories were identified through the coding process and will be considered in turn:

(a) Stressors
- (i) Feeling different-Others' perceptions
- (ii) Identity
- (iii) Responsibility
- (iv) Relationships

(b) Coping strategies

(c) Appraisal
- (i) Threats to self and positive self image
- (ii) Controllability
- (iii) Beliefs about responsibility

Stressors

Feeling Different.

A key stressor was being made to feel different because of other peoples' reactions to their caring and/or association with illness and disability. In some cases this

stigmatisation took the form of bullying and name calling directed either at the young carer or at the care recipient. In other cases the young carer perceived others to hold a trivialising or negative view of their role as carers and their capabilities. One female young carer commented that some adults 'looked down' on young carers, thinking 'you don't want to do that you just want to be a child'. These comments and actions by others were usually perceived as resulting from a lack of understanding about young carers and the pressures they face.

I think people need to understand why they call us names because our mum or dad or brother or sisters are different, I bet if they were in our shoes they'd act the same as us.

Identity.

How children adapted to their caring role was interesting and new to the literature. Previously the impact of care giving on children's self concept had only been investigated retrospectively with adult samples or investigated using self report measures in siblings of children with learning disabilities. Findings from this study give insight into the intra-personal stressors that affect these children. Children discussed feeling immersed in their caring role to the extent that it excluded other opportunities and experiences for self-validation; 'you're involved all the time ..to the point of anything else.'

> *It affects almost everything... you get engrossed in doing things and don't want (the caring) to go away.*

Others lamented the loss of their caring responsibilities and expressed difficulties in adapting to life without a care-giving role. '...and if you don't give that person your time you just feel....lost.' One girl expressed anger at the loss of her caring responsibilities, 'my brother's in day care now, so it's like I had everything took off me.' These children seemed to have developed a self-concept that had adapted to their responsibilities, which had then become part of their identity, in some cases defining how they viewed themselves in the future. One twelve-year-old boy commented;

If you look into the future you might see yourself as old and on your own all the time caring for everyone else in the family, so I don't look into the future that much if you do you might risk scaring yourself more.

These findings resonate with exploratory interviews with adult carers (Pearlin, 1975). Theories of identity development (Erickson, 1959) suggest that in-order for children to develop a sense of themselves as capable and masterful they must experience a variety of opportunities and challenges. It can be hypothesised that restricted social experiences brought about through extensive care giving might hinder the process of identity development and result in a self image constructed around the care-giving experience. This process has been referred to in the literature as 'parentification'. The comments about 'loss of self' may provide a glimpse into the origins of this process in some young people.

Anxieties about separating from parents and the transition to adulthood, was another prominent theme relating to young carers' identity. This theme was noted in the transcriptions of adolescent young carers. For example one thirteen-year-old boy who cared for his sister commented that caring 'gets between you and your girlfriend' and that it 'hurts that I will never ever get to live on my own.' Others expressed anxieties about leaving their parents and a belief that they should 'always be there for them'.

Responsibility: Vigilance and practical demands.

The burden of responsibility was frequently mentioned. As well as the social restrictions mentioned in other research (see Aldridge & Becker, 1993), key themes were 'the need to be vigilant' and 'practical demands'. Young carers expressed difficulty in switching off from their responsibilities and experienced anxiety about the care recipient's welfare when away from them.

(at school)... you're probably thinking you're not sure if they can cope on their own.

Many children expressed anticipatory anxiety regarding the care recipient's welfare. One child expressed a need to be prepared in case 'something drastic happens'. For

others there was a need to be careful for their own safety for example 'I have to watch him he bites'. Practical demands of caring ranged from being too busy with care related tasks to socialise, to feeling responsible for the protection of the relative from bullies.

Relationships: tension and loss.

Children in both groups expressed tensions in their relationships with family and friends and conflicting feelings of anger and guilt. One girl caring for her mother explained how she did not reveal her true feelings about the caring experience because it resulted in arguments that she regretted. She also recognised that the care recipient had feelings that were difficult to express.

You don't want to say your feelings toward one another because you both clash.

One of the younger participants explained.

If you say you hate your brother, it's not like that because you love them whatever happens.

Loss and anticipatory loss also featured. Some young carers viewed the care recipient as fragile, particularly those caring for a parent. Confusion around the illness also featured. One young carer commented that his mother might 'faint and die'. Others expressed sadness at their lack of friends and opportunities and the perceived restrictions that caring placed upon their lives in the future.

If you are a young carer you don't seem to have as many friends as other people.

Coping

The coping strategies identified by the young carers are listed in Table Two. Many of them resonate with those identified in other coping literature. 'Helping others' emerged as a new category and included childrens' actions that helped the care recipient. One twelve-year-old boy explained that he coped with stressful situations by cooking a meal; another girl mentioned taking the care recipient on an outing. This category was identified across all methods of data collection. It might function to reduce

guilt or anxiety about the recipient's welfare and is therefore a way of managing distressing feelings associated with the caring role.

Table 2 List of identified coping strategies and comments

Coping strategy	Representative comments from the young carers
Distraction	Find something else to do. Keeping myself occupied.
Relating to others	Telling each other things. He comforts me. God helps me sometimes. The people who are being nasty about it help me cope with it...I don't know how.
Managing tension	It's like a force field holding you back, but it stretches and just breaks and you can't help lashing out. Punch the wall. Get cross and lash out. Sometimes instead of beating up and that I take a shower.
Helping others	I cook a meal Get people to bed early, feed them, you can have a peaceful night.
Avoidance	I'm learning to just leave things alone. I try to ignore problems, or sometimes my friends calm me down.
Wishful thinking	So you're hoping for the best.
Solve the problem	I make XXXX look after her.
Reframing	But once you get used to it you find the time to do everything. I've got so used to it now it's not really affecting me anymore. Learning to cook and deal with problems is coping for your age.
Proximity seeking and distancing	Cope by being with my dad ....you know they are safe and they're there. Getting away from it helps you, so you can settle down. I cope by being with my dad, and sometimes my mum.

Alternatively, immersing themselves in the role might be a form of avoiding outside pressures and function to increase the young carers' self esteem and feelings of competency.

One boy explained that he coped by being around his father so that he would know that he was safe. Others mentioned distancing themselves as a way of coping. Regulating their proximity to the care recipient may function to provide a degree of control over their exposure to stressful situations.

Appraisals.

(1). Threats to self.

Some responses indicated that children viewed their caring experience as a threat to their self-image and health, 'It's making me sick and all that', others reflected on the pervasive nature of the stress of the caring, 'it (caring) affects almost everything'.

One girl, who wondered if she would be able to cope in the future, expressed appraisals about resources to manage the stressor. This type of appraisal is well documented in Lazarus and Folkman's (1984) transactional model of stress.

Some children appraised the situation positively. An older female participant commented that she wouldn't want to be doing what a child was doing, while a younger male noted that his female peers perceived him as more caring because of his responsibilities. These comments suggest that for some young carers care giving can have beneficial effects on self-concept.

(2). Controllability.

All of the respondents who expressed concerns about a lack of controllability referred to beliefs about the future rather than immediate concerns. This was also reflected in the age of the participants, with older carers expressing this concern in particular. Examples of this type of appraisal included the belief that the situation would never change and that they would not be free to lead a life of their own in the future. One girl explained how she wondered if her future would involve caring and explained how this decision was determined by the course of her parent's illness.

> *You're thinking will their health worsen, or will it get better? And you're hoping it will get better cause then it's easier for you and easier for the person...that is an important thing to look forward to.*

A thirteen-year-old male expressed sadness that he would never get to live on his own. These appraisals reflect the developmental stage of the respondents and highlighted concerns for adolescent carers and their transition to independence. It was interesting to note that respondents did not express more immediate appraisals relating to control over their day-to-day responsibilities. This issue is explored in more detail below.

(3) Beliefs about responsibility.

One view, which prompted strong feelings in one of the focus groups, was beliefs about responsibility. A strong theme was loyalty to the care recipient. This discussion was prompted by a young person's comment that he received extra pocket money for carrying out his responsibilities. One female group member expressed anger at this idea.

You don't want to get paid. You don't want to get paid to care.

A number of young people in this group expressed views that caring is carried out because of love and loyalty for the care recipient; 'Your doing it for love aren't ya'. In younger children this loyalty was expressed as a desire to help the care recipient when older; 'When I am older I want to set up a support group for my brother'. Children did comment in some instances that they received additional gains other than financial ones such as feeling closer to family members, knowledge, and new skills.

Corroboration of themes

The young carers' workers who responded to the survey had a mean of 3.2 years of experience in working with young carers, and 90% of respondents were female. Analysis of the survey data was carried out using the code book developed from the focus group transcripts. Each segment of data was assigned a category from the code book. A similar procedure was carried out for the individual interviews (see Appendix E for transcripts). The categories identified in the initial analysis were comprehensive and any segment could be assigned a category. Table 3 gives examples of the support workers' responses and their categorisation (see Appendix E for a copy of the questionnaire).

Table 3 Examples of responses from the survey of young carers' workers and categorisation of responses using the code book.

Theme	Representative Comments from Young Carers Workers
Victimisation	Being bullied Getting picked on
Minimizing	Teachers not understanding the child's caring role. Not being listened to Constantly at the back of the queue, overlooked. Don't make allowances for the caring role.
Identity	Feel that I am part of the person I'm caring for He felt lost without his caring role. Feeling like two people I don't want to leave home she wouldn't manage without me.
Responsibility: vigilance	Hard to relax and switch off, from worrying about mum On-going worry about 'cared for' Worrying that 'cared for' is all right at school
Practical demands	I get tired because of school, caring and... Having to physically care for 'cared for' Feeling tired
Relationships: loss	Mum will have to go into hospital and I will have to go into care Thinking will she be able to care for me in the future.
Relationships: tensions	Family cohesion Tensions in the home
Relationships: conflicting feelings	Have a proper social life without feeling guilty Feelings of guilt and envy Can't tell mum how I'm feeling it would make her guilty
Coping *: regulating proximity	Spending as much time as possible away from home Being close to family member
Coping:* helping others	Shutting themselves off from outside influences. Concentrating thoughts on others, not self. Hiding behind the caring to avoid 'normal' stresses
Appraisal: threat to self or gains	It (caring) gets me down Feeling like they can make a difference
Appraisal: control	I now accept that this is the way life is Trapped I can't see an end to the caring
Appraisal: loyalty	I don't want to stop caring Feeling that they (young carers) are doing what is 'right'.

* Only coping strategies new to the literature were included due to limited space

The single qualitative coping question was responded to by 49 out of 108 of the young carers (45.37%). The majority of responses corresponded with known and identified coping strategies such as talking to a friend, listening to music, playing on a computer to unwind. Five of the responses corresponded with the theme 'caring for others' for

example 'make other people feel good/better about their situation'. Examples of the theme 'regulating proximity' included 'talk to the disabled person about things', ' be near to them' or 'stay around friends house' (Appendix F).

In order to determine inter-rater reliability two independent psychologists re-categorised the original focus group transcripts using the codebook. Good agreement was found between raters (87 % agreement), indicating that the categories could be reliably coded.

Research and Clinical Implications

This study represents a preliminary exploration into childrens' perceptions of the experience of caring for a relative. By employing a psychological and developmental framework and attempting to consider validity and reliability issues within the qualitative paradigm some of the design problems highlighted within the qualitative work conducted in the social literature have been improved upon.

This study was designed with a stress-coping framework in mind, however the findings resonate with the concept of 'parentification' and highlight the potential for care giving to impact upon identity development. Boszormenyi-Nagy and Spark, (1973) consider how loyalty to the family may delay the process of identity development as the child struggles with feelings of guilt about developing commitments outside their caring role. This process can be clearly seen in some childrens' comments, as they reflect upon their concerns about control over their future lives, and in their appraisals of loyalty to the care recipient. The themes of vigilance, conflicting feelings, tension and loss further illustrate the struggle of the young people in this study to manage their anxieties about their family's welfare and balance this with having their own needs met. Societal influences such as stigmatisation and social restriction also appear to interact in the process by exacerbating their sense of isolation and limiting their social experiences. Some of the young people in this study responded by further immersing themselves in the caring experience as a way to cope. Future qualitative work, using grounded theory approaches might focus upon the *process* through which caring might exert its influences upon identity development with the view to developing a model. The identification of young carers' coping strategies and their appraisals of stress in their

lives could be used to furnish items for the development of a measure of stress in young carers.

Clinically, the work suggests the importance of recognising that although caring may be stressful, it can also be a source of pride and mastery, and has the potential to underpin an individual's sense of who they are.

Both methodological and ethical implications must be recognised when considering the findings. Ethical issues did arise. In one group a child raised the issue of self-harm as a coping strategy. In response to this a young carers worker and the researcher met with the child after the group to explore his use of self-harm individually. As it was felt that he was not currently at risk, no further action was deemed necessary. However, it was suggested that the support group consider holding a further group for the young people to consider their coping strategies and to provide an opportunity to raise the issue of self-harm and to provide a confidential opportunity for the child to discuss the issue further if they wished to.

Methodologically, there were problems with sampling across gender. Also, a common critic of focus group methodology is that participants' responses are influenced by socially desirable responding. The use of multiple methods of data collection and selective sampling of females for the individual interviews was an attempt to address these two drawbacks. This, together with the verification of the themes in the literature suggests that the findings could provide useful clues about the meaning of caring in some childrens' lives.

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Main Research Paper

The Application of a Stress - Coping Model in a study of Adolescents with Familial Care-Giving Roles.

Prepared for submission to the Journal of Clinical Child Psychology and Psychiatry

The Application of a Stress - Coping Model in a study of Adolescents with Familial Care-Giving Roles.

Abstract

The main objective of this study was to evaluate the application of a stress coping model to the study of adolescents with familial care giving roles. Referred to as 'young carers', these young people are involved in caring for an ill or disabled family member. The model examined levels of caring, and appraisal of stress as predictors of adjustment difficulties, and the mediating effect of coping style, and perceived support from family and friends. One hundred and eight adolescents aged between 12 and 18 participated. Partial support was found for the model. Levels of caring did not predict distress as was hypothesised, but was related to levels of perceived stress. Supporting Lazarus and Folkman's model (1984), young carers' appraisal of stress was a significant predictor of psychological distress. Avoidant coping and Social coping styles were also found to be direct significant predictors of adjustment difficulties. Results suggest that those who feel overloaded, undervalued and respond by adopting avoidant methods of coping are at risk of suffering from psychological consequences associated with being children who care.

Introduction

Within the social welfare field, a growing body of literature concerns itself with children who have responsibility for caring for an ill or disabled family member (see Page, 1988; O'Neill, 1988; Bilsborrow, 1992; Aldridge & Becker, 1993; Becker, Aldridge & Dearden, 1998; Tatum & Tucker, 1998). These children are referred to as 'young carers' and are defined as children who provide 'a substantial amount of care on a regular basis' (Department of Health, 1996a:p2). Estimates suggest that approximately 50,000 children are involved in levels or types of care that are developmentally inappropriate and that may have adverse effects on their development and health (Becker, Aldridge & Dearden, 1998).

'Care giving' in the context of informal family care is defined by both the types of care and the level of care provided by the caregiver. A certain amount of household responsibility may be functional to a young person's development, however a distinguishing feature of 'family care giving' is that tasks and activities surpass the boundaries of what is 'normative' or 'usual' given the individual's age and relationship to the care recipient (Schulz & Quitter, 1998). Not every child whose family is affected by illness or disability will necessarily become a young carer. Adult family members or support services provide care in many families.

To date the research into 'young carers' has been predominately descriptive. Surveys and small-scale semi-structured interviews have aimed to identify the extent and nature of care giving by young people (Dearden & Becker, 1995; Aldridge & Becker, 1993). These studies have resulted in the recognition of young carers' rights by legislative bodies (Department of Health, 2000a; Department of Health, 2000b).

Despite this growing interest and concern amongst government and social bodies, the academic and psychological literature has generally neglected to take account of childrens' involvement in care giving roles. This is in contrast to a vast, theoretically driven literature that examines the impacts of informal family care upon adults (see Biegel & Schulz, 1999; Gaugler, Davey, Pearlin & Zarit, 2000; Nolan, Grant & Keady, 1996).

Two bodies of literature that have specifically concerned themselves with the psychological implications of children as carers, are the literature on 'parentification' (for a review see Earley, 2001a; this volume), and studies on the responsibilities of siblings of children with learning disabilities (for a review see Damiani, 1999).

The parentification literature is based in the notion of the family as a unit, and the roles that members adopt in relation to each other (Boszormenyi-Nagy & Spark, 1973). It emphasises the long-term developmental implications of childrens' involvement in caring roles. The focus is on emotional care, usually provided to a parent and studies are often retrospective in nature (see Chase, 1999 for a description of research).

Studies examining siblings as caregivers have focused on more task orientated care with a view to determining if siblings have increased responsibilities when compared to comparison groups of children without a disabled sibling, and whether or not this responsibility impacts upon adjustment. The studies have produced mixed findings, which may be accounted for by differences in the methods of data collection and the measures used. The empirical studies have frequently relied on maternal reports of childrens' care giving responsibilities and utilised the child's self report less frequently. In studies where children have commented on their responsibilities, increased responsibilities have been found when compared with comparison groups (McHale & Gamble, 1989; Stoneman, Brody, Davis, Crapps, & Malone, 1991). The use of maternal reports could produce a bias in responding as mothers might be inclined to underestimate their child's involvement in the home, and further more this approach overlooks the child's appraisal of their situation. Appraisal has been shown to be an important factor in determining outcome, and studies suggest that children do perceive their family circumstances in very different ways (Koch-Hatten, 1986; Menke, 1987).

To date the methods used to investigate children as caregivers have suffered from a number of conceptual and methodological shortcomings. Studies in both the parentification and the 'siblings' literature have been criticised as suffering from weak theoretical frameworks (see Earley, 2001a, this volume; Damiani, 1999). For

example, the 'siblings' literature has been criticised for its reliance on selecting comparison groups based on convenience rather than on a conceptual basis, and it has been argued that it may be more helpful to examine 'within group' variables (Stoneman, 1989).

The absence of a theoretical framework for considering findings seems to have limited the progression of research into children as carers. In-addition, variables such as the age of onset of care giving tasks, the duration of the care taking and the level of responsibility held by the child have received little or no consideration. Furthermore, these studies overlook the familial context of the caring and the influence of other family members in recognising and supporting the child with their duties. Finally, investigations into the child's own perception of their responsibility, control over their tasks and duties and impacts upon other aspects of their lives warrants further attention.

Over the past fifteen years the stress paradigm has become the principal model for considering the impact of informal family care giving in adult populations (see Biegel & Schulz, 1999). The stress of care giving in these populations is well documented (Brody, 1985; Ory *et al.*, 1985; Pearlin, Mullan, Semple, & Skaff, 1990) and care giving has been linked to both physical and mental health difficulties (for example Fuller-Jonap & Haley, 1995; Pruchno, Peters & Burant 1995; Li & Selter & Greenberg, 1997). Caregivers of adults with dementia are in poorer physical health than matched controls (Schulz, Visintainer, & Williamson, 1990; Schulz, O'Brian, Bookwala, & Fleissner, 1995), and when compared to the general population, consistently report more symptoms of anxiety and depression (Shultz *et al*, 1995). The social welfare literature has highlighted possible sources of psychosocial stress for young carers. Some of the issues identified are poor school attendance, loss of social opportunities, impacts on future plans and independence (Aldridge & Becker, 1993), bullying, social stigma, and the isolation brought about through concerns about being considered different from friends (White, 1989; Meredith, 1992). Young carers experience not only the conflicting demands of care and social and educational concerns but also the pressures of developmental tasks and transitions. Adolescence is a time of increasing social and educational pressures, which may be in direct conflict with their care giving obligations in the home. It is feasible that care giving

and the associated social, educational and familial impacts represent significant stressors for young people, particularly if they come into conflict with developmental transitions. Adolescence is a time when the likelihood of assuming caring responsibilities increases (Hobbs, 1992). However, currently samples generally consist of broad age ranges or focus on young children, thus limiting conclusions about the implications of caring for different age groups.

The present study was designed to investigate the psychological adjustment of adolescent young carers as informed by the stress coping model (Lazarus & Folkman, 1984) and the adult care-giving literature. This model upholds that when an individual is confronted with a stressor they evaluate whether or not it is a threat to them, and, secondly, if they have the resources to cope with it. If a child perceives themselves as under stress with few supports and resources to cope, then the model proposes that negative emotional consequences are likely to result from the care-giving experience.

Coping strategies and perceptions of support received from parents and peers are two important variables that have been investigated in the child and adolescent literature as protective factors in stressful situations. Reviews provide convincing evidence of the relationship between low levels of parental social support and poor psychological adjustment among adolescent samples (see Barrera & Li, 1996). A similar pattern has emerged for peer support (for a review see Hartup, 1996). Social support is a multi dimensional concept consisting of different sources of support (e.g. parent and peers) and different types of support such as information, emotional, and practical support. Two effects of support on well-being have been postulated: a main effect and a stress-buffering model. The main effect model proposes that support has a direct impact on well-being since it provides a positive effect and stability in one's life. The buffering effect proposes that support is related to psychological symptoms only for people experiencing stress (Cohen & Wills, 1985) and that it intervenes between the stressful event and the psychological impact. However, regardless of the pathway, under stressful conditions adjustment should be higher for those individuals who perceive themselves as supported, compared with those who do not (Wolchik, Sandler, & Braver, 1987).

Coping strategies can be understood as efforts to adapt to circumstances that are perceived as challenging, threatening or unsafe (Lazarus & Folkman, 1984). These coping strategies have been further categorised along a variety of dimensions. Lazarus and Folkman (1984) identified groupings, which they termed problem and emotion focused coping, where problem focused coping represented efforts to act on the sources of stress to alter it, and emotion focused coping is described as efforts to regulate emotions associated with the stressful events. There have been categorisations along other dimensions of coping for example Roth and Cohen (1986) who distinguish between approach strategies and avoidance strategies. Approach strategies maximise the possibility of gathering information to take action and provide opportunities for emotional release. Avoidance strategies minimise the emotional impact of an event. They may function to protect the individual from becoming overwhelmed. There is evidence however that avoidant coping appears to be related to an increase in psychological distress (Compas, Malcarne & Fondacaro, 1988; Ebata & Moos, 1991). Others propose that coping strategies can be classified into three coping styles, (Cox, Gotts, Boot & Kerr, 1985; Frydenberg & Lewis, 1990; Seiffge-Krenke & Shulman, 1990). These styles are described as 'solving the problem', 'non-productive strategies' (associated with avoidance and an inability to cope), and 'reference to others'. They have been identified through qualitative methods involving thousands of adolescents (Frydenberg, 1997; p33). Coping *style* differs from coping strategies, in that it represents the tendency to act in a consistent way in particular situations.

Early investigators into adult care giving explored the effect of the care recipient's level of disability in explaining the emotional health problems experienced by care givers (Robinson, 1983; Pruchno & Resch, 1989). Studies suggest however that the tangible and emotional demands of care giving are only weakly correlated with health outcomes for caregivers (Gilhooly, 1984; Kinney & Stephens, 1989a). More important is the caregiver's appraisal of the stress incurred through care giving (Zarit, Todd & Zarit, 1986). Findings suggest that environmental conditions like familial relationships, social support, carer's attitude to caring and the stresses incurred through caring responsibilities play a more crucial role in determining health outcomes than the nature of the disability or amount of help required (see Nolan, Grant & Keady, 1996).

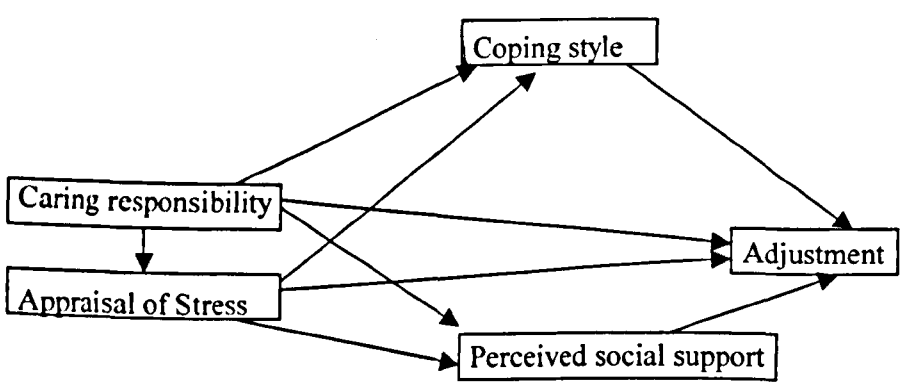
One obstacle in researching stress in adolescents with a caring role is a lack of an appropriate stress scale designed to draw upon the specific problems faced by these children, taking into account their varying circumstances and their developmental stage. For example, scales have been developed to investigate siblings of children with chronic illness (e.g. Carpenter & Sahler, 1991). However, they focus upon the impact of the illness itself, and neglect to take account of the wider social, educational and developmental issues. Stress scales (for example Rowlinson & Felner, 1988; Kearney, Drabman & Beasley, 1993) aimed at assessing the 'daily hassles' of adolescents also have drawbacks. Although they generally cover an extensive variety of sources of day-to-day stress they can be very lengthy (e.g. Rowlinson and Felner's measure has 81 items) and have been criticised for being adapted from adult measures (Kearney *et al*, 1993). It would not be possible to assess stressors specific to young carers using these measures. Some researchers have used semi-structured interviews to ask children about the stresses they encounter. Gold (1993), examined the adjustment of siblings of autistic boys employing this method using a Yes-No response format. This approach has drawbacks with respect to ease of administration and problems of acquiescence. A plethora of measures exist to assess stress in adult carers (examples of the better known measures include Robinson, 1983; Zarit, Reever, & Bach-Peterson, 1980). However, many of them have been developed with dementia carers in mind, and focus upon specific issues such as memory loss and aggressive behaviour of the care recipient. There is a need, therefore, to devise a measure of stress in adolescent young carers and this forms the first step in this study.

The principal aim, however, is to test a theoretical model of stress and coping in adolescents with familial caring roles. An initial model to be tested is described in Figure 1. It is based upon a theoretical conception derived from Lazarus and Folkman's, (1984) model of stress and coping and the adult care giving literature. It examines the extent of caring responsibility and appraisal of stress as predictors of psychological adjustment difficulties. It is hypothesised that perceived levels of social support and coping style will mediate the relationship between the predictors and the outcome variable.

The study attempts to overcome some of the conceptual and methodological shortcomings of previous research in the following ways:

1. With the application of a theoretical model, thus addressing previous difficulties with atheoretical designs that have been highlighted in the 'siblings' literature.
2. By utilising childrens' appraisal of caring responsibilities and independent raters' reports rather than reliance upon maternal reports.
3. Through the recognition of parents as providers of support not just as care recipients and acknowledgement of a familial context to care giving.
4. Through recognition of mediating factors not considered in the young carer literature.
5. By considering a defined age group of adolescents aged 12-18.
6. By addressing the absence of a measure of stress in young carers by developing a suitable scale for use in this study.

Figure 1. Hypothesised model of the relationships between appraisal of stress, caring responsibility, coping resources, social support and adjustment.



The following hypotheses are based on Baron and Kenny's (1986) conditions for the validation of a mediational model.

Hypotheses

1. The predictor variables, 'appraisal of stress' and 'levels of care giving' will be positively related to the mediator variables of perceived social support and coping.

2. Levels of perceived social support and coping will be positively related to the outcome variable of psychological adjustment, after controlling for the predictor variables of appraisal of stress and levels of care giving.

3. After controlling for the mediator variables of perceived support and coping the predictor variables 'levels of care giving' and 'appraisal of stress' will have a direct positive effect on adjustment.

4. The effects of levels of care giving and appraisal of stress on adjustment will at least partially be explained by coping strategies and perceived support.

5. Caregivers' appraisal of stress will be a better predictor of psychological adjustment difficulties than levels of care giving.

Method

A cross sectional survey design was employed to address the research aims.

Participants.

Participants were 108 adolescents between the ages of 12 and 18, with a mean age of 13.6 years (S.D. = 1.5). Broad inclusion criteria were set to aid the recruitment process and increase generalisability. Children were selected if they were living at home, attending full time education and provided practical care for a family member resident in the household with a physical illness or disability.

Table 1. Composition of sample with respect to age, care recipient and illness/disability

Characteristic		% of total sample
Sex	Male	42.6
	Female	57.4
Care recipient	Mother	54.6
	Father	5.6
	Sibling	27.8
	More than one family member	8.3
	Grandparent	2.8
Illness/disability	Chronic illness	39.8
	Learning disability	21.3
	Physical disability	14.8
	Acquired intellectual impairment	3.7
	Sensory impairment	0.9
	Combination of illness/disabilities	15.7
Ordinal position	Eldest	50.0
	Middle	13.0
	Youngest	23.1
	Only	11.1

To limit the diversity in the sample, children caring for family members with mental health difficulties, drug and alcohol problems, or HIV and Aids were excluded from the study. On average the children had performed a caring role for 5.7 years (S.D. = 3.5). Support workers described 30.7% of children as coming from families where there was financial hardship, while the remainder were described as not suffering hardship. Of the childrens' families, 39.8% had one family member in paid employment. Those in receipt of respite or day care services totalled 39.9 %, while the remainder did not receive help from other agencies. Those children described as 'primary carers' with sole responsibility for caring totalled 22.2% of the sample. The majority of the sample was Caucasian (13.2% were from ethnic minority groups). The composition of the sample with respect to gender, disability/illness, care recipient, and ordinal position in the family is described in Table One. The sample is very similar to Dearden and Becker's, (1998) statistical profile of 2,303 young carers in the UK, with slightly more females than males in the sample, and approximately 50% of care recipients being mothers. It is also similar with respect to the distribution of illness and disability (when excluded categories such as mental health have been accounted for).

Measures.

Perceived social support. - Perceived levels of social support received from family and friends were measured by the Perceived Social Support Scale (Procidino & Heller, 1983). This measure consists of two 20-item subscales addressing perceived social support from family members and friends, respectively. Most items appear on both subscales with identical wording, apart from changes in the referent of the statement (e.g. "Members of my family are good at helping me solve problems" vs. "My friends are good at helping me solve problems"). The measure is designed to reflect a variety of instances of support including emotional, information, feedback and reciprocity (i.e. provision of support by the individual).

This aspect was considered particularly important when examining support perceived by young carers who are involved in the provision of support themselves. For each item, the response 'Yes' indicating perceived social support is scored as 1 so that scores range from 0 indicating no perceived support to 20 indicating maximum perceived support; 'Don't know' items are not scored. Studies on American early adolescents (n=241) mean age 13.5, indicate adequate internal consistency for both of the scales (family, $\alpha = 0.87$; friend, $\alpha = 0.88$) (Dubois, Felner, Brand, Adan & Evans, 1992). Predictive validity in this age group has been established in longitudinal studies with regard to a variety of measures of psychological distress (Dubois *et al*, 1992) and have been found to be related to a range of social asset traits, for example social competence (Procidano & Heller, 1983), (see Appendix G for all questionnaires).

Coping style- Coping style was measured by the Adolescent Coping Scale- short form specific (ACS; Fryenberg & Lewis, 1993b). The short form of the ACS consists of 18 items selected from the 79 items on the long form plus a final item that asks individuals to list any other things they do to cope, other than those describe in the preceding 18 items. This measure was selected as it is brief, covers a comprehensive range of coping strategies, and has been specifically developed for use with adolescents.

Each of the items on the short form represents a separate scale of the long form. Eighteen strategies of coping are assessed which represent three coping styles;

Problem Focused (consists of 6 items including, work at solving the problem to the best of my ability, keep fit and healthy, improve my relationship with others), Reference to Others (consists of 4 items including for example, talk to other people about my concern, pray for help and guidance), and Non-Productive coping (consists of nine items including for example, worry about what will happen to me, I have no way of dealing with the situation, find a way to let off steam). Each factor was found to have moderate reliability. Alphas of 0.66 (Solving the problem), 0.66 (Reference to others), and 0.69 (Non-productive coping) are reported. In this sample an exploratory factor analysis using principle component analysis with varimax rotation revealed three factors with eigenvalues greater than 1 accounting for all eighteen items (Appendix Ji). They were generally consistent with those of Fryenberg and Lewis, (1993) however small differences in the item loadings were found. The factors were identified and labelled as (1) Avoidance (α = 0.75), (2) Attend to the problem (α = 0.81) and (3) social coping (α = 0.70) (see Appendix Ji for items).

Respondents complete the questionnaire by indicating whether the coping behaviour described is used 'a great deal', 'often', 'sometimes', 'very little' or 'doesn't apply or don't do it'. Items were summed for each of the three identified coping styles to provide three scores for avoidance; attend to the problem, and social coping.

Psychological Distress- The General Health Questionnaire (GHQ) (Goldberg, 1972,1978,1981) was initially developed for use with adult populations. However, its utility in adolescents has also been demonstrated. It is a widely used instrument to assist in the detection of psychological distress. The 12-item version, GHQ-12 has been shown to have a high internal consistency and a unidimensional structure across a community sample of British adolescents (Banks, 1983). Internal consistency with this sample was good (α = 0.79). The GHQ has also been employed with younger school age adolescent populations (Houlihan, Fitzgerald, & O'Ragan, 1994; Marinoni, Degrate, Villani & Gerzeli, 1997). Recently, Parker, Yiming, Tan and Rutter, (2001) found evidence for the validity of a pattern of general psychological distress in children, employing a parent report adaptation of the GHQ with a community sample of two thousand English speaking children in Singapore.

There are two ways to score the GHQ-12. Likert scoring assigns separate scores for each response category (0-1-2-3) providing a maximum total score of thirty-six. This method was used to provide values for the regression analysis. The GHQ method involves assigning scores of 0 and 1. The first two responses indicate the absence of a symptom and are assigned 0, while the second two answers indicate the presence of a symptom and are assigned 1. This scoring method was used in accordance with the manual directions to provide a measure of 'caseness', that is the presence of mental ill health. Banks, (1983) suggests a cutting score of 3 or 4 for greatest specificity with the GHQ-12, in a young community sample. Specificity is the proportion of non-cases correctly identified. A conservative approach was taken with this sample and a cut off of four was used to determine 'caseness'.

This measure was selected, as it is a brief, robust, self-report measure that was developed for use with community samples. It therefore enabled a general assessment of the psychological functioning of participants. A general approach to psychological assessment was thought appropriate given the limited literature on the mental health of the young carer population.

Perceived stress – The young carer perceived stress scale (YCPSS). The content of the YCPSS was based on the findings of a qualitative study examining young carers perceptions of stress (Earley, 2001b, this volume), as well as the social literature on young carers (for example Aldridge & Becker, 1993) and studies of stress in adult care givers (for example Nolan, Grant & Keady, 1996). Sub-domains were developed that aimed to assess a comprehensive range of potential sources of stress. These were labelled as social restrictions, school –caring conflict, family tensions, identity issues (problems with developing independence), vigilance, burden, concern for relative, victimisation, devalued (described as a lack of understanding of young carers' pressures by others) and the positives of caring. Items were devised to reflect each domain and have face validity for young people. The questionnaire was labelled as 'Caring Ups and Downs' and each of the items is answered on a five-point response scale, scored from 0 (never) to 4 (always). Items are summed to provide scores for each domain and totalled to provide an overall stress score. The factor analysis is reported in the results (See Appendix Ji).

Care giving responsibility- 'What do you do to help?' Concrete and emotional assistance was measured by a 19-item index of help provided. This covered four areas, household duties, personal assistance, sibling responsibilities and emotional support. It was adapted from a semi-structured interview used with young carers (Aldridge & Becker, 1993). It aimed to assess key tasks and duties commonly carried out by young carers that have been identified in the literature. Participants were directed to consider the help they had provided over the past month and rate each item according to the frequency they had provided the help. This is rated on a five point scale from once a month or less (this also included the response never), two or three times a month, once a week, two or three times a week, or everyday. A total score is obtained by summing the scores for each item. An exploratory factor analysis using principle component analysis with varimax rotation was performed on the nineteen-item scale (Appendix Ji.). Six factors were found to have eigenvalues greater than 1, but the three largest factors were identified and labelled as (1) Practical tasks ($\alpha = 0.75$), (2) Emotional support ($\alpha = 0.78$) and (3) Intimate personal care ($\alpha = 0.77$). These first three factors accounted for 46 per cent of the total variance. The remaining factors could not be identified however the overall internal consistency high ($\alpha = 0.83$) indicating that the total score for the scale could be reliably used in further analysis. Evidence for its concurrent validity was provided by a moderate Pearson's correlation between support group managers' independent ratings of each child's level of care involvement and scores on the measure ($\alpha = 0.44$ $p < 0.01$).

Procedure

Participants were recruited through 'young carer support groups'. These are voluntary organisations that provide recreation and support to young carers. Groups were identified through 'The National Handbook of Young Carer Support Groups' (Aldridge & Becker, 1998). They were initially selected on the basis of accessibility from the author's home. When the study necessitated the inclusion of more distant groups they were selected at random from the handbook. The group manager was contacted by telephone, brief details of the study were explained and they were asked if they would like to receive an information pack. Each pack consisted of an information sheet (see appendix C), a copy of the questionnaire pack (Appendix

G), a copy of the parental consent form (Appendix D), and an information leaflet for the young people (Appendix C). In total 28 groups were contacted of which 20 agreed to participate. Those groups that declined stated staff shortages or a lack of interest from the young people as being their main reasons.

The young carers' group sent each family who met the inclusion criteria a copy of the parental consent form explaining the study, together with a leaflet for the young person. All information clearly stated that participation was entirely voluntary and in no way affected the child's right to access the support service. Unfortunately not all groups kept accurate records of the number of families they initially contacted so it is difficult to comment on precisely what percentage did participate. Generally however, the response rate was high and represented around fifty percent. Of the approximately 250 families that were approached 137 agreed to participate. Of those who agreed to take part, twenty-nine later declined, were unable to attend on the designated research day, or did not meet the criteria for inclusion. Informal feedback from young carers' support groups suggested that non-responders might represent families where children were involved in very extensive caring and were therefore concerned about the implications of participating in the research.

A time was arranged when the author would attend the support group and supervise the completion of the questionnaire packs by the young people. When groups were located beyond reasonable travelling distance the young carer group manager supervised this process. Seven group managers participated in this role. Each received a brief training over the telephone and written instructions (Appendix H) to ensure consistent and ethical administration. The questionnaires were administered to small groups of between 5 and 10 young people. Questionnaires took approximately 40 minutes to complete. Following completion of the questionnaires a small group discussion was facilitated to receive feedback and comments from the young people and to provide an opportunity to de-brief. In addition, individual time was offered to all participants if they wished to discuss any issues relating to the research in private. Two participants took that opportunity. A telephone number was also made available if they wished to make contact regarding the research at a later date.

Young Carer support group managers filled out a background information sheet (Appendix G) for each young person based on their knowledge of the family, and information from assessment records. Information was collected on the young person's demographic details, estimations of the care recipient's level of dependency upon the carer, and the extent of the young person's caring responsibilities.

Results

Statistical analysis

Data was analysed using SPSS (version 8.0) in three stages. Following descriptive statistics, the factor structure of the YCPSS was investigated using exploratory factor analytic techniques. The rotated component matrix (Appendix Ji) was interpreted taking into consideration the size of the factor loading, and the meaning of the factors. Overall reliability for each of the identified factors and the total YCPSS was determined using Cronbach's Alpha (Appendix Jii). The second stage of analysis involved examining the correlations between variables using Pearson correlations. A correlation matrix is presented in Table 4. Finally, a path analysis was performed using hierarchical multiple regression analysis in order to determine the validity of the theoretical model proposed in Figure 1. It must be noted that this correlational technique does not provide evidence for the direction of causality. However, it does provide evidence for the relative strengths of different pathways between variables.

Descriptives

Means and standard deviations for each of the measures are presented in Table 2. Mean scores for the GHQ were calculated using Likert scoring. Univariate analysis of variance (ANOVA) indicated that boys perceived themselves to have significantly less social support from friends compared with girls ($F(1,104) = 8.77, p < 0.004$). Boys and girls did not differ significantly on any other measures. The GHQ was also scored using the GHQ method, which revealed that 47.2 % of respondents were classified as cases. One-way ANOVA's were conducted to determine if there were significant differences between cases and 'non cases' on any of the other measures (Appendix Jiii). Significant differences were found between cases and non-cases on the mean scores for each group for overall stress ($F(1,106) = 19.94, p < 0.001$), avoidance coping ($F(1,106) = 11.34, p < 0.001$) and attend coping ($F(1,106) = 5.51, p < 0.02$), and the individual factors of the stress measure, feeling devalued

($F(1,106) = 24.92$, $p < 0.001$), overload ($F(1,106) = 21.01$, $p < 0.001$), and concern for care recipient ($F(1,106) = 23.09$, $p < 0.001$). There were no significant differences between cases and non-cases with respect to gender.

Table 2 Means and Standard Deviations for each of the measures for males and females

	Boys		Girls		Total	
Measure	M	SD	M	SD	M	SD
GHQ	14.11	5.48	13.16	5.62	13.64	5.67
Support- Friends	23.45	7.15	27.02	5.24	25.53	6.23
Support-Family	25.14	8.42	26.37	5.51	26.37	5.51
Levels of Caring	27.86	12.54	31.77	14.09	30.18	13.43
Stress (YCPSS)	58.84	19.99	61.77	23.15	60.59	22.09
Coping Avoidance	11.70	5.18	12.15	4.42	11.96	4.73
Coping Attend	19.86	7.40	22.63	5.17	21.48	6.31
Coping Social	12.86	5.13	15.03	3.51	14.13	4.37

Factor Analysis and reliability of the YCPSS.

The data from the YCPSS was subjected to factor analysis. An exploratory factor analysis that used principle component analysis with varimax rotation was performed on the fifty item YCPSS. Ten factors were found to have eigenvalues greater than 1, but the seven largest factors were extracted in order to examine their correspondence with the original subscales of the questionnaire. These seven factors, consisting of 40 of the original items, were identified and labelled (see Table 3) the remaining factors were not identified. Two items did not load on to any factor. There is some agreement with the original subscales. However, several items loaded onto different factors. This suggests that they were interpreted by the young carers' to have a different meaning from those originally intended. Each factor was tested for internal reliability with a view to creating composite factor scores for further analysis. Items identified as lowering the internal consistency were removed if this procedure did not affect the overall interpretability of the factor (see appendix Jii for reliabilities).

The seven factors, together with their factor loadings are shown in Table 3. As can be seen, they form interpretable clusters of variables resulting in meaningful factors. Scores on each of these seven factors were calculated for further statistical analysis. Internal consistency for the total YCPSS was high ($\alpha = 0.89$).

Factor 1, labelled as 'devalued ' consisted of eleven items. Items 32 (which had a negative factor loading), 8 and 45 were removed to increase the internal consistency, leaving eight remaining items (α = 0.87). Item 32 also loaded on to factor 2, labelled as 'personal value attached to caring role'. Testing the internal consistency of factor 2 suggested that including item 32 and removing items 6,15,20, and 27 improved the internal consistency, leaving six remaining items (α = 0.83). Factor 3, was labelled as 'overload'. Items 8 and 42 also loaded on to this factor and when included increased the internal consistency (α = 0.83), resulting in eight items. Factor 4, labelled as 'social restrictions' had an internal consistency of α = 0.74, after items 24 and 37 were removed, leaving five remaining items. Factor 5, labelled as 'concern for care recipient', consisted of four items (α = 0.62). Factor 6, was labelled as 'family cohesion', after removal of item 44, three items were left (α = 0.80). Factor seven, 'vigilance' originally consisted of four items (α = 0.54), however removal of items 9 and 18 resulted in two items clearly related to 'vigilance' (α = 0.74).

Table Three. Factor loadings for the items of the seven original factors, which were identified and labelled. Cronbach's alphas for the adjusted factors are indicated.

		Factor loadings
Factor 1: Devalued	Cronbach's alpha following removal of items marked * and addition of items marked † 0.87	
25. It bothers me that people never say they are pleased with my caring.		0. 73
23. It bothers me that I don't know where I belong in the family.		0. 71
26. It bothers me that I can't have a life of my own.		0. 69
47. I feel left out in my family.		0. 57
12. Feeling different from other kids is a problem for me.		0. 53
32. My family let me know how pleased they are with the work I do as a carer. *		- 0. 55*
8. I feel that there is no break from caring.*		0. 53*
41. I worry about what I will do in the future.		0. 56
13. It bothers me that caring takes over everything in my life.		0. 53
45. I feel caring takes over everything in my life. *		0. 50*
22. It bothers me that other people don't understand what I do to help my family.		0. 50
Factor 2: Personal value	0.83	
49. I feel closer to people in my family because of the caring I do.		0.84
40. Caring for my relative helps me feel important in my family.		0.78
46. Having an ill or disabled relative helps me think about the good things in life.		0.70
48. Caring helps me to feel better about my relative's illness or disability.		0.70
14. Caring makes me feel trusted by my family.		0.63
32. My family let me know how pleased they are with the work I do as a carer.†		0.42†
15. I am bothered about what will happen to my relative in the future. *		0.57*
20. I feel worried about people in my family. *		0.52*
27. It feels good to know that I can help my relative. *		0.40*
6. It bothers me that I can do things that my relative who is ill can't do. *		0.37*

Table 3. Continued

		Factor loadings
Factor 3: Overload	Cronbach's alpha following removal of items marked * and addition of items marked † 0.83	
39. It bothers me what other kids will say if I take time off school.		0.70
19. I am bothered that I have missed too much school.		0.75
11. I worry that if I wasn't caring I wouldn't know what to do with myself.		0.61
50. It bothers me that the teachers don't understand about my caring.		0.58
33. I feel tired because of the caring I do.		0.49
38. It's hard to get a rest from caring.		0.48
42. It bothers me what teachers will say if I fall behind at school. †		0.43 †
8. I feel there is no break from caring. †		0.44 †
Factor 4: Social restrictions	-0.73	
37. Caring makes it difficult to make new friends. *		0.35 *
3. I have plenty of energy for doing other things.		- 0.75
16. Caring can get in the way of having a boy or girlfriend.		0.65
4. I find looking after my relative easy.		- 0.63
1. Getting teased about being a carer is a problem for me.		0.53
7. It bothers me that I can't take part in clubs or activities after school.		0.45
24. I feel that I can care for my relative and still have time for other things. *		-0.44 *
Factor 5: Concern about the care recipient	0.62	
31. It bothers me that the person I care for is always on my mind.		0.65
36. I feel my relative's illness is my fault.		0.60
2. I worry about the person I care for when I am at school.		0.51
30. I sometimes feel awkward about my relative's illness or disability.		0.46
Factor 6: Family Cohesion	0.80	
34. It bothers me that my family argues.		0.75
21. My family get on well together.		-0.72
44. Everyone in my family is treated equally. *		-0.56 *
29. I get extra money like treats or privileges because of the caring that I do.		-0.46
35. I feel I know more about how to look after myself than other people my age.		0.45
Factor 7: Vigilance	0.74	
10. When I am away from home, I can forget about caring.		0.62*
18. I always have to keep an eye on the person I look after.		0.55
9. I have to be on the alert to help the person I care for.		0.54
43. It bothers me when people say nasty things about my relative.		0.38*

Correlations

Values for the correlations of all measures and YCPSS factors are displayed in Table 4 and described below. The significance level was set at $p < 0.01$ to reduce the number of type 1 errors.

Correlations of YCPSS with other measures. It can be seen that the total score of the YCPSS is moderately, and significantly, correlated with the GHQ mean, levels of caring, avoidant coping, and 'attend to the problem'. Thus, suggesting that higher levels of perceived stress are associated with higher levels of emotional distress as

Table 4 Correlations of the YCPSS subscales identified in the factor analysis with outcome measures.

	Deval	Value	Ovld	Socre	Concer	Famcoh	Vigilan	Stress Total	GHQ	Supfam	Supfrie	Levcar	Avoidc	Attenc	Socialc
Deval															
Value	0.20														
Ovld	0.72*	0.23													
Socre	0.31*	0.14	0.31*												
Concer	0.56*	0.28*	0.47*	0.15											
Famcoh	0.04	0.36*	0.12	-0.06	0.17										
Vigilan	0.36*	0.40*	0.43*	0.20	0.36*	0.32*									
Stress	0.81*	0.49*	0.87*	0.41*	0.67*	0.31	0.61*								
GHQ	0.48*	-0.12	0.38*	0.06	0.41*	-0.00	0.07	0.37*							
Support Family	0.00	0.39*	0.53	0.10	0.06	0.15	0.18	0.18	-0.11						
Support Friends	0.94	0.15	0.70	-0.47	-0.01	0.08	0.17	0.12	0.07	0.27*					
Levels of Caring	0.26*	0.37*	0.31*	0.16	0.24	0.26*	0.44*	0.42*	0.07	0.27*	0.30*				
Avoidance Coping	0.35*	-0.02	0.30*	0.24	0.39*	0.15	0.17	0.36*	0.38*	-0.00	-0.05	0.17			
Attend to the problem	0.21	0.52*	0.28*	0.05	0.36*	0.20*	0.06	0.42*	0.09	0.49*	0.29*	0.31*	0.40*		
Social coping	-0.09	0.30*	-0.07	0.00	-0.05	0.20*	0.06	0.04	-0.19	0.32*	0.21	0.11	0.28*	0.56*	

* $p < 0.01$

Key. Deval = Feeling devalued; Value = Positive feelings about caring role; Ovld= Overload; Socre= Social restrictions; Concer = Concern for Relative; Famcoh= Family Cohesion; Vigilan = Vigilance; Supfam = Percieved support from family; Supfrie = Perceived support from friends; Levcar = Levels of carin; Avoidc= Avoidant coping; Attendc = Attend to the problem; Socialc = Social coping

measured by the GHQ, higher levels of caring and more avoidant and 'attend' coping.

The YCPSS factor, which correlated most strongly with the GHQ, total score was 'Feeling devalued'. 'Overload' and 'Concern for relative' also, although to a lesser extent, significantly correlated with the GHQ. Examination of the correlations in Table Four, suggests that the greater the young carer's perception of being devalued by others, the greater the levels of emotional distress, greater the levels of caring and greater the levels of avoidance coping. The coping style 'attend to the problem' was also associated with 'feeling devalued' although did not reach the $p < 0.01$ level of significance ($r = 0.21, p < 0.05$).

The factor 'Personal value attached to caring' showed a small negative association with GHQ scores however this was not significant. Significant associations were found between this factor and levels of caring, as well as the coping styles, 'attend to the problem'; and 'social coping'. Not surprisingly, 'Value attached to caring' was associated with perceived familial support, as well as coping styles that focus on recognising and attending to the problem and those that emphasise social aspects of coping. Interestingly, this factor is also positively and significantly correlated with levels of caring, suggesting that as care giving increases so does its importance to young people, and the stress associated with it. Overall however, the value the young person placed upon the caring role did not relate to overall levels of distress as measured by the GHQ.

'Overload' did significantly correlate with the GHQ, as well as with levels of caring, avoidant coping, and the coping style 'attend to the problem'. As might be expected, feeling 'overloaded' is associated with greater levels of caring and more distress as measured by the GHQ. The coping styles 'avoidant coping', and 'attend to the problem' are also associated with this factor. A similar finding was found for the YCPSS factor 'Concern for relative' which was significantly and positively related to GHQ, avoidant coping, and attend to the problem.

Other factors of the YCPSS such as 'social restrictions', family cohesion, and vigilance, were not significantly associated with GHQ scores.

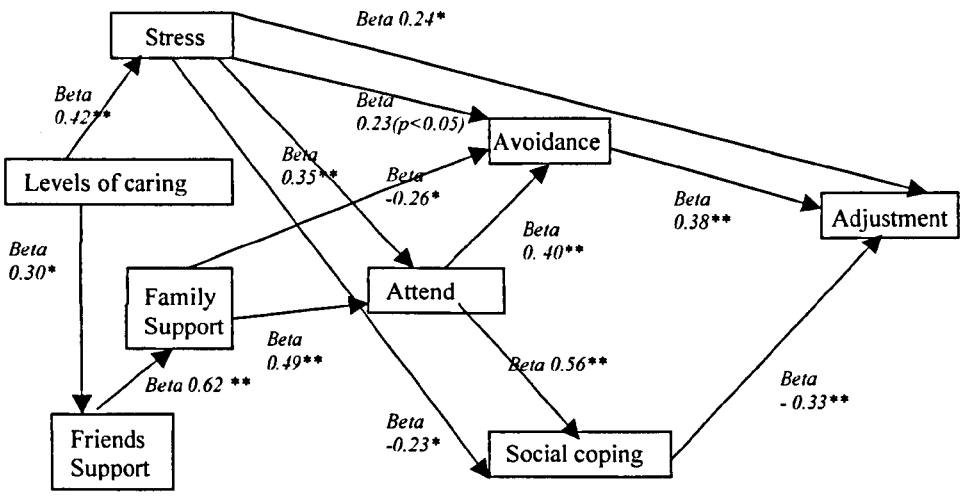
Correlations of Perceived Support Measure with other measures. Surprisingly, perceived levels of support from either family or friends, was not significantly related either positively or negatively to YCPSS or GHQ. However as might be expected, the two support measures correlate significantly together. Moderate significant relationships are found between perceived support and levels of caring for both family and friends. This suggests that the higher the level of caring, the higher the perceived support from both sources.

Correlations between Coping and other measures. Avoidant coping has a significant positive relationship with a number of variables. A moderate positive relationship was found between avoidance and GHQ, total stress score, and the individual factors; 'Devalued', 'Overload', and 'concern about care recipient'. This indicates that an increase in avoidant coping is associated with an increase in these variables. Avoidant coping also has moderate correlations with 'social coping' and 'attend to the problem'. The coping style 'Attend to the problem' shows significant moderate positive relationships with perceived levels of support from both family and friends. Indicating that as perceived levels of support increase so there is an increase in the use of the coping style 'attend to the problem'. A negative association was found between the use of the coping strategy 'social coping' and overall distress as measured by the GHQ although this did not reach the $p < 0.01$ level of significance ($r = -0.19, p < 0.05$). It does suggest that the greater the use of this coping style, the lower overall distress as measured by the GHQ. As would be expected perceived levels of support from family is significantly associated with 'social coping' (although support from friends did not reach the $p < 0.01$ level of significant; $r = 0.21, p < 0.05$).

Theoretical Model Validation

Hierarchical regression analysis was performed to evaluate the impact of the independent variables (coping style, perceived social support, stress and levels of care giving) on the dependent variable, adjustment. Table 5, shows the results of the regression analysis. It details the strength of the pathway (*beta*), the percentage of variance accounted for by the variables following an adjustment for the number of variables and sample size (*adj* r^2) and the significance of the pathway (Appendix

Figure 2 Path diagram for the relationships between stress, levels of caring, support (family and friends), coping and adjustment, showing path coefficients.



*$p< 0.01$; ** $p<0.001$

Jiv). Figure 2, illustrates the significant standardized Beta values between the variables in the form of a mediational model.

Total scores for each of the three coping styles, perceived support (family and friends), stress and levels of caring were entered into the equation. Three predictors were found to have a direct significant effect. These were Avoidant coping (*beta* = 0.38), Social coping (*beta* = -0.33) and Stress (*beta* = 0.24). These three predictors accounted for 27.4% of the total variability in GHQ scores, (r^2 = 0.27). In the second step, avoidant coping was taken as the dependent variable. The coping style 'Attend to the problem' (*beta* = 0.40), Support (*beta* = -0.26), and Stress (*beta* = 0.23, p< 0.05) were found to be significantly related to the dependent variable, avoidant coping. In the third step the coping style 'Social coping' was entered as the dependent variable. 'Attend to the problem', (*beta* = 0.56) and Stress (*beta* = - 0.23) were significant predictors.

Family Support (*beta* = 0.49) and Stress (*beta* = 0.35) were found to be significant predictors of the dependent coping variable 'attend to the problem'. The dependent variable, Family Support was predicted by a single variable, Friends Support (*beta* = 0.62). As the dependent variable, 'Support from Friends' was predicted by the 'Level of Caring' (*beta* = 0.30), and 'Levels of Caring' was predicted by the independent variable, Stress (*beta* = 0.42).

Table 5 Hierarchical Regression Analysis testing the mediational model of stress and coping in young carers.

Dependent variable	Model	Predictor	Adj r^2	beta
Adjustment (GHQ)	1.	Avoidant coping	0.14	0.38**
	2.	Avoidant coping x Social coping	0.23	-0.33**
	3.	Avoidant coping x Social coping x Stress	0.27	0.24*
Avoidance coping	1.	Attend coping	0.15	0.40**
	2.	Attend coping x family support	0.19	-0.26*
	3.	Attend coping x family support x stress	0.23	0.23 ($p < 0.05$)
Social coping	1.	Attend coping	0.18	0.56**
	2.	Attend coping x Stress	0.34	-0.23*
Attend coping	1.	Family Support	0.23	0.49**
	2.	Family Support x stress	0.35	0.35**
Family Support	1.	Support friends	0.38	0.62**
Friends Support	1	Levels of caring	0.08	0.30*
Levels of caring	1.	stress	0.17	0.42**

** $p< 0.01$; ** $p<0.001$ Adjust r^2 are shown for each model. Beta values are displayed for each pathway.*

The results are considered in relation to the hypothesised relationships, in order to test the validity of a mediational model of stress and coping in young carers.

Hypothesis 1. The predictor variables, appraisal of stress and levels of care giving will influence the mediator variables of social support and coping.

Partial support is found for this hypothesis. The greater the levels of stress perceived by the young carers', the greater their use of both avoidant and 'attend to the problem' coping strategies. As stress increases their use of 'social coping' decreases. No significant pathways were found between stress and social support however. With respect to the predictor variable 'levels of caring', a significant relationship was found with 'support from friends'. The greater the levels of caring, the greater the perceived support. No significant relationship was found between levels of caring, the three coping styles or support from family.

Hypothesis 2. Social support and coping will influence the outcome variable of adjustment, after controlling for the predictor variables of appraisal and levels of care giving.

Partial support was found for this hypothesis. Perceived levels of social support from family and from friends are not significantly related to levels of adjustment. Coping style is related to levels of adjustment. Avoidant coping is the strongest direct predictor of adjustment levels overall. An increase in avoidance is related to an increase in GHQ scores, thus indicating an increase in distress. Social coping is also directly related to adjustment in the opposite direction. An increase in social coping is related to a decrease in GHQ scores.

Hypothesis 3. After controlling for the mediator variables of support and coping the predictor variables levels of care giving and appraisal will have a direct effect on adjustment.

Partial support is found for this hypothesis. The predictor variable stress does have a significant direct positive relationship with adjustment. Indicating that as levels of perceived stress go up, scores on the GHQ rise, indicating greater distress. The levels of care giving are not a significant direct predictor of adjustment.

Hypothesis 4. The effects of levels of care giving and appraisal of stress on adjustment will at least partially be explained by coping strategies and perceived support.

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studies by Grant and Compas, (1995) who looked at increased family responsibilities in adolescents whose parents had recently received a diagnosis of cancer. They found that girls showed more psychological distress than their male counter-parts and provided evidence for an increase in family responsibilities as mediating this relationship. McHale and Gamble, (1987) attempted to examine the relationship between increased time spent in household tasks and adjustment in siblings of children with a disability. They found a significant relationship with anxiety but no significant relationships with other measures of adjustment. Others have found different results. Cuskelly and Gunn, (1993) found an inverse relationship between conduct problems and household duties, while Damiani, (1993) found no significant relationships between responsibility and adjustment. The results of this study support those of Damiani, as no significant relationship was found between the levels of caring carried out by the young person and overall distress. However, in keeping with the stress coping model proposed in this study, the young carers *appraisal* of stress incurred through caring was linked to the level of caring and overall distress. This finding is not only supported by the stress coping model but also by extensive research in the adult care giving literature (for example Neunorfer, 1991).

An aspect of the study involved developing a measure to study stress in adolescent young carers. The results indicate that the total fifty item scale has high internal consistency. In this study seven identifiable factors were returned which were similar to the original sub domains included in the subscales, however not completely consistent with those built into the measure. For the purposes of this investigation the identified factors were labelled, and composite scores were derived in order to explore their relationship with overall adjustment. At this stage of development, however, researchers are advised to continue to use the total scale, rather than reconstitute items according to factors, which at present are only based upon single samples. Future studies must also look towards establishing test retest reliability and more extensive validation, including further exploration of the factor structure.

As expected, based upon the hypothesised model of stress and coping in young carers, the YCPSS was positively related to distress as measured by the GHQ as well

with levels of caring. Indicating that, as levels of caring rise, so does stress as well as scores on the GHQ (indicative of greater emotional distress).

Of the factors returned, 'Feeling Devalued' accounted for 24 per cent of the variance in the total stress score. It also had the largest correlation with emotional distress. An examination of the items loading on to the factor 'Feeling devalued' indicate that some items relate to an original subscale included in the YCPSS to measure issues pertaining to 'identity' (e.g. 'It bothers me that I don't know where I belong in the family'; 'Feeling different from other kids is a problem for me'). Young carers seemed to associate these items with a feeling of being devalued. This is indicated by the item's association with other items loading on to this factor such as; 'It bothers me that people never say they are pleased with my caring', 'It bothers me that other people don't understand what I do to help my family', and 'I feel left out in my family'. This appears to suggest that a major source of stress for young carers is in establishing a clear familial role, and purpose outside of caring, and that they associate these difficulties with feeling devalued by others.

This finding corresponds with a study by Carpenter and Sahler, (1991) who found that problems with *interpersonal* relationships differentiated adjusted and 'non adjusted' siblings of chronically ill children over and above other factors such as concerns about illness, communication with parents, and worries for care recipient. They suggested that siblings with adaptational problems perceived themselves to be 'ignored, unwanted and misunderstood'. A similar finding was also reported by Sloper and While, (1996). These studies suggest that the YCPSS is assessing an important source of stress for young carers. These interpersonal difficulties are likely to be particularly pertinent to adolescent young carers, as they attempt to make transitions towards independence.

'Overload' was also significantly related to GHQ scores. It includes items relating to the day to day burden of care, such as 'Feeling tired because of caring', and items about school/caring conflict, 'It bothers me what kids will say if I take time off school', 'It bothers me that the teachers don't understand about my caring'. This illustrates the stress that young carers experience in balancing the demands of care giving and school life.

Understandably, 'concern for relative' was also associated with distress. Some of the original items relating to 'vigilance' also loaded on to this factor and it is not surprising that worries about the relative are important. Some of the items also suggest feelings of guilt or misconceptions about their relative's condition, and these problems have also been identified by other authors (for example, Koch-Hattem, 1986).

The overall score for the stress measure was entered into the regression model. Results of the analysis indicated that avoidant coping was a significant direct predictor of distress as measured by the GHQ, as well as mediating one of the pathways between stress and distress (stress also has a direct effect). This is consistent with the developing literature on coping in adolescents (for example Ebata & Moos, 1991; Seiffge-Krenke, 2000; Seiffge-Krenke & Klessinger, 2000). A negative relationship was found between perceived family support and avoidant coping in the regression analysis, which suggests that when children perceive their families as supportive they are less likely to employ avoidant methods of coping. It is not possible to comment on the direction of the association, however further explorations into the relationship between avoidance coping and perceived support may be beneficial in understanding the contextual circumstances that are related to the use of avoidant coping, particularly in view of the impact that it seems to have upon adjustment. 'Perceived Support from Friends' however responded differently in the model, however seemed to take on increased importance as the levels of caring increased. This might suggest that as caring in the home becomes more extensive, children begin to utilise sources of support that are outside of the family.

Another significant coping style was 'Social coping'. This had a direct negative relationship on psychological distress and mediated a pathway between stress and adjustment. An examination of the items relating to this factor reveals an emphasis upon leisure and relationships. This finding might suggest that children who are able to engage in leisure pursuits and positive relationships are by nature more psychologically healthy, than those who do not, or alternatively that this type of coping buffers the impact of the stress on psychological health. This 'stress buffer or main effect debate' has been frequently referred to in the social support literature

(Cohen & Wills, 1985). The coping style 'social coping' correlates with the social support measures used in this study and seems to be assessing coping strategies that rely on social interactions. Due to the cross sectional nature of the study it is not possible to unravel the temporal relationships between these variables. Relationships also exist between the different coping styles. One explanation could be that as stress increases individuals begin to use more diverse coping strategies in an effort to manage the stressor.

Surprisingly, perceived levels of social support from family and friends did not play a mediating role between stress and adjustment as was hypothesised. This was interesting given the finding that social coping did have an effect. Tremblay, Hebert and Piche, (1999) in their study examining stress and coping in child sexual abuse victims found that whilst parent support was a mediator, support from friends was not. One thing that the current study has in common with Tremblay's study is the intimate nature of the stressor. Tremblay *et al,* (1999) suggested that children might not use their friends for support due to the stigma associated with the occurrence of abuse. Anecdotal reports suggest that many young carers do not tell their friends about their caring responsibilities because of a fear of being stigmatised. Young carers might therefore perceive their friends as supportive, but choose not to utilise this support, unless as previously discussed the caring becomes extensive. In the case of the parents of young carers, they too have significant stressors themselves, and children are often acutely aware of this. Children may not utilise parental support in an effort to protect their family from increased worries and pressures. Although perceived social support is related to social coping, it differs, in that social coping is focused upon joint activities and leisure rather than the more emotional aspects of support, thus social coping may have more utility for young carers, who for reasons of loyalty could be reluctant to discuss their concerns with others. An alternative explanation for the finding is that family and friends are not able to respond to the specific needs of a young carer. It is also possible that a generic social support measure as used in this study, is not suitable for this population, as it does not capture the particular supportive actions that young carers might find helpful.

Future studies may need to focus on the complex interactions that may occur between support and stress when the stressor is of an interpersonal nature, as well as

addressing the limitation in this study by running different models for boys and girls (significant differences were found between genders for support from friends). Unfortunately, the sample size did not permit the splitting of the data in this way in this study.

In this sample, 47 per cent of respondents were classified as 'cases' using the GHQ method. This, must be interpreted with caution as norms for the younger adolescents are not available. To set this value in context, reports from world wide epidemiological surveys in similar aged community samples estimate that the prevalence of psychological distress ranges from 17.6% to 22% (Offord, 1995), while more recent authors quote a value of 15% for adolescents (Essau, Conradt & Petermann, 2000). Those who have employed the GHQ in young adolescent community populations found that just over 30% were classed as 'cases' (Houlihan, Fitzgerald & O'Regan, 1994). Clearly, the results indicate that a substantial proportion of young carers in this study are suffering from elevated levels of psychological distress compared with community sample estimates, and that this warrants further investigation. It must be considered however that these young carers may have been referred to support groups because of an identified need, and that this sample could represent young carers who are struggling with their demands.

In summary, the presented data provide partial support for a stress - coping model. It is important to note that the focus of this study was stress, coping and support and their relationship to adjustment, rather than on developing a comprehensive model of psychological health in young carers. The model was powerful however, and accounted for 51% of the variance in GHQ scores (calculated by summing the contribution made by direct and indirect pathways). This study did not examine the influence of illness variables such as severity, although it did consider concern for the relative as a stressor. The influence of this and other external factors, together with internal resources (i.e. locus of control, self efficacy etc) may help to make the model more complete. The study is limited by its cross sectional design and future studies may focus on longitudinal methods to enable a better understanding of how the variables interact. It must also be considered that some of the measures used in the study are in development and until future studies have confirmed their validity, the results should be interpreted tentatively.

Currently, the main body of literature on young carers (Aldridge & Becker, 1993) emphasises the social restrictions placed upon them. This has led to the development of support groups aimed at facilitating social opportunities. The results of this study suggest that it is the interpersonal difficulties faced by young carers, which are most distressing. In particular feeling devalued both in and outside their family. While social clubs may help young people to feel more valued, family interventions focusing upon raising awareness of the young carers unique contribution to the family may help to combat this significant stressor. Results from this study also indicate that young carers experience significant burden trying to manage the demands of school life and caring tasks, and interventions focused upon raising teachers' awareness, and encouraging their liaison with families may help to ameliorate this pressure. Attention also needs to be paid to the child's coping strategies. Interventions focused upon helping children and their families facilitate more open communication and recognise their coping styles, may help to provide increased opportunities for communication and thus decrease the interpersonal isolation experienced by some adolescents with caring responsibilities.

Ultimately, caring is a complex phenomenon, not least when the recipient is a loved one or indeed a parent. Each child and their family are likely to face unique challenges and have distinctive strengths and resources. This study does however suggest that some young carers are facing significant difficulties at a time when their resources may already be stretched by the demands of a taxing developmental stage. The findings suggests that those who feel undervalued, overloaded, and respond by adopting avoidant methods of coping, are most at risk of suffering from psychological consequences associated with being children who care.

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Research Review

An exploration of some wider issues relating to the research

Research Review

This paper reviews some of the wider issues relating to the research. It is broadly divided into two sections. The first, considers the wider social context of young carer research, and includes a discussion of some of the ethical issues encountered in the study. The second section focuses on theoretical and methodological concerns, and the personal challenges encountered in accessing participants. My own reflections on the research process and my personal learning are referred to throughout the two sections.

Ethical issues and the wider context

Olsen, (1996) in a critic of the social welfare literature pertaining to the study of young carers writes: -

> *Seeking to research the relationship between childrens' responsibilities and adult disability is a political activity, and should be sensitive to broader arguments about autonomy, disability and disadvantage.*

This statement raises an important ethical issue regarding research into young carers, and suggests that researchers have a duty to examine their own attitudes, beliefs, and motivations for investigating the chosen area of study. This standpoint is more familiar territory for those who come from a qualitative paradigm, where it is accepted that the positivistic notion of 'objectivity' does not exist as a reality. Qualitative researchers are required to explore their own biases and values, and to consider how they might prejudice the research process. It is less frequent to observe quantitative researchers questioning their assumptions, beliefs and motivations in devising and carrying out their research. This is in spite of the fact that their studies may serve to shape the development and provision of services for individuals, and impact on the lives of the participants in global and far reaching ways.

One of the most challenging, yet fortuitous, aspects of my study came out of the conversations I had with staff and volunteers at the young carer support groups. They not only played an invaluable role in organising access to participants, but also

challenged me to reflect on my own values and beliefs, in relation to the research, and also more widely regarding the profession of clinical psychology.

It was not unusual for my initial contact with young carers' staff to be met with suspicion. Many people I came into contact with held a negative (although valid) view of researchers and clinical psychologists generally. Two of the most frequent criticisms I encountered were that clinical psychologists hold a 'medical model ' of illness and disability, and that they 'pathologise' individuals. These criticisms challenged me to question my values and perceptions of 'young carers', as well as ill and disabled people, and to learn more about the differing perspectives on disability. Two key, yet opposing stances are briefly described below.

The 'medical' stance places an emphasis upon the nature of the impairment. The consequence is that the individual and those associated with them are viewed as disempowered. Psychologists have been criticised for adopting this model (Abberley, 1993; Oliver, 1983). An alternative approach is the social constructionist model, which upholds that the barriers and expectations placed upon disabled people by society are stigmatising and oppressive (Finkelstein & French, 1993) and it is these expectations that disable individuals. This literature is primarily concerned with disabled adults and their civil rights.

My emphasis and concern is largely on the experiences of the *children* in these families. The conversations I had with those working with young carers, however led me to investigate and understand their criticisms, and recognise the wider issues and debates involved in undertaking research in this area.

Olsen, (1996) writes that one of the central weaknesses in the young carer literature is the neglect of disabled parents as caregivers. Through meeting those working in the field, and the young carers themselves, I came to understand that I had a responsibility to challenge the 'medical' assumptions of early literature and produce research that at least attempted to recognise parents and families as providers of support and care for their children. Antononovsky, (1992) refers to the *salutogenic* perspective, which aims to identify factors that contribute to families' successful functioning.

In my conversations with young carers' workers I attempted to address their concerns by explaining that my study examined parental support and childrens' coping resources and therefore attempted to address some of the drawbacks of previous research. Taking the step of learning about the wider issues, and understanding others' concerns rather than seeing them as an obstacle to my goal, underpinned the success of the project, and gave me a valuable insight into others' observations about the profession of clinical psychology.

In the qualitative phase of my study children did identify new skills and benefits in relation to their caring duties. I found however, that the question that seemed most difficult for young carers to answer and in turn for me to ask, was one that referred to the things they felt they had achieved, learnt or gained from their caring experiences. For some young people it seemed that this question underlined their difficulties and their losses. This, I think, highlights a dilemma in conducting valid, sensitive and balanced research. Whilst it is important that researchers do not pathologise individuals, and give young people the opportunity to express an unbiased view of their situation, an over statement of the benefits may equally deny their experience. This brings me to consider an important facet of qualitative research, which is the interaction between the researcher and the participant.

Qualitative research upholds that the participants' reality is created through the experience of the group or interview (see Kleinman & Copp, 1993 for a discussion). Participating in research might alter how participants view their experiences. For many young people, the focus groups in this study were the first time they had had an opportunity to share their experiences together. Informal feedback suggested that many of them had found the experience enjoyable, and validating. However, the process of talking and discussion, or indeed completing questionnaires, encourages people to review and construct their views. I was aware that this might bring anxieties to the forefront of awareness, where previously they had been hidden. Methodologically, the issue of the validity of the participants' responses was dealt with by triangulating the data using individual interviews and a survey. Ethically however, the matter of raising the participants' awareness is more difficult to address. I was particularly conscious of this in the first focus group, where it was apparent that one participant did not understand the concept of a 'young carer' and

considered the young carers' group he attended to be nothing more than a social club. Clearly, he did not consider his family situation to be unusual, and was confused by other participants' responses. Fortunately, my research was carried out in the context of a support group, which afforded the unusual advantage of being able to monitor and follow up participants if necessary, as happened in this boy's case. However ideally this participant would have been selected out of the group during the recruitment phase. If time had allowed a possible solution may have been to have assessed the children in a short interview prior to their inclusion in the group, although in this study time constraints did not permit this. Although children were de-briefed and provided with optional individual time, 'what is known cannot be unknown', and one draw back to researching young carers is that it may serve to emphasise their own sense of 'difference'.

In summary, some of the key things I learnt were the value of having a broad perspective on the research topic, particularly if accessing the participants places you in contact with people who may have differing perspectives and priorities. Understanding their viewpoint enabled me to examine my own values and position more critically. Also, that research does not occur in a vacuum, but can have reverberations not only on the micro level of individuals' lives, but also by influencing the broader political agenda.

Methodological and Conceptual Issues

Conceptual Considerations

'Young caring' as an academic topic interfaces with an array of literatures across a broad spectrum of disciplines. In developing my knowledge in this area I have journeyed through literatures on care giving, stress and coping, social support, identity, siblings of children with a learning disability and familial disability and illness. I have considered systemic, psychodynamic, and social perspectives and not least asked the young people themselves. Whilst this area has afforded an invaluable learning opportunity, the breath of the topic has had some drawbacks. It has not been possible to consider the impact of the illness/disability itself in influencing either care or adjustment due to the diversity of the sample, and it could be argued that the sample was too broad, and therefore compromised the internal validity of the

study. However, to my knowledge this study represents the largest empirical study of young carers *per se* and a large sample was necessary for the development of a measure. This could only be achieved by keeping the criteria broad, although it must be recognised that the type of illness or disability and the relationship to the care recipient may well have an important effect.

Some authors have argued for a 'non categorical' approach to the study of illness and disability (Pless & Pinkerton, 1975; Stein & Jessop 1982). They uphold that classifying children and families according to the specific nature of the illness is a medical view, which places an inappropriate focus upon the illness characteristics, rather than the commonality of the stresses encountered in families lives. Furthermore some illnesses (e.g. cancer) may have a multitude of differing prognosis dependent upon the type of cancer, its stage, and treatment. Classification according to illness type therefore also seems problematic. What may be more pertinent to the well child in a caring role is not the label attached to the care recipient, but the extent to which it disrupts theirs and their families' lives. The focus group research seemed to uphold this view. Each group contained a mix of young people caring for care recipients with a range of illness and disability, yet overall what was striking was the commonality in their concerns and experiences. This seemed to be borne out across a variety of methods of data collection. Perhaps this suggests that researchers would do well to ask those whom they seek to research about their issues and concerns before deciding on the questions that are most crucial to be answered.

Methodological Considerations

Confounding.

An important critique of research examining the links between stress and adjustment is the issue of confounding. Dohrenwend and Shrout, (1985) argue that similarities often exist between the items on stress measures and the items on self-report measures of adjustment. This might result in correlations, which reflect the shared variance attributable to confounding rather than a genuine relationship. They argue that individuals who have adjustment difficulties might be more inclined to appraise their life circumstances as more stressful. This generates uncertainty about the direction of the relationship between the variables. In my study one way to address

this would have been to use both child self-report and parental indices of adjustment. This would have controlled for the possibility that depressed children were rating their lives as more stressful because of the impact of the depression. This had to be ruled out for reasons of feasibility. In defence of the use of cross sectional methods to study stress-adjustment relationships, researchers have found significant correlations between indices of adjustment and levels of stresses, even when steps are taken to address possible confounds (e.g. Rowlison & Felner, 1988). Studies have also attempted to control for cognitive appraisal as a source of confounding. It has been shown that the subjective rating of the impact of a stressful event adds to the strength of the association with adjustment but does not account for the majority of the predictive utility that stressful events have been found to have (Johnson, McCutcheon, 1980; Rowlison & Felner, 1988; Swearingen & Cohen, 1985). This of course raises questions then about the utility of transactional models of stress, which claim that appraisal of the stressfulness of an event is central in determining the emotional impact upon an individual. Clearly transactional models, and the relationships between stresses, symptoms and supports are complex and may involve reciprocal patterns of influence. My study suggested that the perceived level of social support was related to the use of avoidant coping. The less perceived support, the more avoidant coping that was used by the individual. Prospective studies are required to unravel the interactions between contextual factors. In devising the young carer perceived stress measure that was used in this research care was taken to ensure there was no obvious replication of items with items on the adjustment measure.

Measures.

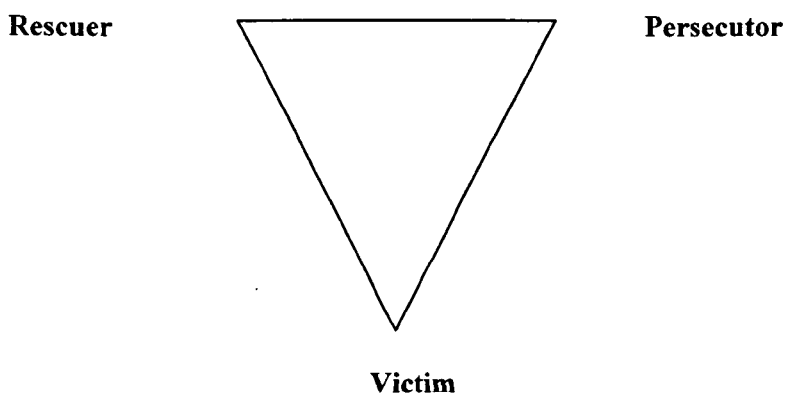
One difficulty experienced in this study was a lack of appropriate self-report measures for studying the constructs of interest. An emphasis was placed upon the brevity of the measures used due to a concern about over burdening the participants. The measure used to study adjustment was chosen in preference to more traditional but lengthy measures, such as the Children's Self Concept Self (Piers, 1984), the self report version of the Child Behaviour Checklist, YSR (Achenbach, & Edelbrock, 1987) or a combination of measures designed to study depression (e.g. Birleson, 1981) and anxiety (e.g. What I think and feel; Reynolds & Richmond). The decision was taken to use the GHQ-12 (Goldberg, 1978), as it has been shown to be a very

robust and reliable research instrument across a broad spectrum of samples. It provides a measure of general psychological well being, and has the advantage of brevity.

Access to participants

I have already indicated how access to participants through young carer support groups challenged me to consider my values and beliefs. At times I felt angry, judged and stigmatised by the responses to my initial tentative requests for access, and occasionally guilty too. I came to understand that I had become caught up in a powerful dynamic in which I represented 'the professional', and that the feelings I experienced might parallel those of the young carers and their families. Karpman's, (1968) 'drama triangle' (see below) is helpful in considering the dynamics within this process.

Figure One **The drama Triangle**



Karpman's, (1968) triangle set out in Figure One offers a valuable framework for interpreting the reactions that I sometimes experienced from the young carers' workers. Karpman proposed that individuals move around the triangle taking up different roles, based upon their expectations of others. These it is claimed are derived from childhood relationships and experiences. At times the reactions I experienced from workers' seemed out of proportion with the nature of my requests, and I suspect that I was caught up in the workers' counter transference. That is, they

were transferring relationship expectations based upon early life experiences onto their current relationship with the young carers and myself. I (and other professionals) became the persecutor, the support group workers were the rescuer(s), and the young carers were the victims. It is not unusual for those who work with young carers to have been young carers themselves. It is possible that this may explain the response I sometimes received. I seemed to represent the professional(s) or possibly a family member that had perhaps neglected to acknowledge, respond, or help the child, in a constructive way. In occasional cases I felt that this dynamic could have negative consequences for the young carers, as the implication of the dynamic was that they became victims who need protection from outside influences. In odd cases it did seem that this worked to limit the young carers' opportunities and experiences and led to them being further isolated. There was sometimes a reluctance to refer to other agencies and services, which might have benefited the young carer, because the service was not perceived as understanding young carers' needs. This circumstance did seem to be rare, fortunately, and in spite of my initial struggle, many groups did support the research, and I am indebted to them for they help they provided.

Conclusion

In conclusion, the research process provided me with opportunities beyond developing an understanding of research methodology, statistical analysis and data collection, although these were also important learning experiences. It afforded me the chance to consider research, and the ethics of it, more broadly and to view the profession of clinical psychology through the eyes of a social perspective. It also taught me that basic clinical skills such as listening, empathising with the perspectives of others, and problem solving, are equally applicable in the research field, and thus provided me with a bridge between the clinical psychologist as a practitioner and the clinical psychologist as a scientist.

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APPENDICES

APPENDIX A

Journal specifications; notes for contributions to authors.

Qualitative Health Research
Clinical Child Psychology and Psychiatry

NOTES FOR AUTHORS – Qualitative Health Research

- Everything is double-spaced: title, abstract, text, references, appendix(es), footnotes, block quotations, tables, captions, author's note/acknowledgments. Use 12 point font.
- Everything is left-justified, with a ragged right-hand margin (no full justification).
- Underlining is used for italics. No bold or italic type is used.
- Each section begins on a separate page in the following order: title page, abstract, text, references, appendix(es), author note/acknowledgments, footnotes, each table, figure captions, each figure. Number all pages except those with figures consecutively.
- Title page includes title, author(s) name, and institutional affiliation. An "author's note" (acknowledgments, correspondence address, etc.) may also be added to the title page. Manuscripts will be sent out for blind review, so please do not include any biographical statement or other identifying information within the manuscript.
- The second page of the manuscript contains an abstract of 120 words or less (no abstracts are necessary for submissions to "Computer Monitor").
- Footnotes are grouped on a separate page. Do not place footnotes at the bottom of pages.
- All in-text citations are included in the reference section. All references have in-text citations.
- The reference list and reference citations follow the APA guidelines set down in the Publication Manual of the American Psychological Association, Fourth Edition. Please refer to pages 168-234 for examples of references in APA style.
- All figures appear exactly as they are to appear in the journal except for size.
- Written, signed permission has been obtained where necessary for all quotations, figures, photographs etc. Copies of all letters granting permission accompany your article.

Submit 4 copies of manuscript to

- **Dr. Janice Morse, Editor**
  Qualitative Health Research
  International Institute for Qualitative Methodology
  6-10 University Extension Centre
  University of Alberta
  Edmonton, AB, Canada T6G 2T4

Please do not send a disk until the manuscript has been accepted.

Notes for Authors- Journal of Clinical Child Psychology and Psychiatry

The Editor apologizes for the apparent pedantry of these instructions, but emphasizes that adherence to them will ensure rapid and efficient processing of your contributions, and will enhance the article itself.

Peer review process. The Editor will screen manuscripts for their overall fit with the aims and scope of the journal. Those that fit will be further reviewed by two or more independent reviewers. Papers will be evaluated by the Editorial Board and refereed in terms of merit, readability and interest. Unsolicited manuscripts will not be returned to the author.

Submission of MSS. Four copies of each manuscript, **typed in double spacing throughout**, and on one side only of white A4 or US standard size paper and a copy on disk (preferably PC compatible) should be sent to the Editor at the address given below. All pages should be numbered.

Format of MSS. Each manuscript should contain the following, in the correct order.

(a) Title page to include the title of the paper, full name of each author, current professional position and work context, and indicators of which author will be responsible for correspondence. A word count should also be included.

(b) Abstract page: the abstract itself not to exceed 200 words (150 for preference), and up to 5 key words to be listed alphabetically on the same page. This page should carry the title of the paper but not the author name(s).

(c) Main text: not usually to exceed 7500 words and to be clearly organized, with a clear hierarchy of headings and subheadings (3 weights of heading maximum).

(d) References: Citation of references follows APA (American Psychological Association) style. References cited in the text should read thus: Brown (1955: 63-64); (Brown, 1995, pp. 63-64; Green & Brown, 1992, p. 102, table 3). The letters a, b, c, etc., should distinguish citations of different works by the same author in the same year (Black, 1989a, 1989b). All references cited in the text should appear in an alphabetical list, after the Notes section.

(e) Figures, tables, etc.: should be numbered consecutively, carry descriptive captions and be clearly cited in the text. Keep them separate from the text itself, but indicate an approximate location on the relevant text page.

(f) Author biographies: On a separate sheet provide a one-paragraph bio-bibliographical note for each author – up to 100 words for a single author, but none to exceed 65 words in a multi-authored paper.

Style. Use a clear and readable style, avoiding jargon. If technical terms must be included, define them when first used. Use plurals rather than he/she, (s)he, his or hers: 'If a child is unhappy, he or she...' is much better expressed as 'When children are unhappy, they...'.

Spelling. British or American spellings may be used (the 'z' versions of British spellings are preferred to the 's' versions, as given in the Oxford English Dictionary).

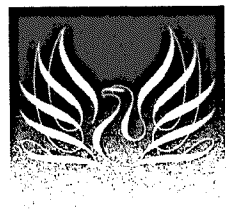
Punctuation. Use single quotation marks, with double inside single. Present dates in the form 9 May 1996. Do not use points in abbreviations, contractions or acronyms (e.g. DC, USA, DR, UNESCO).

APPENDIX B
Ethical Approval for Research.

Dean of School
Professor Donald C Pennington
BA PhD CPsychol AFBPS

Coventry University
Priory Street Coventry CV1 5FB
Telephone 024 7688 7688

School of Health and Social Sciences
Direct Line 024 7688
Fax 024 7688 8784



Our reference

Your reference
nab 101.00

Date

14 August 2000

Louise Earley
73 Hartledon Road
Harbourne
Birmingham
B17 OAA

Dear Louise

ETHICAL CLEARANCE OF PROJECT

I write to confirm that your proposal has been approved by Chair's Action by the Dean of School on behalf of the School Research Ethics Committee. Please find attached a copy of the form giving immediate approval and duly signed.

Apologies once again for the confusion and delay over seeking approval for this form. We hope this hasn't inconvenienced you too greatly.

Please contact me if you need any further assistance.

Kind Regards,

Mrs Nicola Boyle
Administrative Assistant and Secretary to Ethics Committee
School of Health and Social Sciences

Cc: Dr Tony Cassidy
Dr Keith Sharp
File Copy

APPENDIX C

Letters and Correspondence sent as part of the recruitment process for both brief and main studies.

Information leaflet for support group managers and accompanying letter for both studies.

Information leaflet for young carers for both studies.

Dear

Following our telephone conversation, I am writing to send you an outline of my research. As you know I am a clinical psychologist in training studying at the Universities of Coventry and Warwick. For my thesis I am a researching child as care givers. I an exploring how the young person's coping strategies and social support from friends and family may help to protect them from stress associated with their role. Dr. Tony Cassidy of Coventry University supervises my work.

I am currently approaching groups to ask if they would be able to support the research. In the first instance I am looking for young people to take part in two 'discussion groups'. This would involve the young people coming together to talk with each other about the issues of coping, support and caring. I would be available to facilitate the discussion and the group would be tape-recorded. I need between four and ten young people to take part in each group and ideally a mix of gender and caring roles. It is expected that the groups would take place between July and October and a time that is convenient for you. An outline of the research is enclosed for your information.

I look forward to hearing from you soon, however in the meantime please feel free to contact me should you ha any queries. Thank you for your co-operation.

Yours sincerely,

Louise Earley
Clinical Psychologist in training

ADOLESCENTS AS CARE-GIVERS: THE ROLE OF COPING AND SOCIAL SUPPORT

Introduction

It has been estimated that 50,000 young people are involved in looking after family members in the United Kingdom. There has been considerable discussion on the restrictive impacts of caring in relation to a young person's education, social life and physical and emotional health. Through this research I intend to explore how young carers cope with the stresses of care-giving, by examining the coping strategies they use and the support they feel they have from others (e.g. friends and parents).

Why study this ?

Caring can be stressful, yet we know that young carers are all individuals, and that some young people cope better with the daily demands of teenage life and looking after someone. This study aims to explore how stress associated with care-giving impacts upon their well-being, and the role of support and the individuals own coping in protecting them from role related stress. If we can begin to understand these processes, we may be in a position to offer help to enhance their methods of coping with this demanding situation.

Procedure

The first aspect of the project will involve the young peoples' participation in 'discussion groups'. The groups will each last about one hour and will involve the young people talking together on the topics of the 'ups and downs of caring', coping, and what helps them to manage. The group will be tape recorded for later transcription, however no child will be identified in this process. It is anticipated that the groups will take place sometime between July and September 2000 at participating young carer groups. The information will be used to devise a questionnaire on stress in young carers, for use the in main phase of the study.

Participants

Young people aged between 12-18 caring for a family member with a physical illness or disability.

Ethical Considerations

The research has been approved by Coventry University Ethics Board.

Consent and confidentiality

Initial agreement from the young carers group co-ordinator will be sought. A written consent form explaining the study will be given to the young carer to be signed by their parents/guardians and returned to the carers' worker before the young person completes the questionnaires. The young person will be given a leaflet explaining the research, providing assurances of confidentiality, and asking if they would be interested in taking part. All information will be treated in strict confidence, people can withdraw from the research at any time, and the childrens' names will not be recorded.

Duty of Care

As a precaution, and in the event of a concern arising about a child's welfare the questionnaire packs will be numbered, and a record kept by their carer group of the number of each child's questionnaire pack.

Debriefing

Following completion of the questionnaires the young people will have an opportunity to discuss the research with either myself or a member of the young carers staff. A telephone contact number will be provided should the young person have any further questions or issues they wish to discuss regarding the research.

If you require further information, myself or my research supervisor Dr. Tony Cassidy, will be happy to answer your queries.

Dr. Tony Cassidy
Louise Earley (Clinical Psychology Doctorate)
School of Health and Social Sciences
Priory Street
Coventry
CV1 5FB
Tel 01203 838762

What's it all About?

Hello, my name is Louise Earley and I am a student at Coventry and Warwick Universities. I am researching how people aged 12-18 cope with looking after a family member. I am asking young people if they would like to take part in my study.

Why am I studying this?
Helping to look after someone can sometimes be an extra strain on top of school, and daily life. I am trying to find out more about how young people see the ups and downs of caring and what helps you to manage.

What would I have to do?
I am holding 'discussion groups' with young carers. This is a chance for you to talk together with other people from your group about what life is like as a young carer. The questions I am interested in are, what do you think a young carer is, what are the ups and downs of caring from your point of view, and who helps you to manage? The group will take about an hour and will be tape-recorded so that I can remember what everyone said, and later write about the group. **Your name will not be recorded and everything is private.**

What do I do now?
Decide if you would like to take part. Don't worry if you agree, you can still change if mind at any time. Let the young carers staff know if you are interested and they will give you a form that your parents must sign. Take it home and talk it through with them. If you still want to take part then return the consent form to the young carers group.

What if I want to know more?
If you or your parents have any more questions then myself or my supervisor, Dr. Tony Cassidy at Coventry University will be happy to answer them, our details are below. Or you can speak to the young carers staff and they can get back to me with your questions. THANK YOU

Louise Earley/ Dr. Tony Cassidy
The University of Coventry
School of Health and Social Science
Coventry University
Priory Street
Coventry Tel. 01203 838762

Dear

Following our telephone conversation, I am writing to send you an outline of my research. As you know I am a clinical psychologist in training, studying at the Universities of Coventry and Warwick. For my thesis I am studying adolescents as care-givers. I am exploring how the young person's coping strategies and social support from friends and family may help to protect them from the stress associated with their role. My work is supervised by Dr. Tony Cassidy of Coventry University.

I am currently approaching young carers groups to ask if they can support this research. In the first instance I am looking for volunteers aged 12 -18 to participate in the main part of the study. Their participation would involve the completion of four questionnaires. Where possible I would attend one of your meetings to go through the questions with the young carers. It is expected that data collection for the main study will take place between September and December at time that is convenient for you. An outline of the research is enclosed for your information.

I look forward to meeting you soon, and in the mean time if you have any queries, then please do not hesitate to contact me. A number is provided above. Thank you for your co-operation.

Yours sincerely,

Louise Earley, Clinical Psychologist in training

ADOLESCENTS AS CARE-GIVERS: THE ROLE OF COPING AND SOCIAL SUPPORT

Introduction

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Why study this ?

Caring can be stressful, yet we know that young carers are all individuals, and that some young people cope better with the daily demands of teenage life and looking after someone. This study aims to explore how stress associated with care-giving impacts upon their well-being, and the role of support and the individuals own coping in protecting them from role related stress. If we can begin to understand these processes, we may be in a position to offer help to enhance their methods of coping with this demanding situation.

Procedure

The main focus of the project will involve the young people completing questionnaires. The questionnaires are designed to measure coping strategies, social support, the stresses/satisfactions of care-giving and adjustment. The stress/satisfaction questionnaire will be devised by myself, from information derived from "discussion groups". The questionnaires are designed to be age appropriate and the young person will normally be able to fill them out with minimal support. It is estimated that in a group setting it will take approximately 30 minutes to fill them out. It is anticipated that the questionnaire data will be collected sometime between September and December 2000 at participating young carer groups.

Participants

Young people aged between 12-18 caring for a family member with a physical illness or disability.

Ethical Considerations

The research has been approved by Coventry University Ethics Board.

Consent and confidentiality

Initial agreement from the young carers group co-ordinator will be sought. A written consent form explaining the study will be given to the young carer to be signed by their parents/guardians and returned to the carers' worker before the young person completes the questionnaires. The young person will be given a leaflet explaining the research, providing assurances of confidentiality, and asking if they would be interested in taking part. All information will be treated in strict confidence, people can withdraw from the research at any time, and the childrens' names will not be recorded.

Duty of Care

As a precaution, and in the event of a concern arising about a child's welfare the questionnaire packs will be numbered, and a record kept by their carer group of the number of each child's questionnaire pack.

Debriefing

Following completion of the questionnaires the young people will have an opportunity to discuss the research with either myself or a member of the young carers staff. A telephone contact number will be provided should the young person have any further questions or issues they wish to discuss regarding the research.

If you require further information, myself or my research supervisor Dr. Tony Cassidy, will be happy to answer your queries.

Dr. Tony Cassidy
Louise Earley (Clinical Psychology Doctorate)
School of Health and Social Sciences
Priory Street
Coventry
CV1 5FB
Tel 01203 838762

What's it all About?

Hello, my name is Louise Earley and I am a student at Coventry and Warwick Universities. I am researching how people aged 12-18 cope with looking after a family member. I am asking young people if they would like to take part in my study.

Why am I studying this?
Helping to look after someone can sometimes be an extra strain on top of school, and daily life. I am trying to find out more about how young people see the ups and downs of caring and what helps you to manage.

What would I have to do?
I am asking the young carers group if I can come along to one of your meetings to take you through some questionnaires. The questions are about the topics of coping, support, caring and mood. Don't worry you do not need to write much it is mainly ticking boxes. They will take about 40 minutes to go through, and one of the young carers staff will be there as well. I do not need to know you name and your answers are private. **I will hopefully write my project up so that people who are interested in young carers can know what I found but your name will not be mentioned. I will also let you know as well.**

What do I do now?
Decide if you would like to take part. Don't worry if you agree, you can still change if mind at any time. Let the young carers staff know if you are interested and they will give you a form that your parents must sign. Take it home and talk it through with them. If you still want to take part then return the consent form to the young carers group.

What if I want to know more?
If you or your parents have any more questions then myself or my supervisor, Dr. Tony Cassidy at Coventry University will be happy to answer them, our details are below. Or you can speak to the young carers staff and they can get back to me with your questions. THANK YOU

Louise Earley/ Dr. Tony Cassidy
The University of Coventry
School of Health and Social Science
Coventry University
Priory Street, Coventry Tel. 01203 838762

APPENDIX D

Parental consent forms.
Consent forms for children over sixteen years of age.

Dear Parent or Guardian,

Louise Earley is studying at the Universities of Coventry and Warwick and she is interested in how young people manage the day to day stresses of caring for a family member. She is researching what they do to cope with things like school, friendships, thoughts about the future, as well as family life, and how the support they receive helps them. It is hoped that information about the ways in which young carers cope with the demands in their lives, may help them to be supported in their roles effectively.

Louise has asked us if she can hold a 'discussion' group with the young people. She would like your permission for (child's name) to take part. The group will involve the young people discussing together their views on life as a young carer. The group will take about 60 minutes and a member of the young carers staff will be present. The group will be tape recorded, so that later the themes can be examined. The young people will not be identified on the tape or in written transcripts.

All the information is confidential and the young person's name will not be recorded. Their date of birth and carer group means that you could be informed if for any reason there was a concern about your child. Participation is entirely voluntary, and if you agree, you can still change your mind at any time. **Your decision will in no way effect your child's right to access our support group or any other service.**

It is likely that the research will be written up and published in articles read by people who may work with young carers. The young person's confidentiality will of course be protected.

If you would like any further information before making your decision, Louise or her supervisor Dr. Tony Cassidy, (Psychology Group, School of Health and Social Sciences, Coventry University, Priory Street, Coventry) will be happy to answer any queries; Tel. 01203 838762. If you agree that ---------- can take part, please fill in the consent slip below.**Thank you for taking the time to read this information.**

Today's Date --------/--------/---------

Child's full name ---------- **(please print)**

I have read and understand the information regarding the young carer research project. I agree to my child taking part.

Name of parent/guardian ---------- **(please print)**

Signature of parent or guardian ----------

I would like to receive a summary of your research findings. Y / N

Dear Parent or Guardian,

Louise Earley is studying at the Universities of Coventry and Warwick and she is interested in how young people manage the day to day stresses of caring for a family member. She is researching what they do to cope with things like school, friendships, thoughts about the future, as well as family life, and how the support they receive helps them. It is hoped that information about the ways in which young carers cope with the demands in their lives, may help them to be supported in their roles effectively.

Louise has asked us if she can come along to a meeting to go through some questionnaires with the young people. She would like your permission for (child's name) to take part. Each young person will be asked to complete some questionnaires, about the topics of coping, support, caring and mood. The questions will take about 40 minutes to go through and Louise and a member of the young carers staff will be there should any-one have any questions.

All the information is confidential and the young person's name will not be recorded. Their date of birth and carer group means that you could be informed if for any reason there was a concern about your child. Participation is entirely voluntary, and if you agree, you can still change your mind at any time. **Your decision will in no way effect your child's right to access our support group or any other service.**

It is likely that the research will be written up and published in articles read by people who may work with young carers. The young person's confidentiality will of course be protected.

If you would like any further information before making your decision, Louise or her supervisor Dr. Tony Cassidy, (Psychology Group, School of Health and Social Sciences, Coventry University, Priory Street, Coventry) will be happy to answer any queries;Tel. 01203 838762. If you agree that ---------- can take part, please fill in the consent slip below.**Thank you for taking the time to read this information.**

Today's Date --------/--------/---------

Child's full name ---------- **(please print)**

I have read and understand the information regarding the young carer research project. I agree to my child taking part.

Name of parent/guardian ---------- **(please print)**

Signature of parent or guardian ----------

I would like to receive a summary of your research findings. Y / N

Date

Dear

My name is Louise Earley and I am a student at Coventry and Warwick Universities. I am writing to ask if you would be willing to take part in my research into 'Stress and Coping in young carers'.

About the study

The study is looking at how young carers cope with the demands in their lives, such as school, home, friends, family life and caring duties. I am interested in finding out how coping and the support people have from others helps them to manage. It is hoped that the more we know about what helps young carers, the better people can support them with their responsibilities.

What do I need to do?

It will involve filling out some questionnaires on the topics of coping, support, caring and mood. You do not need to write anything, but it will involve ticking boxes with the answer you agree with. I will come along to one of your support groups to be on hand if you have any questions while you complete the pack. It will take about 30 to 40 minute to complete.

Who will know what I have written?

Any information will be treated with confidentially. Your name will not be recorded but the group will keep a number of the pack you were allocated just in case I need to get in contact at a later date.

What will happen to the findings?

A summary of the findings will be circulated via the young carers groups to all participants. I also hope to publish the results so that people who come into contact with young carers can be aware of the findings. No individual will be identified in any report.

If you have any more questions regarding the study then please feel free to get in contact; myself or my supervisor will be happy to answer your queries, or ask your support group worker and they can contact me.

Contact Details: Louise Earley/ Dr. Tony Cassidy, Clinical Psychology Doctorate, School of Health and Social Sciences, Coventry University, Priory Street, Coventry, CV1 5FB **Tel. 01203 838762.** Thank you for your time.

Yours Faithfully,

Louise Earley

APPENDIX E

Information on the procedure for conducting the focus groups, individual interviews and the support workers postal survey.

Focus group questioning route
Focus group transcripts
Transcripts for interviews 1, 2 and 3
Survey for support workers and covering letter

FOCUS GROUP TOPIC GUIDE

1. INTRODUCTION (10 minutes)

a. Hello, I want to start by saying thank you to you all for coming alone today. My name is Louise and I am researching the experiences of young people who care for someone. Now I know that some young people don't like the term young carer, but if you don't mind I will use it today as it makes life easier. Is that OK with every one? Good. So this is a chance for you to have your say on life as a young carer. In a few minutes I will ask some questions about the day to day hassles of caring and the things you think are good about it. I am interested in the different things you do to cope with the job of caring, and who you think helps you in that job.

b. I am recording the group so that I can remember the things that you have said and so I can get an idea of everyone's point of view on the questions I ask. Everyones view is important and it is OK to disagree with other peoples view. It is a chance for you to talk to each other and there isn't a right answer to any of the q's I ask and nobody is being judged on the things they say, so please try to speak as honestly as you feel you can.

c. OK before we start I think it's important to have some rules that we agree on while we are together for the group.

Activity: Louise; write up on a flip chart " Rules of Our Group". Can you shout out one at a time what rules you think it's important that we have in the group.

(flip chart paper and marker pen, bluetack to stick on wall.)

Discuss importance of everyone respecting confidentiality, each others' feelings and opinion, **only one person speaking at once,** no shouting or swearing, being honest, if someone wants to leave then just let us know and one of us will come with you. (Check out the usual rules of the center.)

The information you say here is **confidential** and I will make sure that nobody knows what you have said. The only time I would break this is if a any-one told me that they were going to hurt themselves, or some-one else and then I would have to let other people know, and that's something I say everytime I work with someone. The tape with the information on from today will be destroyed when I have finished with it next year. Can I asked that we don't use second names so they aren't recorded on the tape.

d. Brilliant thanks for that. Now I know most of you know each other but I don't know your names, so to help me learn them I have a qick name game to play.

Ice breaker exercise.

bean bag thrown around the room and answer a question each time. (5 mins)

Can you each put on a name tag with your first name on it. Hand out labels and pens to YC's. **TAPE ON**

Now for the tape so I can recognise your voice can you go round and tell me your name, age, the person or people that you care for and how long you have cared for them.
(Coloured pens for group, and sticky labels for name badges)

2. THE ROLE OF A YOUNG CARER; SELF PERCEPTIONS

- Great lets start. Can you explain to me what a young carer is and the sorts of things they do? (5 minutes)

Probe views

- Do you think that other young people your age do these kinds of things ? (APPRAISAL)

- So how does it feel that you do them ? (APPRAISAL)

3. THE DAILY HASSLES OF CARE-GIVING

- Sometimes when people have an important thing to do which takes up a lot of their time it has an effect on lots of different area's of our lives. What areas of your lives do you think caring has an effect on.

probe: school, future, family, friends, self

- Some -times when people have a lot to do they can feel "hassled". Do people know what hassled means? Can anyone tell me what they think it means? Yes, that's right a hassle is a day to day stress that gets you down a bit. It can happen even if we want to do the thing we are doing that is making the hassles. This is mine, the big job I have to do is train to be a psychologist, this is a good thing, but it does make a lot of hassles in other bits of my life. It is easier to cope with if the hassels aren't going on for ever. One hassle for me that results from my job, is travelling a long way to work through heavy traffic, or not seeing my friends so much because I'm busy. I'm interested in what day to day hassles you have as a result of caring. Here is my hassel circle. The different rings stand for the different parts of my world, that we have just talked about. Can you label the different parts of your world on your papers, that you see as important to you, and in the rings list the hassles that you have to deal with in that area.

(Hassel circles and my example, pens)

Probe:

So what things do people have on their papers, can someone explain their's to me ?
Do other people have anything different ?
Discuss hassles of school, home, family, friends, health etc. ?

4. Satisfactions of Caring

- So, we've been talking about all the down sides to caring, but what about the good things, are there any, and what do you think they are ?

5. PERCEIVED SUPPORT

- What helps to make your life easier ?

probe: Who/What do they do ?
Consider emotional, practical /respite and informational support.

6. COPING

Support is one way of coping, but their are many other ways which we used to help ourselves when things are stressful. Think of a recent time when you felt stressed about the caring you do. Keep that in your mind and write down how you handled the situation. When we have finished we are going to make a "first aid" box, with things that we can use when we are feelings stressed.

probe : *What sort of things have people written down ?*
Do they work ?

8. DEBRIEFING (5 minutes)

- Round up and thank you. Collect in papers and pens. Boxes to keep. Summary of the topics discussed, give a balanced view of the positives and negatives.
- Any comments or anything any body didn't get a chance to say and wanted to?
- If you could give one piece of advice about how we could best help support young carers what would it be?
- What have people thought about doing the focus group.

probe. difficult feelings raised, offer additional support and a contact number if they should wish to discuss any thing about the research. Encourage to talk to Abbey (YC worker) if anything has been raised about the research that is bothering them.

Focus Group One- Transcript

F1 Let's make a start. The first think I wanted to ask you is what do you think a young carer is? What do you think it is, the sort of things you do. You don't have to go around, but if someone would like to make a start. What's a young carer ?

L2 Knowing all your secrets.

F3 What's that again?

L 4 Knowing all your secrets.

F5 Knowing all your secrets OK. Can you tell me what you mean ?

L6 (In audible.)

F7 What would you like to say ?

Le8 Somebody who cares for someone in the family.

B9 Someone who looks after a disabled brother or sister.

F10 OK, so someone who looks after a disabled brother or sister. You don't have to put your hands up, you can just chip in.

P11 Someone who takes care of someone and is there all the time.

F12 Right, so it's taking care of someone and giving up your time.

P13 Your own time.

F14 Your own time. OK, and who do they look after ?

Le15 Probably someone in their family. Or someone (inaudible).

P16 It's somebody of a young age who's involved all the time (inaudible) to the point of anything else (inaudible) they give their own time.

F17 So, it's a young person and their giving up something of their own. Do other people think that or have a different view, because it's OK to have a different view?

L18 Play games.

F19 Play games, OK that's what you do is it? As a young carer you play games? Do you, alright. So what sort of things do young carers do then?

? You said about playing games, looking after your brother or sister, spending lots of extra time with them.

Le20 They care.

F21 Hmm, Hmm, they care.

? 22 Spend lots of their time.

F23 OK, so they spend lots of their time.

P24 Always being on their backs all the time.

F25 Always being on their what sorry?

P26 Always being on their back, taking care of them and that, making sure that they don't do anything to harm themselves.

F27 Uhh, mhh

L28 There's two groups though isn't there, and there isn't that many people in each group?

F29 Saturday and Monday group? What other things would you say a yc did? If you were describing to someone who's never hear the word before?

? 30 Somebody who looks after someone in their family whose disabled.

B31 (inaudible) ... and they spend lots of their time with them, their spare time and they are always there for them.

F32 That's very well said. So do you think that most people your age do those types of things?

?33 No.

P34 They probably do because they probably have a disabled relative or person in their family. (inaudible). So basically as well as taking up their own time, as well as helping them, they help around the house as well, do not have children, so basically they take up their time as well, just to make them comfortable.

F35 Hm, yeh, that's brilliant. So I suppose what I'm wondering is, is it unusual, to look after someone, would you say it was?

L36 Me?

F37 No, I'm asking any one really.

Le38 'Spose you get used to it though don't you? So it won't be unusual.

F39 Hmm Hmm

P40 I suppose it might be to other people it is, because other people see you can't come out and you're too busy, and stay in the house and do other things and they think at your age you should be coming out but they don't understand it from your point of view they're looking at it from a different perspective.

F41 OK, so one of the things you've found is that other people don't understand what it means to have all this responsibility. Have other people found that perhaps people who aren't YC don't understand what you do? Is that anything anybody else has found?

Lu42 It's a club

F43 Hm
(laughter)

A44 So you mean like a club, but not for young carers.

Lu45 Yes

F 46 Hmm, so for you it's a place to go and have some fun, you said. Yeh, OK

Le47 I found out that er most of my friends would like to help me and that they are there to care for me as well.

F48 So you found your friends are helpful to you.

P49 But sometimes when you go out with that person, you get an odd look or stare or what ever, and you like, you do get the odd people who look or whatever, and you just feel there aren't so many people around, and you just feel, there aren't so many people around and you just feel .....isolated.

(inaudible)

F50 Yeh, hmm; you what sorry?

L51 You might fall in love with someone.
(Laughter)
He has though (Points to T).

F52 So is that about meeting people when you come to the group? (nods)
Yeh, well that's important isn't it? Yeh, alright, well you never know!
So we've talked a bit about what a young carer is, and views about it and I'm wondering what it's like? What does it feel like for you to be a young carer?

E53 Sometimes it gets you annoyed, but then you have a break or something, and you want to go back. You want to carry on because you get used to it so much.

F54 Right, OK, your nodding (to R), what do you agree, what do you think ? (R shakes his head no)

N55 'Cause you feel sort of as if your not, cause like my brother's in day care now, so it's like I had everything took off me. So you sort of want to, wanna sort of go back and help sort of, cause you don't feel, cause you've given him all your time, and if you don't give your time to that person it just feels.....lost.

P56 You feel lost.

N57 Yeh, you feel lost.

P58 And you're wondering what are you going to do now? Because at the end of the day you don't forget the person you've been caring for, for a period of time, and then even though you if you go back to caring you will probably find it stressful, but at then end of the day you love that person and you look back to it and say I did do a good thing. You may not care what other people think. OK, that person may be getting a lot of help, but from different people, but you have to look at yourself.

N59 So when your done you feel like you can sit back and.....

E60 You feel like your responsible for them.
(Inaudible)

F61 So your talking about very important things here, and it sounds like what the girls are saying over there, is that caring is a big part of their life really, and if it's not there then it feels a bit... lost. Am I right saying that? Your nodding as well, would you like to say anything, is that how it is for you ? (To R; he shakes head; no)

L62 Is there a club for old people as well? I seen eer..

T63 You should be asking Abbey that (yc worker).

L64 Cause I seen xxx...
(Laughter)

T65 Bob builder?

T66 No.

A67 Are you asking me, xxx if there is a club for older people who care?

L68 Yeh

A69 Yeh there are.

L70 'Cause I seen xxx go.

A71 Have you? Well it might be that carers are just, there are, you are young carers but there are people who care that are not just old people but sort of all ages, yes.

L72 Are they called old, old carers?

A73 No, they are called carers.

L74 Oh.

T75 Alright.

L76 It's only a question.

T77 OK

(inaudible)

F78 So can anybody, we've heard from the people over there, can anybody else say what is like to be a young carer?

Le79 In audible.

F80 What was that?

Le81 I can but I don't want to.

F82 You can but you don't want to.

F83 Would anybody else like to say anything, no, OK? Anybody else, what is it like to be a young carer?

LE84 Stressful.

B85 Sometimes stressful, sometimes hard, but you enjoy it at the end of the day.

F86 Good, thank you. So you were saying it's stressful sometimes.

F87 Ok, so we talked a little bit about what a young carer is. You've given me some ideas about how you see it. You've already said that caring sometimes effects different parts of your life. I want to ask more about what parts of your life do you think if effects? Thinking about all the different things you do from the time you get up to the time when you go to bed. I wanted to ask a bit more. What parts of your life does caring have an effect on?

B88 The bits when your alive.

F89 The bits when your alive? Can you say more about that?

B90 You can't care when your dead, so, you need to make the most of it.

F91 So you think you need to make the most of life? OK. Yeh. So, what bits of our life, if you think about perhaps, school, and friends, and home. What bits of your life do you think caring has an effect on?

B92 It effects almost everything perhaps like there are certain types (inaudible) and like, you can do things and you get engrossed in doing things and don't want the caring to go away. It brings you closer to other people.

F93 Brilliant, so you've got new friends. So, you can see that a good effect it has on your life, because it brings you in touch with friends perhaps and they chip in and give you a helping hand. Do other people find that? That it has a good effect in their lives?

P94 Yeh, cause there's times when you care for a person and then you do your own thing. But once you get used to it you find the time to do everything. You go out with friends, you go to school, you (inaudible) as well as caring for your own family member, and then you may find yourself stressed, and it does get stressful, but at then end of the day you cope with it, as well as (inaudible) so it does have good effects on you, cause you do find the time to do things.

F95 OK, well thank you. You were saying no, you don't think there are any real benefits (looking at Le).

Le96 No, I don't (Le looks upset.)

F97 OK

N98 *Leaves the room followed by (A) her young carer's worker.*

F99 Yeh, she has gone to the toilet, we'll stay here and A will come back in a minute. So, you (looks at P) were saying that there are good bits, and it's obvious that to others there aren't good bits, and that can be quite hard to talk about sometimes. Hm, you don't have to say what the hard bits are but can you say where they are. Is it school, is it home?

Le100 At home.

F101 At home, thank you for that.

B102 Well, there not really any bad bits now, there was at the start, I can't really remember it I've got so used to it now, that it's not really effecting me any more.

F103 OK, so for you, Xxx you've found that you've got used to it and there aren't any bad bits anymore. Yeh, but for Xxx, it's a bit, it's a bit, tricky at home for you isn't it?

Le104 Yeh, because, when, you go to school, you're on your own and you can have a good time, and the person you are caring for, their, usually at home aren't they? So, the problems not there with you at school, so when you go home the problems waiting for you to go home.

T105 But the problem is you never go home.

F106 Sorry, what was that you said there?

T107 I never go home.

F108 You never go home, can you say why that is?

L109 My sister goes on holiday for two weeks- Scotland.

C110 Don't you go home after school?

T111 Sometimes yeh.

C112 I walk you home every day after school.

F113 But, perhaps, what it's a bit about, is that it's hard to go home.

T114 Yeh.

F115 OK so, home's quite difficult, what's school like?

B116 Hard because you have to do French.

F117 Hard because you have to do French.

C118 And German, I do my exams tomorrow.

P119 You do find it hard at school as you worry about the person, the person you are caring for, you're probably thinking (inaudible) not sure that they can cope on their own.

R120 Thinking of what's at home.

F121 So, you say Xxx, you're thinking of what's happening at home?

R122 Yeh, (inaudible)

E123 Yeh, that is true because people do wonder, and the kids at school always shout about, saying your going to be dumb when your older, but if your looking after someone....

R124 You can't help it.

E125 You can't help having time off.

F126 No, of course.

E127 It gets....

L128 I never tell my school because every time my mum's sick, I think, it will make me, make me, sort of uneasy, cause I'm scared that something might happen to her so (inaudible) make me feel sick so the next day I don't go to school, because I'm scared to go and see, face up to my friends.

F129 Yeh, yeh , that must be really hard. Yeh, do other people find the same thing happens to them? You know if you have to take time off it's quite hard to get back into it isn't it and explain where you've been isn't it?

Le130 My friends are really understanding.

F131 That's good. That's good. OK. So it sounds like friends seem important, schools a bit of a problem, homes a bit of a problem, what about the future do you ever think about that?

C
L }Yeh
B

F132 In what way?

E133 Just hope the person your caring for gets better and ...

E134 But you could still, like, do a bit of a caring role for them, and get on with it.

P135 Your wondering if you'll cope with it, and be caring for them in the future because (inaudible) if it's difficult now will it be difficult in the future and your thinking will their health worsen, or will it get better, and your hoping it will get better, cause then it's easier for you and it's easier for them 'cause, that is an important thing to look forward to. So your hoping for the best, for both the carer and for the person you see.

F136 Hmm, Hmm

P137 So.

F138 Yeh, so you have hopes that the person might improve. What about hopes for yourself. You'd like to say something?

C139 I worry about the future 'cause, say you've got a disabled person in your family, your mum's not going to stay around forever is she, and you're going to have to take care of your sister on your own, so, err, you like, got a girl-friend it gets between you and your girl-friend doesn't it and it's hard for yourself.

F140 Thank you for saying that.

B141 Well, I don't really think about the future. I don't really like to think of the future. I make the most of what's now, I don't like to think ahead unless, it's like on my schedule. I don't like to think of the future. I think about what's going on now, and it there's something important I try not to think about it.

F142 OK, so Xxx you try not to think about the future, yeh, and you try to just focus on what's happening, OK.

Le143 Yeh, I don't think of the future cause sometimes if you think of the future you, you can actually scare yourself because you loose your mum and dad don't you? So, if you look into the future you might see yourself as old and on your own all the time caring for anyone else in the family, so I don't look into the future that much, if you do, you might risk scaring yourself more.

F144 Yeh, so that's perhaps a way you manage things, yeh? You'd like to say something, your sat with your hand up, what would you like to say?

L145 Inaudible.

F146 You just say when you can think of it. Alright, so, you've said about school and the hassles there...go on.

L147 Sometimes, I think in the future, cause, when everyone dies there's only my sister left in my family, my sisters the youngest, I don't know whose going to look after her.

F148 Yeh, that's quite a worry for you then? Yeh, well thanks for saying that. That's to you all for being really honest about that, because I think these are difficult things to talk about and you've all talked really honestly. Is there anything anybody else would like to say about the different areas of their life. We talked a bit about school, we talked a bit about the future, eer a bit about the family as well, and as, xxx you were saying, about how it might, sort of make you think about...would you like to say something else xxx.?

C149 It's like really difficult, cause it hurts that you'll never, ever, get to live on your own.

F150 Right....well....yes ?

P151 I think the best thing about being a young carer is that you grow up more, you grow up more, this, you know more things, like you know how to cook, and stuff like that, and it's good for when your older, but all this, some adults look down on you, but 'you don't want to do that you just want to be a child'; but you get used to it and you enjoy it.

F152 So, for some people, there's definitely good things isn't there and we'll move on to some of those things. I wanted to find out a bit more of the good things, but it sounds like there can be different hassles, in different areas and it creates a clash really, because you've got all these things going on in different places, and how do you balance it all?

P153 It's the same for your social life as well because if you are to go out other than school, you've got to (inaudible) as well, you want to go out with your friends to something different as well, and you have to arrange for someone to be there as well to look after the person you are caring for any way, but then you do worry about the person your caring for, then, as well. So, it is a bad thing as well, so, it's not just school all the time in school, and what the people say about it as well. It doesn't matter. So, it's a possibility that, that person will get better and you won't have to be so desperate for the rest of your life, and as I said before learning to cook and deal with the pxxxlems that is coping for your age. Because what age you are now, you wouldn't want to be doing everything a child is doing, but then when you get more into an adult, you know more for the future as well.

F154 Right, OK. What do you say? You have your hand up.

L155 You know more if you go to Saturday club.

F156 Yeh, you like going there don't you?

T157 He can't go anymore.

F158 OK, so we've talked a bit about the good things about caring there. Can anybody else think of any of the good things about caring, any gains you get?

Le159 When you're caring, you get to come to the young carers and they let you get away from the caring for a bit, they let you have a rest, because caring can mainly stress you up, cause it's getting my dad stressed up, and it's making me sick and all that, and, er, getting away from it helps you all that, so, you can settle down and hope that it's going to be alright when you go back.

F160 So, you really value this carers group and it sounds a good thing for you as well (looks to Lu) as you've mentioned it before. OK, what else might be a gain, a benefit.

C161 If you look after your sister or your brother or carer, or that, then your parents give you more, like more pocket money.

F162 Right, so they give you a little bit of a tip do they, for looking after them, and make sure your OK for money and things like that?

C163 Hmm.

B164 I don't get extra pocket money.

F165 You don't get extra pocket money, you don't get extra pocket money, Xxx ? Do you get anything else from caring?

B166 A lot more than money.

F167 What was that sorry?

B168 A great deal, a lot more than money...

F169 A lot more than money.

B170 I wouldn't want money anyway, I do it for anything.

F171 You'd do it for anything?

L172 So would I.

Lu173 Money isn't everything at the end of the day.

Lu174 Your doing it for love aren't ya?

B175 You don't want to get paid, you don't want to get paid to care.

Lu176 Can I go to the toilet?

C177 No, I don't want to get paid?

B178 No, I'm just saying. You don't do things for the money in that way...

R179 You do it for nothing.

F180 You'd do it for nothing would you Xxx ?

B181 You do it for the love basically.

F182 OK

Le183 I know what you mean cos, I'd do it for nothing....

F184 Err, Xxx, can you come and sit down please (C wanders to toilet). That's it we can't have everyone leaving...

Le185 I'd do it for nothing because if there's two people... (noise).

F186 Please, can we respect each other please, these are difficult things we are talking about.

Le187 If there's two people in your family then they'll need all the money they can get for the other person and who they're caring for.

F188 Yeh, yeh, so you'd do it.. so you're all kinda saying that you'd do it regardless. There's more benefits than money isn't there? I'm mean you said yourself that you've learnt skills and stuff like that. Does anybody else feel like they've learnt skills and things? What about you down there do your think have you learnt anything by looking after anybody?

Lu189 Where's Xxx gone?

F190 He's gone to the loo.....don't know?

Le191 Can we just, you know, just listen to other people?

R192 Don't know.

F193 You don't know, OK, OK, so we've got some of the good things about caring, you said Xxx that your friends help you with caring, what else or who else helps make your life easier?

Le194 Young carers.

E195 They do help a lot. If you've got any problems...

R196 You can talk to them if you like. If you've got any problems.

F197 Yeh, so talking to someone helps.

Le198 Yeh, expressing your feelings, and they can counsel you for a bit, so (inaudible).

F199 Right, OK, so there are the young carers staff. What or who else helps you?

P200 Cross-roads helps my mum.

C201 Cross-roads what's that?

E202 It's like a caring agency, cause I have that for my mum.

C203 And you feel like you've gained something for your mum, cause your mum gains someone she trusts to look after your sister.

P204 (inaudible)

F205 OK, Xxx can you come in please without stomping. Lovely, come on this chaps waiting to go (toilet) he's dancing around, OK that's it, sit down.

So we were talking about what helps you, and who helps you, and people said that the young carers staff were really good at helping you out. Yeh, carers staff (noise) no sit down xxx please.

L206 What's that on the board, respect other people, you wrote it down.

C207 Well you told me to.

F208 OK we're talking about who helps you. Who helps you xxx, who helps you with all you have to do? What helps you, can you think of anyone?

C209 My cat.

F210 Your cat, yeh?

B211 I'm not religious...

C212 Because she plays with my sister and it makes her laugh.

B213 I'm not religious but I think God helps me sometimes.

F214 Yeh, so do you go to church?

B215 Sometimes, well you don't have to go to church for God to help you. What about other people do they have things, or people or ideas that helps them?

B216 My teddy.

F217 Hmm, your Teddy, yeh.

Le218 Well, when my mum's getting sick or having a panic attack I used to go to my bedroom and let out all my temper onto my pillow. It usually gets all my anger out, and then sometimes I just try to get away from my mum because it gets you down after a while.

F219 So, we've not got much longer to go. You've all done really well. We talked about support, come on xxx.

C220 I've got to go (toilet).

F221 Yeh, so that's quite a good way of getting anger out isn't it. Yeh, it's a good idea that.

P222 Because it's annoying cause the one you look after, they can get stressed out about the way they're feeling, and then, and then, they make you stressed out.

(inaudible)

P223 You don't want to say your feelings towards one another 'cause then you both clash. So because me and mum do argue sometimes and I let her calm down in her way and I calm down in my way. Because I do want to clash with her, but I just leave it because I know that if we clash then things will worsen, and you just end up saying or doing things that you regret at the end of the day, and then I've said things that I've regretted, and I've done things that I've regretted. I have felt really guilty for that as well, but now I'm just learning to leave things alone. Cause we just argue about the caring situation. I just leave it alone.

(N and A return)

F224 OK, carry on...so we were just talking about what helps you, yeh, and we heard young carers staff, some people help your mum, cross-roads, some people like cuddly things like toys and things like that, and sometimes having a god as well. So there are lots of different ways that people get help.

L225 (inaudible)

F226 When he comes back.

F227 So, we've not got much longer to go. You've all done really well. We talked about support, come on xxx, well done.

L228 I've got to go (toilet).

F229 OK, alright. So what about support I noticed that xxx was talking about coping a little bit and when he gets wound up he goes and hits a pillow, and that's a way of coping with feelings.

C230 Remember that time in the talking thing (to A) when we took our temper out on a piece of paper?

A231 That's right xxx when we had group support, the talking thing, and um we looked at....

End of tape 1.
Start of tape 2.

F232 OK, just calm down a little bit, we've got some rules up there. We talked about support, yeh, we talked about how it can be good to have something to cuddle. It can be good to have god

to talk to sometimes, and I was just saying Xxx, that you were talking about hitting a pillow when things get a bit much, and that's a way of coping, and I was, the last thing I wanted us to talk about today, how do you cope, what do you do to let off steam when things get stressful, what are your ways of managing it really?

Le233 I hit the pillow or sometimes I tried to ignore my problems or sometimes my friends calm me down, like or just going out.

C234 Can I draw for a bit?

F235 No, we're talking at the moment. Is there anything you'd like to say about coping? How you cope, you've said one thing haven't you about scribbling on a bit of paper and ripping it up?

B236 I hit my teddy.

F237 Hit my teddy?

C238 What's you teddy done to you?

(inaudible)

F239 OK, so you hit your teddy, and let your anger out that way.

B240 I'm mean like it relaxed ya, and I have to sew it back up after.

F241 Right, OK

Le242 Actually ripping paper, or sometimes people actually hit themselves.....or hurt themselves.

C243 I did that once you know.

Le244 Or burn themselves.

F245 There are different ways of coping, and some are sometimes helpful to us and some are not as helpful. What would you like to say xxx?

N246 Sometimes things build up or whatever, sometimes you let things just set you off or what ever and the little things that people say to you or whatever just... (inaudible)....have a go at everybody.

F247 Yeh, so you tend to have a go at people then when that happens. That's quite common, a lot of people do that. What do you do to stop things building up?

N248 Have a go at my brother.

F249 Right.

F250 What about other people, what do other people do?

L251 I make xxx look after her.

F252 xxx, who's xxx?

L253 My sister.

F254 So do you get a bit of a break when that happens ?

L255 No

F256 No

Le257 Sometimes instead of beating up and that, I just have a shower, a cold shower.

N258 Punch the wall.

F259 Go for a walk?

N260 No, punch the wall.

F261 Oh, punch the wall, sorry, go for walks that's what I do.

Le262 I've got a special wall (inaudible) from ages and it's got all blood covered on it where I've hit it.

F263 Right

B264 I, I, like to cook a meal I do.

F265 You cook a meal do you, do you cook anything special?

B266 Nah

(inaudible)

F267 So, you just cook something.

B268 And it's like you just get engrossed in something else.

F269 So, you put your attention somewhere else? So we've got quite a few good coping ways here, we've got perhaps taking your anger out on something soft. What would you like to say xxx?

C270 Something hard. (inaudible) You know, you know once, it's about anger, it was on a Sunday and it was the last match of our season, to play for the cup and it was the final cup (inaudible) and my mum said (inaudible) and I'll let you go to the final match, 'cause I was really arguing with her and everything and in the end I was just going boof, (indicates hitting head with hands), boof, boof, and shouting let me go.

Le271 That's not really funny xxx, it actually seems rather childish.

A272 Did you feel better xxx?

C273 Yeh, I did actually.

F274 So, it sounds like you've got a few different ways of coping haven't you, and you've also got people who help you out. You've got friends who help, you out from time to time, hmm, you've got here (young carers group) which you talked about, and a few different ways of sorting things out. I mean do they work?

Le275 Yes, they do, a cold shower for me always works.

F276 Yeh, what does it do when you have a cold shower?

Le277 I don't know, I have a cold shower and it, like, sort of like, cools down the heat in you and stuff which makes you, as if you want to throw a temper, it just cools you down, and gets rid of your temper.

F278 Hm, yeh, calms you down so you loose your temper.

F279 OK is there anything else before we stop on coping that people would like to say about how they cope.

B280 (inaudible) I say I don't really, but I need to have a go.

F281, So you let it all build up to a point, and then let it out. OK, alright, anything anybody else would like to say? OK, well there was something else that we were going to do afterwards.

A282 Can I just say that the bus is coming at 8.30.....

Summary of Group and de-brief to end.

FOCUS GROUP TWO

Focus Group Two-Transcript

F1 Can someone tell me what is a young carer, and what sort of things do you do?

S2 Play.

F3 You play, OK.

J4 We look after our parents.

F5 OK, so you look after your parents.

H6 Or brothers and sisters.

F7 Or brothers and sisters, well done.

J8 We have to do things like do the washing up, or carry the shopping or something, if they got a disability or something.

A9 I have to watch himbecause he bites.

F10 OK, so you've got to watch people have you? Yeah.

Js11 I've got to take my brother up the stairs because he's disabled in the legs, crippled.

F12 I see.

A/S13 I've got to keep a lock on my door because my brother goes into people rooms and trashes them.

F14 Right.

A/S15 He's got brain damage.

F16 Right so you've got to keep things safe? Yeah, OK.

F17 So a yc is someone whose looking after someone, and it sounds like that's a brother or a sister or sometimes a parent.

J18 I mean who's parents (children put their hands up)?

F19 Right, OK, so you've all got people you look after and you've mentioned a few things you do.

S20 When you, you have to be brave when you get bullied in case your mum has to go somewhere with your brother like to the Dr's for some pills and that, and she's disabled.

F21 Right, so you think part of being a young carer is being brave? Yeah, yeah, and is that one of the problems of being a young carer, something that you get picked on by other people?

J22 That happens a lot to like most people.

A23 It happens to me the most.

F24 Yeah?

J25 It happens to me actually, I get battered everyday.

S26 I get bullied nearly once a year.

F27 Do other people find that?

J28 Sometimes if you're a young carer you don't seem to have as many friends as normal people.

S29 My, brother plays this game, and other people keep taking stuff off him, cheating on him, and he doesn't realise it, so, I got to go and tell them off.

F30 So, sometimes you have to stick up for other people as well.

S31 At school sometimes, when I have to walk to school with my brother they say, "Oh, what's, wrong with your brother," and um, I say that he's got a special needs and they like start bullying me and calling me names like thick and that.

St32 There's a lot of people who don't understand it because they don't see it from others point of view.

F33 Can you say a bit about what you mean about that.

A34 They look at their own point of view and just think that the other people are really stupid because they have to look after their parents or anything, and they don't look at it, the person who has to look after their parents, and that, cause if they looked at it from our point of view they'd realise that they'd really hate it.

?35 Really, really, hard.

A36 They can't see it.

St37 They don't see the problem that, the problem with the other people, like they have to look after (erased by mistake)...why that's so different and so they start to pick on people 'cause they can't see what's so different about it.

F38 Hm, hm, so other people don't seem to understand the way that you have to do things.

S39 Because my mum has had to go to school, and every time my mum goes in this boy called D keeps picking on me saying "Oh your mums disabled " and things like that and she walks about with crutches and a stick but people, people, don't know that because sometimes, some days she can walk without anything and others she's really bad.

F40 Hm, hm.

St41 But a lot of people think that, like that, they keep like saying that my mum's like because she's got problems with her joints and her knees and stuff and doing her arms and that, and every thing like in school they keep saying like at school "Ahh your mums a cripple" and they start making nasty comments about my mum, and it's just they can't see it at all, it's just not right, and a lot of the time when you say it the teachers, they just laugh.

F42 Right, I was going to ask a bit more about school, and you know, I mean you've said...

J43 I mean like sometimes my mum goes into school, and they just get people laughing at her when she goes past, and the teacher never listens to my mum she always tries to blank her out, or tries to agree with her, but then say my mum will say don't be so hard on J, as you

seem to be picking on him, and that and she will do the opposite and pick on me more, like making it worse all the time for me, and she's not very nice.

F44 How do other people find school ? What's school like for you?

H45 Schools alright for me, the thing is if you go into town with my mum and have people stare at us, then you just stare at them back (laughter) until they look away and you keep staring.

F46 So, you've found a good way, then.....

St47 I think it's very hard to make friends as I have to go off and make sure my brother's OK.

F48 Hmm, yeah, big job isn't it.

St 49 School life's really hard because you can't get as many friends and everyone starts picking on you about like, other people you help and it's a bit stupid really, if they see it the other way then, they'd know and start to think about it a bit more. They'd know and start to think about it a bit more, and not be so horrible to people but because we have to look after out parents, or brothers and sisters and everything we have to put up with people who start being horrible to us and try not to tell the teacher cause other wise the teachers will do nothing. Like today when there was a lad picking on me because about my brother I told the teacher and the teacher had a mouthful me, so it's just easier to try and just think their being stupid and they don't know what they're saying.

F50 OK

St51 My, my brother, his friends don't understand what's up with him, so when they get into trouble they all run off, and my brother ends up getting into trouble, and he doesn't understand why they're running off.

F52 Right that's a shame.

Js53 This boy at school, he's called (deleted) he's in the (deleted) year, he keeps on calling, when we are playing, he keeps on calling my dad, he always calls my dad a mad driver because he's disabled because when he's (inaudible) he's——

F54 OK

J55 That's not, not necessarily a problem for most people, but it's mainly the people in school that, that, give you a hard time, like a lot of the time when parents go into talk to other people instead of being being a bit easier on you and that they make it hard a lot of the teachers think they're being silly and that there's nothing wrong with them.

St56 I find my brother makes a lot of noise because he's banging and clattering around, when he's not the....

J57 I don't find that a problem...

St58 When I go home I can't always go home because when I'm in the kitchen trying to do my homework they're always banging and things, then umm...

J59 There's an easy solution to that, why don't you go in your bedroom?

F60 One at a time please, let Sam say what he's saying.

S61 Then after a while I get really annoyed, and I can't help it, I just shout at them, and go to my bedroom.

F62 Yeah, yeah, OK.

J63 I think there's an easy solution to that . Why don't you just go to your bedroom, because you'll be able to do it a lot quicker, and if they go somewhere else where they won't get distracted people will go somewhere where they don't get distracted.

S64 When I do my homework, I don't often get it, my mums always organising these trips and they tend to be when my mum's organising these trips. Take yesterday for an example, because I didn't have time to do my homework as it was ten o'clock when we got back, and I didn't have time, my dads always yelling and saying do this as my dad has epilepsy.

J65 Yeah, my mum's got that and she got, you know ME and fibromyalgia and that causes her a lot of problems as well.

F66 OK, so we've talked about problems with school, problems with homework and problems with being picked on by other people.

J67 Sometimes you even get people in the street who stare at you as you go passed because they just don't see it.

F68 One of the other things I wanted to ask you is what do you want to do when your older, how do you see yourselves when your older? You're nodding, what have you got to say?

St69 I've got several things.

F70 Go on.

St 71 A biochemical engineer at NASA.

F72 A what?

St73 inaudible

F74 I don't even know what that is?

J75 I want to work in the RAF.

?76 I want to set up a support group for my brother.

S77 I've got loads of things I want to be, a , I've got loads of things I want to be. First I want to be a driver in the water to find...., then I want to be a Dr. to help patients, or a vet 'cause I like animals, I've got five baby rabbits in my house, well one's died a few weeks ago and her sister is going to have babies.

F78 Wow, so you've got little bunnies to look forward to.

S79 We're going to have one, I know it's cruel but my mum can't cope with too many.

F80 What about other people?

Js81 I don't know what I really want to be when I grow up but I'd rather be a Dr. or someone who works in hospital, as I want to help my little brother get better.

F82 So, is it important to you that you look after someone?

J83 I want to work in the RAF, or else be someone like in child support or else someone who looks after children or helps people get better.

?84 When I'm older I'd like to set up a group to try to help other people understand what they are going through when they're brother or sister or parents have a problem, and try to help other understand the problems and things.

F85 OK, we talked about someone the difficult bits of looking after someone, haven't er, and the problems with school....

J86 A lot of it's quite difficult, there's not much that's easy.

F87 Wait a minute I'm talking, a minute. So we talked about some difficult bits and I suppose I'm wondering what are the good bits, yeah, what do you think you get out of it. Are there any?

J88 Well, you get to come here which is quite cool, so well, er, a lot of people get different things.

F89 What do you get, what do you think you get, and then we'll ask other people.

J90 Hmm, I don't really get that much, but it's good to come here and just chill out for a bit, but a lot, most of the time it's quite hard and difficult.

F91 What about H?

H92 Well if you get people to bed early and you feed them what they want, and that stuff, then you get the satisfaction that you can have a peaceful night and that they've gone to bed and have eaten a whole meal, instead of a half or a quarter or whatever and stuff.

F93 Yeah, yeah, so, so, for you the satisfaction is knowing that someone is looked after?

J94 It's nice to know that most people are healthy and that.

A95 I like it that I feel like, because my mum and dad are usually out doing things on our new house, hmm, I'm usually the one that usually changes my brothers nappy and helping him up the stairs and putting him to bed and helping and things like that, and it's, hmm, it's hmm, I forgot what I was going to say...

F96 That's alright. We were talking about some of the good things about looking after someone.

St97 A lot of people think that it's quite nice to be looked after by like, if, it's a parent or a big brother or something, it's nice to think that it's someone younger than them, that's actually helping, or if it's really little kids, you've got your little brother looking after you instead of your parents.

A98 I get the satios..satisfactory....

F99 It's a hard word.

(laughter)

A100 ..that I know I've looked after my brother, and where he doesn't know what time it is, I get to stay up a bit later, and do things that I wouldn't do if C wasn't there.

F101 Ah, so do you think you sometimes get to do a bit more? Do other people think that you get to do a bit more?

?102 Yeah

F103 In what ways.

S104 Well, I get to do a bit more because often my parents are busy sorting out bills or money, so I get a bit of extra time playing with my brother and helping him.

A105 A lot of the time with people who are brain damaged, it's good to help them, because if you can help them and try and get them to understand things because I know someone else were trying to help him, and get him to say more words, and he's perfect now, there's not much wrong with him.

F106 OK, so what other things, good things, do you get out of it ? What about you two over there, are you OK (laughter)? Can you think of anything that you get out of it ?

A107 I get girl-friends a lot. (laughter) because...

F108 Go on, go on..

A 109 They've seen me look after my mum and they think...

F110 Your, your going to look after them?

A111 Yeah. (laughter).

A112 Everybody wonders how I get them.

F113 One at a time, one at a time, please.

F114 So, that's a bit of a bonus isn't it?

?115 He's probably had more kisses of girls than he's had of his mum.

F116 OK, so there's a few good things we thought about can any body think of anything else? We're not all lucky enough to have extra girlfriends, but..(laugher)

A117 I fund it quite hard because if your parents or whatever have got problems, is, err, it's serious, then you've go to be prepared and know all the basic things in case, umm, they, like faint or something, because you've got to be prepared to look after them or get an ambulance or something.

F118 Right, so that's knowing about health is it? Do other people find they have to know about that.

J119 Yeah, my mums, like had epileptic fits and a couple of years ago, she fell over in the town, and she fell unconscious because it was her epilepsy thing, umm, well that wasn't her epilepsy cause when she fell over she ruptured a blood vessel in her head which gave her the epilepsy, but she had problems before that and we had to phone them for the ambulance.

A120 My brother doesn't always feel pain, and once he got a big gash in his check, and my mum didn't notice, until he came in holding his chin, with all the tools, gushing blood.

F121 Oh, dear, but what was that like for you?

A122 I just don't like blood.

J123 A lot of people don't.

A124 I need to be prepared in case my mum goes into hospital because she might, not all plain sailing because if she goes in she might just faint and die on the operating table.

F125 Right, right.

J126 I think that's what you find with a lot a people that you have to be prepared and ready just in case something happens that they have to be ready near a phone.

F127 So, are you always having to look at for things....

*128 {Yeah

...looking out for the phone and keeping a check on things.

J129 Yeah, we have to be near to a phone just in case something drastic happens. There is, I mean a lot of people think that's not going to happen, but there is the odd chance that it's going to happen,

F130 Hmm, hmm, is that a bit of a worry for you? What would you like to say?

S131 At school, because we're doing health and safety, because I've got to be quite careful because of my brother and people say "oh well if he faints that's that " but it's not like that because, like 'cause like, if you say, you hate your brother, it's not like that because you always love them whatever happens.

F132 Hm, hm

J133 Yeah, but a lot of the time you just feel on the outside and you can't help letting it out like, "Oh I hate you mum" or what ever, but actually down inside you don't know what, what, you don't quite know what your doing, but down inside you actually love her all the time.

F134 Hm, hm, but I guess it brings up difficult feelings when you have so much on your plate, and one of the things I was going to ask you about really, is how do you cope with all the things you have to do?

J135 It's just, just we get used to it and you tend to cope.

St136 I find keeping myself occupied all the time by playing on my computer, reading books, watching TV.

F137 Yeah, OK, what else?

Js138 I just cope by, like being with my dad, and sometimes being with my mum, just you know they're safe and they're there.

F139 Yeah, do you look after your mum or your dad?

Js140 I look after both of them. I keep my dad occupied because he watches me playing on my computer games and sometimes my mum does as well.

F141 Right, so you find being around them, and making sure, knowing they're OK, helps you cope?

A142 Yeah.

F143 What about other people?

St144 Well, I find it quite hard to cope, but my mum and some of my friends help me, because one of my friends has to put up with, err, both they're parents have got no problems, and they're sisters got the same problem as my brother, and ehh, (inaudible) always try to help each other and if we find something else to in our spare time, we can help each other by telling each other and things.

F145 Right, so you talked it through with friends?

S146 ...and like when I don't want to go out because like, it's hassle. It's just like when I get annoyed with my brothers, I go, I don't want to go out, because my friends will annoy me, but it's hard for me cause when my brothers are annoying me, I find it really hard.

F147 Yeah.

J148 I think a lot of people find it hard unless they're around their parents or who ever got the problem 'cause they know if their around them they've got less chance of hurting themselves.

F149 OK, who wants to go next, go on how do you cope.

Js150 When I was in Cornwall, right, we were on the (inaudible), there was a really high hill, and my dad had to, umm, carry my brother up, over a hill, and I was really scared he was going to trip over and fall down the hill back again.

F151 Yeah, and hurt himself.

Js152 So then I like just stayed beside him.

F153 So is that how you coped with that time you stayed beside him?

Js154 Hmm

F155 Yeah

A156 I'm lucky that the few friends I've got do actually understand what's wrong with .....

J157 I have a lot of friends who don't.

S158 My friend called (deleted) his mum and dad are divorced and sometimes he comes over to my house and on Thursdays we go to a club called boys brigade and we get to talk there and share our feelings together.

F159 Yeah, good.

S160 ..and he helps me cope when I'm feeling.., because I've swapped schools because when I'm there he helps me cope with a lot of things.

F161 That's good, do he's a good friend to you? So what other ways of coping, it sounds like we've got taking your mind of things,, you were talking about..

J162 I think a lot of people just find it easier to cope with when their around the person with problems.

F163 Sticking by the person, yeah, making sure they're around OK, yeah.

J164 Yeah, I think that's what most people are afraid of.

F165 Hmm, OK, what other ways, you said sticking by the person as well. What would..

S166 Well, I don't know why but the people who are being nasty about it, they help me sort of to cope with it, I don't know how but...

F167 No, but that's what you find. OK thank you for that, so you've got your own way of coping with difficult feelings yeah, what about, we know that friends help you out. Is there anybody else who helps you out?

A168 My pap does because he understands about problems more than anybody.

F169 Right, whose that sorry? It's you dad, oh your granddad. Yeah, yeah.

A170 Because he like comforts me when I go over and I'm really upset, and go over there (inaudible) 'cause I have speech problems and she helps me get through them 'cause I could like say the words and she could answer me back.

F171 Right, so they've been really important to you.

S172 I find I can talk to my parents, but I find it very hard to talk to anyone else, sometimes, I find it hard to even talk to my parents.

F173 Yeah, do you find their helpful to you? Yeah, who else, who else sort of gives you a helping hand, really when things are difficult?

?174 I used to talk to my friend xxx his name's xxx, and I'd talk to him, but I can't talk to him anymore because when we were in the old school, when we left in year (deleted) and we left to go to our other school, he left and went to a different school, so I don't see him very much and can't get to talk to him and the same happened for xxx, he went to the same school as xxx. So I can't talk to them now, as they're not at the same school.

F175 OK, so that's a shame for you. So, these people that help you what do they do?

J176 They usually just like talk to you and like help you get through hard times.

F177 What do other people think? How do people help you? If you were going to give a piece of advice...

A178 They like comfort you in many ways, because they speak to you and tell you like 'don't worry you'll be alright and things like that.

F179 They give you reassurance?

A180 Yeah.

F181 Anybody else, what other ways can people help you? Anything ?, No ? OK, so we've done a lot of talking really haven't you ? We've covered quite a bit. I mean you've told me about some of the difficult things...would you like to say something else?

H182 The rest is just like alright.

F183 The rest is OK, so the caring is difficult, but the rest of your life is OK, cause that's important to know. Do people find that, not for every one maybe.

S184 Hmm, my parents have had to come in once (to school) because of people bullying me sometimes, if people are talking about my brother in a nasty way, I sometimes get cross and lash out, so my parents had to come in because I was lashing out at people.

F185 Hmm, that does (inaudible) maybe that's a way you've coped and that's what happens sometimes when we've got difficult feelings.

A186 Some people make fun of my surname because it's like a girls name, but it isn't, 'cause people say things like "oh, so and so". I can't really tell you my surname because everyone will laugh, and they make fun of me, and sometimes I trip them over, and I get them on the grass and throw them over because I'm fed up, and once my friend called xxx, who isn't my friend any more, 'cause he tried to nick some of my Pokemon cards off me, said "oh your a looser"...so I kicked him in the lounge.

F187 So, do other people find that, that someone, 'cause it's difficult you do just take it out on other people...you lash out?

} Yeah

....because there's quite a lot going on for you isn't there and sometimes when that happens you do lash you a bit.

J188 A lot of people seem to make you lash out and like start winding you up and like people get wound up, they can't help it?

F189 Hmm, it's very difficult isn't it?

J190 It's just automatic.

S191 Like an elastic band, if you wind it up.

F192 Yeah...I...

A193 It's like a force field that's holding it back, but it stretches and just breaks and you just can't help it but lash out.

S194 Hmm, at school when I came home today, because loads of people had been making fun of me, I kept saying I didn't want to come here, and eventually, I just lashed out at my mum...shouted at her.

F195 Hmm, yeah, and how did you feel about doing that?

S196 Well, at the time I didn't care because I thought she deserved it, that was when I did lash out, but after that I felt guilty and I really regretted it.

F197 Hmm, but I think when you have a lot on your plate as you have, it is like as you say an elastic band that gets stretched tighter and tighter and sometimes it does snap a little bit, err and it's a way a lot of us cope when we've got a lot on out plates, but are there other ways of coping as well, like distracting yourself.

Js198 Whenever I want to play football at my school because I'm coloured people say no you can't play, people say racist things to me and prejudice things and because I'm really chubby.

F199 Hmm, hmm.

J200 Yeah, a lot of people are like racist and like they, say that word that comes from Pakistan, at the beginning, and like at everyone whose coloured, and it's not right, and they say the opposite of the white man, and it's not right.

F201 OK, so we we've got a few minute left, you've got something to say what would you like to say.

S202 Well, once, when my brother was playing with matches he set one alight and dropped it and soon everyone found out in school and were calling him names like Paki and that.

F203 Hmm

S204 ..and that's why my mum had to come to school because I lashed out at that.

F205 OK, so if I was to ask all of you given that your saying people aren't always that helpful, and if I was to ask all of you for one piece of advice for me to take away thinking about what was helpful for people looking after people...

H206 Shall we go 'round?

F207 Yes, you could do, yes, because you'll all have something different to say.

J208 I would like to say that too many people are slack, and they need to stop being so nasty about other people.

F209 Hmm, yeah, thanks.

H210 I'd say do the staring thing.

F211 You'd say that.

J212 A lot of people take staring as...

F213 As coping, a way of managing, yeah?

J214 When you stare at people it's as if...

F215 What about you?

A216 If people say nasty things about you and if the teacher don't take any notice at all, just don't listen to them, or just think if you call me stupid or that, what does that say about you then, or something, say that and that helps you get a booster.

F217 Brilliant.

S218 You need to help people to see what they're saying to you and maybe then I think people need to understand why they call us names because our mum's or dad's or brother and sister's are different but if they were in our shoes I bet they'd act the same as us.

F219 Would you like to say anything, a piece of advice about how we could help people who care....you don't have to, no, that's OK. Anything you want to say, no, what about you S anything else you want to say? No, that's OK, no, alright, well, thank you for saying so much, because as you say it's not easy to talk about these things.....

End of transcription

Debriefing to end.

Individual Interview One With A Thirteen Year Old Girl Caring For Her Mother With Multiple Sclerosis

F Facilitator
C Child

F So, can you start by telling me how old you are?
C I'm thirteen years old.
F Ok and who do you look after?
C My mum.
F Your mum, and what's the matter with your mum?
C She has MS.
F Ok, and who else is in your family?
C My step- dad, and my two sisters.
F Two sisters ok, and you're the eldest in your family aren't you?
C And how long have you been looking after your mum?
C About a year and a half.
F About a year and a half, right, so can you explain to me what a young carer is?
C Well I think a young carer is a person who helps another person in their family who maybe has a disability problem.
F Ok and what sort of things do you do to help?
C Odd jobs around the house, look after my mum.
F What sort of things do you do to look after your mum?
C Sometimes I make her cups of tea, and help her to sit down.
F Anything else.
C Just little things because other things she can do, or she doesn't want to ask me to do because she thinks it puts a strain on me.
F So do you think your mum worries that you look after her?
C Yeh.
F Does that bother you?
C No because I wouldn't be bothered about doing it anyway, if it was that much of a strain.
F So do you think that other people you age do these types of things?
C Maybe some of them.
F How does it feel that you do them?
C I just feel proud.
F Can you tell me a bit more about that, feeling proud?
C Cause I feel that it is a privilege that I get to help my mum.
F So do you think you have any control over where you are a young carer or not?
C Yeh, because I don't have to do the job.
F So what would happen if you didn't do the job?
C Then my mum would be very, it would be hard for my mum to get around and do certain jobs, that I can do.
F So what areas of your life do you think caring has an effect on?
C My friends and family.
F Right can you tell me a bit more about that?

C I don't get to see the rest of my family that much and my friends.
F And what's that like for you?
C Sometimes it can be a bit hard cause I miss them.
F Any other bits of your life?
C Maybe in the future.
F What do you think about the future then.
C Well it will be hard for me, as I might have to pop in at a certain time to see if my mum is alright, or I might have to keep living with her.
F What would you like to do in the future?
C I what to be a teacher, work with young people and be a chef?
F Wow, and what effect does it have on you personally?
C Sometimes I can get a little bit down.
F Could you say a little bit more about that?
C Sometimes I miss going out side.
F So if you think about all the different things
C Maybe that I want to go out sometimes and I can't.
F What's stopping you?
C Because my mum needs help.
F Anything else.
C I feel a little bit down because of my little sister, because I feel sorry for her.
F Could you tell me a little bit more?
C I feel sorry for her, because when I was growing up my mum wasn't ill or anything but my sister is young but my mum's ill.
F So you feel she has missed out a bit on what you had?
C Yeh.
F Anything else you want to say about that, the day-to-day hassles sort of hassles. No that's fine.
C So what are the good things about caring then?
C Because I feel proud.
F What makes you feel proud?
C Because I'm helping my mum when she needs help.
F Any other good things or benefits that you get out of it?
C People say thank you for looking after my mum.
F They say thank you to you?
C Yeh, because maybe they can't be their all the time.
F So what or who helps to make your life easier.
C My sister and my mum's boyfriend.
F Is that your step dad?
C Yeh,
F So what do they do?
C If I want to go out, or give up, then they just help her, and I'll be able to go outside.
F Anybody else?
C My Nan sometimes comes down.
F So, if you could describe everything you have done, or thought or felt to make things better for yourself. Things you have done to cope.
C Well sometimes I go up in my room and listen to my music, and try to solve my problems on my own.
F Anything else that helps?

C Help a bit more.
F Help your mum is that?
C Yeh.
F And what does that do.
C Makes me feel better.
F Anything else that you think or you do or you've felt.
C Sometimes I feel a bit sad.
F Can you say a bit more?
C I wish that my mum wasn't ill.
F Is there anything else you want to say, those are all the questions that I had is there anything else that you would like to add, that I haven't covered that you think it is important that I know?
C No not really.

Individual Interview Two With A Fourteen Year Old Girl Caring For Her Father With Arthritis.

I Interviewer
P Participant

I What do you think a young carer is?
P It's when you care for your brother or sister or relations, help them get around the house help them with shopping, help them get stuff and things.
I And what do you do to help your relative?
P I help him go shopping, make his dinner make his tea, help him get his shoes on, take him if he wants to go shopping, take him and help in other ways as well.
I And do you think other young people do these kinds of things?
P Hmm, if they've got relatives they might do more they might do more or less depending on what's wrong with their relations, they might do more or less.
I And what does it feel like that you do or these different things?
P Hard work.
I Yeh, can you say a bit more?
P It's hard work, sometimes I get really stresses out, sometimes I can't cope, it's hard doing my school work and caring, sometimes I get really tired and have to go to bed early.
I What's the most difficult thing about it?
P Helping him go shopping because if it's really busy it's hard to help him go around, making his teas really hard as well.
I Ok, so you mentioned one area that caring has an affect on, at school, can you say a bit more about that.
P Sometimes I find it really difficult to do my homework and help care for my dad, sometimes I get a bit behind but catch up with it as soon as I have helped care for him, and he is alright for a bit, and then I carry on with my homework.
I Right and what about teachers and other kids like that.
P I don't really talk to them about it.
I Right, keep it to yourself. Do you find then understanding?
P Depends who I talk to.
I And you mentioned that you find it difficult to get out, can you say a bit more about that?
P I haven't been out for a couple of weeks. My friends come around and I say I can't come out. I haven't really been on holiday since I was four, so it's really hard to get out and that.
I And what's that like for you.
P Sometimes it's upsetting that I can't get out and go on holiday.
I Do you ever think about the future at all?
P Sometimes
I Yeh, what are your thoughts about that?
P Thinking that I can get out more, hoping that my dad could get a bit better, so I could go out and go on holiday.
I And what do you think you'll be doing in the future?
P Hoping that I'll do something in college.
I Right so you hope you'll be able to go to college. Any other parts of your life that you think caring has an effect on, you've talked about school you've talked about friends..?

P Sometimes it's hard to have dinner, because sometimes we don't have enough food, because I make my dad's dinner, then my mum makes her dinner, and sometimes I don't have any dinner so I just have sandwiches or something.

I Right, so it's quite hard for you to look after yourself and have a meal?

I Do you think there are any positives to caring?

P I'm not really sure.

I No, can you think of anything, anything that you get from it?

I No, that's OK; it doesn't feel that way for you?

I We talked about coping, and said it was quite difficult to cope sometimes, what ways do you cope, what things do you do, people do you go?

P Sometimes I go upstairs and have a sleep, or listen to some music to relax or just read for a while.

I Ok so you try to find a quiet moment really.

I Ok anything else that you do that helps you?

P Sometimes I go on the computer (inaudible)

I What other things?

P If I get a chance I go for a walk somewhere, go and talk to my friend if I can get out.

I Ok so you've got a mate you can chat to. Ok so there's getting out and about, occupying yourself, maybe talking about it to someone else. They're useful ways aren't they, of easing the pressure a bit?

I Is there anything else you think that's it's important that I know about young carers and what life is like for you?

P That it can be stressing at times and sometimes it can be difficult to cope with all the work you have to do.

I So overall you find it quite a difficult thing really?

I Are there any times when you don't do any caring?

P When I go to school.

I And do you find you can switch off from caring?

P Sometimes.

I But you don't get respite or anything like that.

P No.

I Ok there's nothing else that I wanted to ask.

P OK

Individual Interview Three With A Ten-Year-Old Girl Who Helps To Care For Her Brother Who Has Tourettes Syndrome And An Allergy To Light.

F Facilitator
P Participant

F So you help to look after your brother and your brother's eleven?
P Yeh
F Could you tell me what a young carer is, what do you think they are?
P Where they help brothers and sisters who need help, and help their mum and dads.
F Right and what sort of things do you do to help?
P Play with him, play on the play station with him, fighting with him, all kinds of jigsaws and games, play on the PC with him watch telly with him.
F So you find you're around you brother a lot, ok, and do you think other people your age do these types of things?
P No
F No, so what's it like that you do them?
P (inaudible), play with him.
F Right, so do you find it keeps you busy?
P Not always.
F No, so if you think about all the things you do for your brother, what bits of your life does caring for him have an effect on, what's it like at school?
P Boring
F Boring is it why is it boring?
P Because we've loads of sats to do.
F Oh, so you've got exams to do.
F What about friends and that do you think caring has any effects on that?
P I don't know.
F What do you like doing at school?
P Nothing
F Nothing only PE. Ok, so you look after your brother and you help him and you said you fit with him a bit?
P Yeh, play fighting.
F Play fighting, what sort of things make you fight?
P Where he kicks me so I kick him back, where he pinches me and I pinch him harder, where he pulls my hair so I whack him in the face.
F Oh dear, so do you not get on very well then? So why do you think you argue then
P Because of his disability.
F So does that mean that it's a bit hard him having a disability?
P Where he can't control his swearing, his hitting, his spitting, hitting people, calling them names, and pulling their hair.
F Right so he tends to get a bit worked up does he quite easily, right, what's that like for you then.
P Hard
F What's hard about it, what do you do when he does that?
P Do it back to him.
F Right and then what happens.

P My mum stops us.
F Right, and how does your mum react?
P Not very good
F Doesn't she?
does it make it a bit difficult to get on with people sometimes? So you have this thing that you do, and sometimes he gets a bit worked up and stuff. What are the nice things about looking after someone?
P Don't know.
F Don't know, can't think of any. Can't think of any good things. Do you have fun with him?
P Sometimes
F What sort of things do you do?
P Ride are bikes, beat each other on the skates, whack.., playing chicken on the road, sometimes but not very much riding bikes, playing on the scooters.
F Right, so there are lots of things that you quite have good fun doing? How do other people react to your brother?
P Nastily, because they don't understand his disability.
F Right, and what do you do when they do that?
P Shout at them.
F Do you so you stick up for him?
P Yeh, but if I'm not with him then he sticks up for himself.
F Right so does he shout at people? Oh dear. Ok so it sounds like you're quite good at sticking up for your brother sometimes, even though you argue you find a way to stick up for him. If you think about looking after your brother, sometimes it's a little bit hard, you were saying, can you think of any one who makes it better, anyone who looks after you?
P My mum.
F Your mum, what does your mum do?
P Helps me.
F Does she, what does she do to help you?
P Buys things, looks after us, give us money.
F So you mum helps you, any body else?
P My brother.
F Your brother helps you does he what does he do?
P When Steven hits me, my big brother hits him back.
F Oh, your big brother, right I see. How old is you big brother?
P Twenty-four.
F Oh he is very big then isn't he. And do you get on with him?
P Sometimes when we don't fall out
F Right so your big brother helps you as well. Is there any one you talk to about your brother? No. Is there anything you do? Sometimes when people get sort of worked up they find it good to do things. Is there anything that you do? Sometimes when people get worked up they find it good to do things, sometimes people say that they like to get out of the house.
P He does, but I don't that much.
F You tend not to go out that much? Do you go out and see your friends at all? Hmm, OK. Is there any thing you'd like to tell me about young carers and what you do, any thing you think it's important that I know about what it's like?
P Nothing really.

Dear

You may be aware that I am carrying out a study on stress and coping in young carer's as part of my Doctorate in Clinical Psychology. If your young carers' group has taken part in my survey of young carers may I take this opportunity to express my thanks to you and to the young people for your cooperation. If you are posting questionnaires to me can I remind you that the closing date for returns is February 15th.

Part of my study involves a survey of 'experts' in the young carer's field. I am writing to ask if you would be willing to spend five minutes completing the brief questionnaire I have enclosed. I am interested in gaining information from people who work first hand with young carers. Your knowledge and experience is a valuable resource and may help to support the information I have gained from the young people themselves. *I am aware that there is literature regarding the experiences of young carers however I am specifically interested in your first hand observations.* If you would like to participate would you please complete one of the questionnaires now and return it in the enclosed envelope.

All information is confidential and I do not need to know the carers group to which you belong. Thank you for your co-operation.

Yours sincerely,

Louise Earley
Clinical Psychologist in training

Survey of Young Carer's workers. Return by Feb 12 Th

Please state how many years or months you have worked with young carers ----------

Please state your job title ---------- Male/Female (please delete)

*I am particularly interested in **your experience** of working with young carer's (rather than information you may have read about the area). When answering the questions you may find it helpful to think about a few young people that you know well. Thank you for your help.*

1. Please think about the stresses that young carers you know have experienced in their lives as a result of their caring role. Please **list** the five main stresses that you are aware of below.

-1----------
-2----------
-3----------
-4----------
-5----------

2. Please think about the satisfactions that young carers you know have experienced in their lives as a result of their caring role. Please **list** the five main satisfactions that you are aware of below.

-1----------
-2----------
-3----------
-4----------
-5----------

3. Please think about all the ways in which young carers cope with the pressures of caring. Coming to the young carers group may be one example; others may use less adaptive ways like involvement with drugs. Please think about the young carers you know and the ways they choose to cope, and **list** the five main ways that you are aware of below.

-1----------
-2----------
-3----------
-4----------
-5----------

4. For a minute imagine that you are a young carer. Think about how old you are and who you are caring for. Please write a **few sentences** on what life is like for you.

-1----------
-2----------
-3----------
-4----------
-5----------

*You may wish to de-brief after this exercise. Please take a few moments to orientate yourself. If you would like to talk to someone about completing this exercise then please feel free to leave me a message on - ********** and I will call you back as soon as possible. If you have any further comments you would like to add either about the stresses and satisfactions for young carers or about the exercise in general please write them on the back of this form. Thank you.*

APPENDIX F

Information relating to the analysis of the qualitative data.

Development of categories
Refinement of categories
Code Book
List of coping strategies

Stage 1. of analysis of focus groups.
Initial themes identified upon reading the focus group transcripts and loose description of category.

Stresses

- *Feeling different*; being picked on; feeling different from peers or unfairly treated by others

- *Identity;* The young persons caring role excludes other opportunities. It defines the young persons identity in the present and the future.

- *Relationship tensions*; arguing with other family members, or feelings of frustrations expressed towards or about family or others.

- Re*sponsibility*; using words like 'I have to', or 'got to', needing to be watchful and mindful even when away from home, expressing worries or concerns about what might happen to the relative in the future, who will care for them.

Coping

- Ways of coping; distracting self, letting out feelings, talking to others, engrossing themselves in role, ignoring problems, restraint, improving life of care recipient, reframing.

Satisfactions

- Sense of *competency* in role as carer; feeling able to cope with demands

- Satisfactions of caring; taking pride in their contribution; gaining recognition in the form of extra privileges or material gain; caring personality recognized as an attractive by others.

Appraisals

- Beliefs about caring role and responsibilities. Caring role is perceived as a threat.

Stage 2. of analysis of focus groups. Grouping of segments of transcript that seem related in accordance with the broad categories identified in stage 1. Preliminary categorizing of the data.

The identification code indicates where the theme can be found in the transcripts.

F1	focus group 1
F2	focus group 2
p	page no.
initial	identification of individual.
No.	number of the transaction.

Feeling Different	Included any data where children express feeling different from others or sense that they are considered different by other people.
f2.p2.S20	"you have to be brave.....bullied"
f1.p4.P49	"...you get an odd look or stare..."
f1.p10.E23	"...kids saying your going to be dumb..."
f2.p3.St41	"...kids saying 'ahh your mum's a cripple'..."
f2.p17.S93	"...if people are talking about my brother in a nasty way.."
f1.p11.P152	"...some adults look down on you .."
f2.p3.ST32	".....people who don't understand..."
f1.p3.P40	"...they don't understand it from your point of view..."
f2.p3.St41	"a lot of the time when you say it to the teachers they just laugh."
f1.p4.P49	"...you feel there aren't so many people around, and you just feel.....isolated."
f2.p4.St47	"...I think it's hard to make friends as I have to go off and make sure my brother's OK."
f1.p3.P40	"Other people see you can't come out and you're too busy..."

Identity issues

Include data where the child defines themelves in relation to their caring role. This might be currently or in the future.

f1.p11.Le143	"...if you look into the future.....see yourself as caring for everyone else in your family, so I don't look into the future..."
f1.p2.B31	"...they are always there for them (a young carer).."
f1.p4.E53	"You want to carry on because you get used to it so much."
f1.p7.B92	"It effects almost everything...you get engrossed in doing things and don't want to go away."
f1.p5.P58	"...(loss of care role) and you're wondering what are you going to do now?"
f1.p4.N55	"..and if you don't give that person your time you just feel...(lost)"
f2.p6.?76	"(when I'm older)...I want to set up a support group for my brother."
f2.p7.Js91	"....(when I'm older) I want to help my little brother get better".
f1.p1.P16	"...involved all the time.....to the point of anything else.."
f1.p8.B102	"I've got so used to it now it's not really effecting me anymore."

Satisfactions

Extra privileges/recognition of contribution.

f2.p8.A10	"...I get to stay up a bit later...."
f1.p12.P153	"...you wouldn't want to be doing what a child's doing."
f1.p13.C161	"...give you more pocket money..."

Disturbance in the group dynamics (f1.) on introduction of the topic of "being paid to care".

Caring capacity seen as an asset by others.

Pride in achievements

f2.p8.ST97	"It's nice for them to think that it's (the carer) is someone younger than them."

Relationship tensions

An expression of frustration towards family members, friends etc or their expression of frustration towards the young person.

f2.p11.J42	"...you can't help letting it out, 'Oh I hate you mum' "
f2.p12.S54	"When I get annoyed with my brothers I don't want to go out...."
f1.p16.P222	"...they can get stressed out about the way they're feeling and that can make you stressed out."
f1.p17.P223	"I do want to clash with her (mum)...
f1.p19.N246	"Sometimes things build up or whatever..."
f2.p6.S64	"...my dad's always yelling and saying do this, as my dad has epilepsy."
f1.p10.C139	"It gets between you and your girlfriend"

Ways of coping

f2.p12.St152	"...find something else to do..."
f2.p11.St45	"...keeping myself occupied..."
f2.p11.Js48	"I cope by being with my dad, and sometimes my mum..."
f2.p12.St52	"...telling each other things."
f2.p15.S176	"...the people who are being nasty about it help me cope with it...I don't know how."
f2.p16.A80	"...he comforts me..."
f2.p16.St182	"I find I can talk to my parents..."
f2.p17.S93	"...get cross and lash out..."
f2.p18.A203	"It's like a force field holding you back, but it stretches and just breaks and you can't help lashing out."
f1.p15.R196	"(young carers) you can talk to them if you like."
f1.p15.P200	"Cross-roads helps my mum."
f1.p16.B213	"... God helps me sometimes."

f1.p16.Le218	"...let my temper out on my pillow..."
f1.p17.P223	"I'm learning to just leave things alone(to avoid arguments)."
f1.p19.Le233	"I try to ignore problems, or sometimes my friends calm me down."
f1.p19.Le257	"Sometimes instead of beating up and that I take a shower."
f1.p20.B264	"I cook a meal".
f1.p21.B289	"I need to have a go."
f1.p19.N246	"Have a go at everybody"
f1.p19.N258	"Punch the wall"
f1.p10.P135	"So you're hoping for the best."
f2.p11.Js	"...being with my dad and sometimes my mum...you know they're safe, they're there."
f1.p12.P153	"Learning to cook and deal with problems is coping for your age."
f2.p8.H101	"..get people to bed early, feed them.....you can have a peaceful night."
f1.p101.P135	"You're wondering if you'll cope with it... "
f1.p7.P94	"But once you get used to it you find the time to do everything."
f1.p9.B102	"I've got so used to it now it's not really effecting anymore."
f1. p16. Le218	".. sometimes I just try to get away from my mum..."

Responsibilities and concerns.

The young person indicates that they feel responsible for the care and /or protection of the relative.

f2.p2.S29	"I got to go and tell them off."
f2.p7.H29	"If you get people to bed early and you fed them what they want..."
f2.p8.A95.	"I'm usually the one that usually changes my brothers nappy."
f2.p11.Js140	"I keep my dad occupied because he watches me playing on computer games."
f2.p10.A117	'You've got to be prepared to look after them..."

f2.p11.J129	"...Have to be near a phone in case something drastic happens."
f2.p11.S131	"...people say oh well if he faints he faints but it's not like that."
f1.p8.Le104	"The problems waiting for you when you go home."
f1.p9.P119	"(at school)...your probable thinking you're not sure if they can cope on their own."
f1.p9.R120	"Thinking of what's at home (while at school)."
f1.p10.Le128	"I'm, scared that something might happen to her (mum)."
f2.p10.A27	"...you've got to be prepared and know all the basic things in case.."
f2.p11.S40	"...I've got to be quite careful because of my brother..."
f1.p2.P26	"always being on their backs..."
f2.p1.A9	"I have to watch him, he bites".

Appraisal

What do they think about the role?

f1.p12.Le159	"Caring can mainly stress you up."
f1.p11.C149	"...you'll never ever get to live on your own."
f1.p12.Le143	"...if you look into the future.....see yourself as caring for everyone else in your family, so I don't look into the * future..."
f1.p2.B31	"...they are always there for them (a young carer).."*
f1.p1.P16	"...involved all the time.....to the point of anything else.."
f1. p13. Lu174	"., your doing it for love aren't ya .."
f1.p13. B175	"...you don't want to get paid, you don't want to get paid to care..")
f1. p15.R179	"... You do it for nothing... "

Note: Unrest in group on topic of 'being paid to care'.

Stage 3. The Refinement of categories identified in first two stages and category definition.

Theme 1a-Feeling different: relating to others: victimisation. CODE V

The young person experiences bullying. This can be verbal or physical or segregation by others because of either their role as carers, or their association with illness and/or disability, or the young person's ill or disabled relative is a victim of bullying.

f2.p2.S20	"you have to be brave.....bullied"
f1.p4.P49	"...you get an odd look or stare..."
f1.p10.E23	"...kids saying your going to be dumb..."
f2.p3.St41	"...kids saying 'ahh your mum's a cripple'..."
f2.p17.S93	"...if people are talking about my brother in a nasty way.."

Theme 1b-Feeling different: relating to others: minimizing CODE M

The young person perceives other's to hold a negative or trivializing view of their role as carers or the difficulties they and their family face. This category is the young person's perception of other people's views of them as carers.

f1.p11.P152	"...some adults look down on you .."
f2.p3.ST32	".....people who don't understand..."
f1.p3.P40	"...they don't understand it from your point of view..."
f2.p3.St41	"a lot of the time when you say it to the teachers they just laugh."
f1.p4.P49	"...you feel there aren't so many people around, and you just feel.....isolated."

Theme 1c-Feeling different: practical restrictions. CODE PR

The young person is restricted in their social experiences because of their caring tasks and duties.

f2.p4.St47	"...I think it's hard to make friends as I have to go off and make sure my brother's OK."
f1.p3.P40	"Other people see you can't come out and you're too busy..."

Theme 2a-Identity issues: self concept adapted to caring task. **CODE I**

The young person describes a loss of his or her own identity or expresses difficulty in knowing who they are with respect to the caring tasks or defines themselves in relation to caring in the present or the future.

f1.p11.Le143	"...if you look into the future.....see yourself as caring for everyone else in your family, so I don't look into the future..."
f1.p2.B31	"...they are always there for them (a young carer).."
f1.p4.E53	"You want to carry on because you get used to it so much."
f1.p7.B92	"It effects almost everything...you get engrossed in doing things and don't want to go away."
f1.p5.P58	"...(loss of care role) and you're wondering what are you going to do now?"
f1.p4.N55	"..and if you don't give that person your time you just feel...(lost)"
f1.p1.P16	"...involved all the time.....to the point of anything else.."
f1.p8.B102	"I've got so used to it now it's not really effecting me anymore."
f2.p6.?76	"(when I'm older)...I want to set up a support group for my brother."
f2.p7.Js91	"....(when I'm older) I want to help my little brother get better".
f2.p4.St47	"...I think it's hard to make friends as I have to go off and make sure my brother's OK."

Theme 2b-Identity:separation issues- **CODE S**

The young person indicates difficulty in gaining appropriate emotional distance from their family or caring role in the present, or as they see themselves in the future.

f1.p10.C139	"It gets between you and your girlfriend"
f1.p11.C149	"...you'll never ever get to live on your own."
f2.p11.Js	"...being with my dad and sometimes my mum...you know they're safe, they're there."

f1.p12.Le144	"...if you look into the future.....see yourself as caring for everyone else in your family, so I don't look into the future..."
f1.p2.B31	"...they are always there for them .."

Theme3a-Responsibility:Vigilance **CODE V**

The young person is pre-occupied with the caring role; worrying about the care recipient at school, or when socializing or the young person needs to be watchful.

f1.p8.Le104	"The problems waiting for you when you go home."
f1.p9.P119	"(at school)...your probable thinking you're not sure if they can cope on their own."
f1.p9.R120	"Thinking of what's at home (while at school)."
f1.p10.Le128	"I'm, scared that something might happen to her (mum)."
f1.p2.P26	"always being on their backs..."
f2.p10.A27	"...you've got to be prepared and know all the basic things in case.."
f2.p11.S40	"...I've got to be quite careful because of my brother..."
f2.p1.A9	"I have to watch him, he bites".
f2.p11.J129	"...Have to be near a phone in case something drastic happens."
f2.p11.S131	"...people say oh well if he faints he faints but it's not like that."

Theme3c: Responsibility: Practical demands. **CODE P**

The young person indicates that they feel responsible for the care and /or protection of the relative.

f2.p2.S29	"I got to go and tell them off."
f2.p7.H29	"If you get people to bed early and you fed them what they want..."
f2.p8.A95.	"I'm usually the one that usually changes my brothers nappy."

f2.p11.Js140	"I keep my dad occupied because he watches me playing on computer games."

Disturbance in the group dynamics (f1.) on introduction of the topic of "being paid to care".

Theme 6a: Relationships with others: tensions **CODE T**

An expression of frustration towards family or others, or their expression of frustration towards the young person.

f1.p16.P222	"...they can get stressed out about the way they're feeling and that can make you stressed out."
f1.p17.P223	"I do want to clash with her (mum)...
f1.p19.N246	Sometimes things build up or whatever..."
f2.p11.J42	"...you can't help letting it out, 'Oh I hate you mum' "
f2.p12.S54	"When I get annoyed with my brothers I don't want to go out...."
f2.p6.S64	"...my dad's always yelling and saying do this, as my dad has epilepsy."

Theme 6b: Relationships with others: loss or anticipated loss **CODE L**

The young person expresses feelings of loss (of people, or experiences) or anticipated loss.

F2.p2.J28	"...if you're a young carer you don't seem to have as many friends as other people."
F1.p11.Le143	"...you loose your mum and dad don't you, so if you look into the future you see yourself as old and on your own.."
F2.p10.A124	"...not all plain sailing because she....might faint and die..."
F1.p10.C139	"..your mum's not going to be around for ever is she....going to have to take care of your sister on your own.."

Theme 6c; Relationship with others: Conflicting feelings. **CODE F**

F2. P11. J133	".. you can't help letting it out..... but down inside you love her all the time.."
F2.p15.S196	"...did lash out but after that I felt guilty..."
F2.p10.S131	"...if you say you hate your brother it's not like that because you love them whatever happens."

F1.p17.P223	"...You don't want to say your feelings towards one another because you both clash..."

Theme 7-Ways of coping

Distraction **CODE CD**

Doing things or thinking things to take their mind of difficulties.

f2.p12.St152	"...find something else to do..."
f2.p11.St45	"...keeping myself occupied..."

Relating with others **CODE CO**

Interacting with others this might be with relatives or spiritual beings for comfort or advice.

f2.p12.St52	"...telling each other things."
f1.p15.R196	"(young carers) you can talk to them if you like."
f2.p16.St182	"I find I can talk to my parents..."
f2.p16.A80	"...he comforts me..."
f1.p16.B213	"... God helps me sometimes."
f2.p15.S176	"...the people who are being nasty about it help me cope with it...I don't know how."

Managing tension **CODE CT**

The young person indicates that they cope by either releasing tension, through physical aggression, verbal aggression or by relaxing.

f2.p18.A203	"It's like a force field holding you back, but it stretches and just breaks and you can't help lashing out."
f1.p21.B289	"I need to have a go."
f1.p19.N246	"Have a go at everybody"
f1.p19.N.258	"Punch the wall"
f2.p17.S93	"...get cross and lash out..."
f1.p16.Le218	"...let my temper out on my pillow..."
f1.p21.Le277	"Sometimes instead of beating up and that I take a shower."

Helping others **CODE CV**

The young person indicates that they cope by improving circumstances for the care recipient. This may be a direct action taken by themselves such as helping the care recipient with a task or involving themselves in the caring duties or by indicating that

something or someone else helps them by helping the care recipient.

f1.p15.P200	"Cross-roads helps my mum."
f1.p20.B264	"I cook a meal ".
f1.p15.C200	"You feel like you've gained something for your mum because your mum has gained something for your sister..."
f1.p16.C209	"...My cat....because she plays with my sister and it makes her laugh.."
f2.p8.H101	"..get people to bed early, feed them.....you can have a peaceful night."

Avoidance of problem **CODE CA**

The young person indicates that they ignore or cut off from the problem as a way to cope or indicates that they have no way of dealing with the problem.

f1.p17.P223	"I'm learning to just leave things alone(to avoid arguments)."
f1.p18.Le233	"I try to ignore problems, or sometimes my friends calm me down."

Wishful thinking

The young person hopes for the best, wishes a miracle would happen

f1.p10.P135 "So you're hoping for the best." **CODE CW**

Solve the problem **CODE CP**

The young person indicates that they try to find a way around the problem or to sort the problem out.

F1.p19. L251 "I make Sarah look after her"

Reframing **CODE CR**

The young person tries to re-evaluate the situation and to see it in a more positive light.

f1.p7.P94 "But once you get used to it you find the time to do everything."

f1.p8.B102	"I've got so used to it now it's not really effecting me anymore."
f1.p12.P153	"Learning to cook and deal with problems is coping for your age."

Proximity Seeking and distancing **CODE CP**

The young person indicates they cope by staying close to the care recipient or by distancing themselves from the care recipient.

F2.p11.Js140	"...cope by being with my dad ....you know they are safe and they're there."
F1.p12.Le159	"...getting away from it helps you, so you can settle down.."
f2.p11.Js48	"I cope by being with my dad, and sometimes my mum..."

Theme 8-Appraisal

Threat to self; self image, heath, ability to manage stressor **CODE AT**

The young person views their experiences as having negative effects on their health, their self esteem, and their ability to cope.

f1.p12.Le159	"Caring can mainly stress you up."
f1.p10.P.135	"You're wondering if you'll cope with it... "
f2.p3.St41	"... (bullying).. it's just not right..."
f2.p3.J43	"Sometimes my mum goes into school, and they just get people laughing at her.."
F1.p7.B92	"...It (caring) effects almost everything.."
F1.p13.Le159	"...it's making me sick and all that..."

Positive self image **CODE AP**

The young person expresses some personal gain as a result of care-giving; extra privileges, recognition of their contribution or assets by others; the development of new skills; pride in achievements.

f1.p12.P153	"...you wouldn't want to be doing what a child's doing."
f2.p9.A19	"I get a lot of girlfriends as they've seen me look after my mum.."
f2.p8.A10	"...I get to stay up a bit later...."
f1.p13.C161	"...give you more pocket money..."
f1.p7.B92	"...brings you closer to other people."
f1.p13.P151	"...you know more things."

Controllability **CODE AC**

The young persons statements indicate a lack of control over their lives in the present or in the future.

F1.p11.C149	"...It hurts that you'll never ever get to live on your own.."
F1.p11.Le143	"...if you look into the future... see yourself as caring for everyone else in your family, so I don't look into the future."
F1.p10.P135	(Relating between self and care recipient)".....your thinking will their health worsen, your hoping it will get better 'cause it's easier for you..."

Loyalty/self sacrificing **CODE AL**

The young persons statement illustrates their loyalty to the care recipient and or their motivates to care for the recipient.

f2.p8.ST97	"It's nice for them to think that it's (the carer) is someone younger than them."
f1.p2.B31	"...they are always there for them (a young carer).."
f1.p1.P16	"...involved all the time.....to the point of anything else.."
f1. p13. Lu174	".., your doing it for love aren't ya .."
f1.p14. B175	"...you don't want to get paid, you don't want to get paid to care.."
f1. p14. R179	"... You do it for nothing... "

Code Book

Theme 1a-Feeling different: victimisation. **CODE V**

The young person experiences bullying. This can be verbal or physical or segregation by others because of either their role as carers, or their association with illness and/or disability, or the young person's ill or disabled relative is a victim of bullying.

Theme 1b-Feeling different: minimizing **CODE M**

The young person perceives other's to hold a negative or trivialising view of their role as carers or the difficulties they and their family face. This category is the young person's perception of other people's views of them as carers.

Theme 1c-Feeling different: practical restrictions. **CODE PR**

The young person is restricted in their social experiences because of their caring tasks and duties.

Theme 2a-Identity issues: self-concept adapted to caring task. **CODE I**

The young person describes a loss of his or her own identity or expresses difficulty in knowing who they are with respect to the caring tasks or defines themselves in relation to caring in the present or the future.

Theme 2b-Identity:separation issues- **CODE S**

The young person expresses difficulty in gaining appropriate emotional distance from their family or caring role in the present, or as they see themselves in the future.

Theme3a-Responsibility: Vigilance **CODE VI**

The young person is pre-occupied with the caring role; worrying about the care recipient at school, or when socializing or the young person needs to be watchful.

Theme3c- Responsibility: Practical demands. **CODE P**

The young person indicates that they feel responsible for the care and /or protection of the relative.

Theme 6a- Relationships with others: tensions **CODE T**

An expression of frustration towards family or others, or their expression of frustration towards the young person.

Theme 6b- Relationships with others: loss or anticipated loss **CODE L**

The young person expresses feelings of loss (of people, or experiences) or anticipated loss.

Theme 6c- Relationship with others: Conflicting feelings. **CODE F**

The young person expresses conflicting feelings for another, for example guilt and anger, love and hate.

Theme 7-Ways of coping

Distraction **CODE CD**

Doing things or thinking things to take their mind of difficulties.

Relating with others **CODE CO**

Interacting with others this might be with relatives or spiritual beings for comfort or advice.

Managing tension **CODE CT**

The young person indicates that they cope by either releasing tension, through physical aggression, verbal aggression or by relaxing.

Helping others **CODE CV**

The young person indicates that they cope by improving circumstances for the care recipient. This may be a direct action taken by themselves such as helping the care recipient with a task or involving themselves in the caring duties or by indicating that something or someone else helps them by helping the care recipient.

Avoidance of problem **CODE CA**

The young person indicates that they ignore or cut off from the problem as a way to cope or indicates that they have no way of dealing with the problem.

Wishful thinking **CODE CW**

The young person hopes for the best, wishes a miracle would happen

Solve the problem **CODE CP**

The young person indicates that they try to find a way around the problem or to sort the problem out.

Reframing **CODE CR**

The young person tries to re-evaluate the situation and to see it in a more positive light.

Proximity Seeking and distancing **CODE CP**

The young person indicates they cope by staying close to the care recipient or by distancing themselves from the care recipient.

Theme 8a-Appraisal:Threat to self **CODE AT**

The young person views their experiences as having negative effects on their health, their self-image, and/or their ability to cope.

Theme 8b-Appraisal:Positive self image **CODE AP**

The young person expresses some personal gain as a result of care giving; extra privileges, recognition of their contribution or assets by others; the development of new skills; pride in achievements.

Theme 8c-Appraisal:Controllability **CODE AC**

The young persons statements indicate a lack of control over their lives in the present or in the future.

Theme 8d-Appraisal:Loyalty/self sacrificing **CODE AL**

The young persons statement illustrates their loyalty to the care recipient and or their motivates to care for the recipient.

List Of Coping Strategies Generated In Response To The Qualitative Coping Question.

Ride scooter
Go to cinema
Write stories
Lay on my bed
Go to club
Young Carers project
Talk
Listen to music
Loose my temper
Go to dad for a break
Listen to my mum talking about things (care recipient)*
Spend time thinking about how he might overcome his difficulties.
Washing up or baby-sit my sister (care recipient)*
Take her (care recipient) swimming*
Stay at my friend's house
Talk to the disabled person about things*
Read, listen to music, play computer games
Pray, get out and about more, talk to friends
Read, play on computer
Listen to music, shut off
Talk to family
Go for a run, forget it
Talk to mum and friends
Be organised
Work hard
Take messages, play on play station
Make other people feel good or better about their situation*
Look to the future
Make targets and aims
Hobbies
Go for a run
Take drugs
Time alone
Talk to a relative
Bottle up problems
Hang out with friends
Sleep
Eat
Talk to friends
Listen to music
Play on computer
Go to friends house.

* items which correspond to the strategy 'helping others'.

APPENDIX G

Copies of questionnaires used in the main study and background information sheet.

Background Information
What do you do to help? (Levels of caring)
How are you feeling? (GHQ)
Caring Ups and Downs (YCPSS)
My Family (Perceived support from family).
My Friends (Perceived support from friends).
Coping

BACKGROUND INFORMATION (to be completed by staff)

Carer group---------- **Code**----------

The word CARING in this questionnaire includes any duties the young person carries out to help the person who is ill or disabled. This might be shopping, toileting, emotional support etc.

1. Male ( ) Female ( ) *(please tick)* **1b.** Ethnicity ----------

2. Age _____

3a. Please tick who lives with the carer :

Mother..... ( )
Father..... ( )
Step-mother/partner.....( )
Step-father/partner..... ( )
Brother(s)..... ( )
How many?..... _____

Sister(s)..... ( )
How many?..... _____
Other; please specify _____

3b. Child's age in relation to any siblings:

PLEASE CIRCLE eldest middle youngest only child

4. Are you aware of any unusual circumstances, which might affect how the young person responds to the questionnaires? This might be things like a recent major life event such as a bereavement, or a disability/illness of the young person themselves, or difficulties like severe problems with attention and concentration? Yes ( ) No( )

5. Person cared for;(mother, father etc.) _____

6. Nature of illness or disability? _____

7. **A)** Is the young person the primary/sole carer? Yes ( ) No ( )

B) In your opinion does the care recipient have a high, medium or low level of physical dependency on the young person?

PLEASE CIRCLE: HIGH MEDIUM LOW

C) In your opinion does the care recipient have a high, medium or low level of emotional dependency on the young person?

PLEASE CIRCLE: HIGH MEDIUM LOW

D) Please tick one of the statements below that best describes the young person's involvement in caring tasks.

The young person has extensive care giving responsibilities ( )
The young person has regular care giving responsibilities ( )
The young person has occasionally care giving responsibility ( )
The young person has no care giving responsibilities ( )

8. How long has this young person been caring? _____ Year's _____ months

9. Is anyone in the household in paid employment? Yes ( ) No ( )

10. As far as you are aware is there any financial hardship in the household? Yes ( ) No ( )

11. Do the family receive support services e.g. respite, crossroads? Yes ( ) No ( )

If yes, type of service ----------
Number of times. _____ per week/per month **(please delete)**

What do you do to help?

Please read the list of jobs. If you don't do a job OR do it only once a month or less, then put a tick in the box for the column "less than once a month". If you do the job then tick the box for the column that best describes how often you do it.

	Every day	2 or 3 times a week	Once a week	2 or 3 times a month	Once a mo or les
Help the person to bath or wash or use the toilet					
Help the person to get dressed					
Make meals or snacks					
Clean the house or tidy up					
Go shopping					
Collect prescriptions or medicine					
Make sure the person has taken their medicine					
Listen to their problems					
Get up in the night if they need help					
Help them to walk or push their wheel chair					
Carry them					
Comfort them if they are scared					
Fetching and carrying things for them					
Help person to stay calm					
Hold them to stop them hurting themselves					
Calling doctors or an ambulance					
Helping to looking after well brothers or sisters					
Keeping the person company					
Taking to school.					

How are you feeling?

The following questions are about how you have been feeling in the past month. Each question has four statements underneath. Please put a circle around the statement that you feel is most true for you for each question. Thanks for your help.

In the last month have you;

1. Been able to concentrate on what you are doing?

Better than usual	Same as usual	Less than usual	Much less than usual

2. Lost much sleep over worry?

More than usual	Same as usual	Less than usual	Much less than usual

3. Felt that you were playing a useful part in things?

More than usual	Same as usual	Less than usual	Much less than usual

4. Felt capable of making decisions about things?

More than usual	Same as usual	Less than usual	Much less than usual

5. Felt constantly under strain?

Not at all	No more than usual	Rather more than usual	Much more than usual

6. Felt you couldn't overcome difficulties?

Not at all	No more than usual	Rather more than usual	Much more than usual

7. Been able to enjoy your normal day to day activities?

More than usual	Same as usual	Less than usual	Much less than usual

8. Been able to face up to your problems?

More than usual	Same as usual	Less than usual	Much less than usual

9. Been feeling unhappy and depressed?

Not at all	No more than usual	Rather more than usual	Much more than usual

10. Been losing confidence in yourself?

Not at all	No more than usual	Rather more than usual	Much more than usual

11. Been thinking of yourself as a worthless person?

Not at all	No more than usual	Rather more than usual	Much more than usual

12. Been feeling reasonably happy all things considered?

More than usual	Same as usual	Less than usual	Much less than usual

Caring ups and downs

Below is a list of things that young carer's sometimes say about their caring situation. Please read each sentence carefully and decide if it's true for you. Please tick the box that suits you best.

Remember! The word caring means all the things you do to help the person that you look after.

	Never	A little	Sometimes	A lot	Always
1) Getting teased about being a carer is a problem for me.					
2) I worry about the person I care for when I am at school.					
3) I have plenty of energy for doing other things.					
4) I find that looking after my relative is easy.					
5) I think I work hard at caring but nothing seems to change.					
6) It bothers me that I can do things that my relative who is ill can't do.					
7) It bothers me that I can't take part in clubs or things after school.					
8) I feel that there is no break from caring.					
9) I have to be on the alert to help the person I care for.					
10) When I am away from home, I can forget about caring.					
11) I worry that if I wasn't caring I wouldn't know what to do with myself.					
12) Feeling different from other kids is a problem for me.					
13) It bothers me that caring takes over everything in my life.					
14) Caring makes me feel trusted by my family.					
15) I am bothered about what will happen to my relative in the future.					
16) Caring can get in the way of having a boy or girlfriend.					
17) The people that I know understand about my caring.					
18) I always have to keep an eye on the person I look after.					
19) I am bothered that that I have missed too much school.					

	Never	A little	Sometimes	A lot	Always
20) I feel worried about people in my family.					
21) My family get on well together.					
22) It bothers me that other people don't understand what I do to help my family.					
23) It bothers me that I don't know where I belong in the family.					
24) I feel that I can care for my relative and still have time for other things.					
25) It bothers me that people never say they are pleased with my caring.					
26) It bothers me that I can't have a life of my own.					
27) It feels good to know that I can help my relative.					
28) I worry that I might get the same health problem as my relative.					
29) I get extra money like treats or privileges because of the caring that I do.					
30) I sometimes feel awkward about my relative's illness or disability.					
31) It bothers me that the person I care for is always on my mind.					
32) My family let me know how pleased they are with the work I do as a carer.					
33) I feel tired because of the caring I do.					
34) Family rows about who is doing the caring bother me.					
35) I feel I know more about how to look after myself than other kids my age.					
36) I feel my relative's illness is my fault.					
37) Caring makes it difficult to make new friends.					
38) It's hard to get a rest from caring.					

	Never	A little	Sometimes	A lot	Always
39) It bothers me what other kids will say if I take time off school.					
40) Caring for my relative helps me feel important in my family.					
41) I worry about what I will do in the future.					
42) It bothers me what teachers will say if I fall behind at school.					
43) It bothers me when people say nasty things about my relative.					
44) Everyone in my family is treated equally.					
45) I feel caring takes over everything in my life.					
46) Having an ill or disabled relative helps me think about the good things in life.					
47) I feel left out in my family.					
48) Caring helps me to feel better about my relatives illness or disability.					
49) I feel closer to people in my family because of the caring I do.					

MY FRIENDS

The sentences below are about feelings, which happen to most people at some time or another with friends. For each statement there are three possible answers: YES, NO, DON'T KNOW. Read each sentence carefully and circle the answer that suits you best.

---

1. My friends give me the support I need.....YES NO DON'T KNOW
2. Other people are closer to their friends than I am. ....YES NO DON'T KNOW
3. My friends enjoy hearing about what I think....YES NO DON'T KNOW
4. Certain friends come to me when they have problems or need help.....YES NO DON'T KNOW
5. I go to my friends for support..... .....YES NO DON'T KNOW
6. If I felt that one or more of my friends were upset with me, I'd just keep it to myself. .....YES NO DON'T KNOW
7. I feel that I'm on the edge of my circle of friends.....YES NO DON'T KNOW
8. There is a friend that I could go to if I was feeling down, without feeling funny about it later. .....YES NO DON'T KNOW
9. My friends and I are very open about what we think about things..... ..... .YES NO DON'T KNOW
10. My friends know how to help me if I'm feeling down..... .... YES NO DON'T KNOW
11. My friends are good at helping me solve problems. .....YES NO DON'T KNOW
12. My friends come to me if they need support.....YES NO DON'T KNOW
13. I have a close friendship with a number of kids. .....YES NO DON'T KNOW
14. My friends get good ideas about how to do things or make things from me. .....YES NO DON'T KNOW
15. When I tell friends a secret about how I feel it makes me feel uncomfortable .....YES NO DON'TKNOW
16. My friends call for me or telephone me to play or talk.....YES NO DON'T KNOW
17. I think that my friends think that I am good at helping them solve problems. .....YES NO DON'T KNOW
18. I don't have a friendship that is as close as other people's friendships with their friend's.YES NO DON'T KNOW
19. I've recently gotten a good idea about how to do something from a friend. .....YES NO DON'T KNOW
20. I wish my friends were very different.....YES NO DON'T KNOW

MY FAMILY

The sentences below are about feelings, which happen to most people at some time or another with family. For each statement there are three possible answers: YES, NO, DON'T KNOW. Read each sentence carefully and circle the answer that suits you best.

---

1. My family gives me the support I need.....YES NO DON'T KNOW
2. I get good ideas about how to do things or make things from my family..... YES NO DON'T KNOW
3. Other people are closer to their family than I am. .....YES NO DON'T KNOW
4. When I tell a secret to members of my family who are closest to me I get the idea that it makes them uncomfortable....YES NO DON'T KNOW
5. My family enjoy hearing about what I think... YES NO DON'T KNOW
6. People in my family share many of my interests.....YES NO DON'T KNOW
7. Certain members of my family come to me when they have problems or need advice.....YES NO DON'T KNOW
8. I rely on my family for emotional support.....YES NO DON'T KNOW
9. There's a member of my family I could go to if I was feeling down without feeling funny about it later.....YES NO DON'T KNOW
10. My family and I are very open about what we think about things..... YES NO DON'T KNOW
11. My family is sensitive to my personal needs YES NO DON'T KNOW
12. People in my family come to me for support if they have difficult feelings.....YES NO DON'T KNOW
13. Members of my family are good at helping me solve problems.....YES NO DON'T KNOW
14. I have a very close relationship with a number of people in my family.....YES NO DON'T KNOW
15. My family get good ideas about how to do things or make things from me..... YES NO DON'T KNOW
16. When I tell people in my family a secret it makes me feel uncomfortable..... YES NO DON'T KNOW
17. People in my family enjoy spending time with me .....YES NO DON'T KNOW
18. I think that my family think that I am good at helping them solve problems..... YES NO DON'T KNOW
19. I don't have a relationship with a person in my family that is as close as other people's relationships with their families..... YES NO DON'T KNOW
20. I wish my family were very different.....YES NO DON'T KNOW

REMEMBER: YOU ARE THINKING ABOUT A SPECIFIC CONCERN

	Doesn't apply or don't do it	Used very little	Used sometimes	Used often	Used a great deal
1. Talk to other people about my concern to help me sort it out	1	2	3	4	5
2. Work at solving the problem to the best of my ability	1	2	3	4	5
3. Work hard	1	2	3	4	5
4. Worry about what will happen to me	1	2	3	4	5
5. Spend more time with boy/girl friend	1	2	3	4	5
6. Improve my relationship with others	1	2	3	4	5
7. Wish a miracle would happen	1	2	3	4	5
8. I have no way of dealing with the situation	1	2	3	4	5
9. Find a way to let off steam; for example cry, scream, drink, take drugs etc.	1	2	3	4	5
10. Join with people who have the same concern	1	2	3	4	5
11. Shut myself off from the problem so that I can avoid it	1	2	3	4	5
12. See myself as being at fault	1	2	3	4	5
13. Don't let others know how I am feeling	1	2	3	4	5
14. Pray for help and guidance so that everything will be all right	1	2	3	4	5
15. Look on the bright side of things and think of all that is good	1	2	3	4	5
16. Ask a professional person for help	1	2	3	4	5
17. Make time for leisure activities	1	2	3	4	5
18. Keep fit and healthy	1	2	3	4	5
19. List any *other* things you do to cope with your main concern	1	2	3	4	5

_____

_____

_____

_____

APPENDIX H
Instructions for supervising questionnaire completion.

Guidelines for completion of the questionnaires

Thankyou for your help. The packs are for 12 -18 year olds caring for a family member with a physical illness or disability. PLEASE ensure that parental consent has been obtained before the young person fills out the pack. Return all packs including any that are incomplete, consent forms and background sheets to the address below:

****

- PLEASE TALK THROUGH THE FOLLOWING WITH THE YOUNG PERSON
  1. Confidentiality. No one will know what they have written.Unless there is a worry about their wellbeing.
  2. The questions are about the caring they do for the person in their family and their feelings about it OVER THE PAST MONTH. There are no right or wrong answers, and it is not a test.

- HOW TO COMPLETE THE PACK.
  1. Read through the front sheet with them.
  2. Try the practise scale on the front.
  3. Please encourage them to ask if there is any-thing that they don't understand.
  4. Encourage them to read the brief instructions on the top of each questionnaire before they begin it.
  5. If an answer doesn't match with exactly what they think, then get them to think about which answer suits them best. Tick or circle only one answer for each question.

- WHEN THEY HAVE FINISHED;
  1. Thank them on my behalf, ask them how they found completing it, and if they want to talk about any issues further either now or later.
  2. **Please attach completed background info. sheet firmly to each of their packs with the paper clip provided.** Numbers can be used to help you to match up packs and sheets and please keep a record of the number of each child's pack.
  3. Return all **packs, consent forms**, and **info sheets** in the large envelope that can be reused attaching my address label (above).

If you have anything you would like to discuss further please don't hesitate to call me Tel. **********.**Thankyou for your help, I shall let you know my findings.**

APPENDIX Ji
Data analysis for main research paper:

Factor Analysis of measures

List of Coping items for the Factors corresponding to 'Avoidance', 'Attend to the problem' and 'Social coping'.

Coping Items Corresponding to the three identified factors

Avoidance
See self as at fault.
Shut myself off from the problem so that I can avoid it.
Find a way to let off steam, drink, take drugs.
Don't let others know how I am feeling.
Look on the bright side of things and think of all that is good (negatively related).
I have no way of dealing with the situation.

Attend to the problem
Pray for help and guidance.
Wish a miracle would happen.
Talk to other people about my concern.
Work at solving the problem to the best of my ability.
Ask a professional person for help.
Worry about what will happen.
Work hard.

Social Coping
Spend more time with boy or girl friend.
Improve my relationship with others.
Make time for leisure.
Join with people who have the same concern.
Keep fit and healthy.

Factor Analysis:Adolescent Coping Scale

Communalities

	Initial	Extraction
C11	1.000	.504
C12	1.000	.497
C13	1.000	.373
C14	1.000	.504
C15	1.000	.511
C16	1.000	.412
C17	1.000	.420
C18	1.000	.312
C4	1.000	.412
C5	1.000	.599
C6	1.000	.604
C7	1.000	.429
C8	1.000	.207
C9	1.000	.533
C10	1.000	.225
C1	1.000	.361
C2	1.000	.323
C3	1.000	.338

Extraction Method: Principal Component Analysis.

Total Variance Explained

Component	Initial Eigenvalues			Extraction Sums of Squared Loadings			Rotation Sums of Squared Loadings		
	Total	% of Variance	Cumulative %	Total	% of Variance	Cumulative %	Total	% of Variance	Cumulative %
1	3.089	17.160	17.160	3.089	17.160	17.160	2.837	15.764	15.764
2	2.829	15.719	32.879	2.829	15.719	32.879	2.714	15.077	30.840
3	1.647	9.149	42.027	1.647	9.149	42.027	2.014	11.187	42.027
4	1.466	8.146	50.173						
5	1.152	6.399	56.572						
6	1.024	5.690	62.263						
7	.917	5.094	67.356						
8	.844	4.691	72.047						
9	.794	4.409	76.457						
10	.781	4.337	80.794						
11	.667	3.708	84.501						
12	.545	3.026	87.527						
13	.493	2.736	90.263						
14	.436	2.425	92.688						
15	.402	2.231	94.920						
16	.335	1.859	96.779						
17	.318	1.765	98.544						
18	.262	1.456	100.000						

Extraction Method: Principal Component Analysis.

3

Rotated Component Matrix[a]

	Component		
	1	2	3
C12	.697		
C11	.684		
C9	.669		
C13	.599		
C15	-.526	.400	
C8	.448		
C14		.700	
C7		.612	
C1		.563	
C2		.545	
C16		.543	.341
C4	.383	.514	
C3		.512	
C5	.347		.677
C6	.335		.666
C17			.608
C10			.419
C18			.416

Extraction Method: Principal Component Analysis.
Rotation Method: Varimax with Kaiser Normalization.

a. Rotation converged in 6 iterations.

4

Factor Analysis: YCPSS- Stress scale

Total Variance Explained

Component	Initial Eigenvalues			Extraction Sums of Squared Loadings			Rotation Sums of Squared Loadings		
	Total	% of Variance	Cumulative %	Total	% of Variance	Cumulative %	Total	% of Variance	Cumulative %
1	12.056	24.113	24.113	12.056	24.113	24.113	5.442	10.883	10.883
2	5.492	10.984	35.097	5.492	10.984	35.097	5.154	10.307	21.190
3	2.480	4.960	40.057	2.480	4.960	40.057	4.326	8.653	29.843
4	2.117	4.234	44.291	2.117	4.234	44.291	3.330	6.659	36.503
5	1.896	3.793	48.084	1.896	3.793	48.084	2.951	5.902	42.405
6	1.822	3.643	51.727	1.822	3.643	51.727	2.833	5.666	48.071
7	1.616	3.232	54.959	1.616	3.232	54.959	2.173	4.346	52.417
8	1.470	2.941	57.899	1.470	2.941	57.899	1.935	3.870	56.287
9	1.399	2.797	60.697	1.399	2.797	60.697	1.891	3.782	60.069
10	1.360	2.720	63.417	1.360	2.720	63.417	1.674	3.348	63.417
11	1.238	2.477	65.894						
12	1.214	2.428	68.322						
13	1.093	2.186	70.508						
14	1.065	2.129	72.637						
15	1.009	2.018	74.655						
16	.939	1.878	76.534						
17	.873	1.746	78.280						
18	.832	1.663	79.943						
19	.735	1.470	81.413						
20	.732	1.464	82.877						
21	.678	1.356	84.233						
22	.645	1.291	85.524						

Extraction Method: Principal Component Analysis.

Total Variance Explained

Component	Initial Eigenvalues			Extraction Sums of Squared Loadings			Rotation Sums of Squared Loadings		
	Total	% of Variance	Cumulative %	Total	% of Variance	Cumulative %	Total	% of Variance	Cumulative %
23	.603	1.206	86.730						
24	.591	1.182	87.913						
25	.544	1.089	89.001						
26	.530	1.061	90.062						
27	.491	.982	91.044						
28	.402	.804	91.848						
29	.399	.797	92.645						
30	.377	.755	93.400						
31	.319	.639	94.039						
32	.316	.631	94.670						
33	.279	.559	95.229						
34	.266	.532	95.762						
35	.251	.502	96.263						
36	.236	.472	96.735						
37	.221	.441	97.176						
38	.191	.382	97.559						
39	.176	.352	97.911						
40	.163	.326	98.237						
41	.138	.277	98.513						
42	.130	.261	98.774						
43	.124	.247	99.021						
44	.108	.216	99.237						
45	9.639E-02	.193	99.430						
46	7.920E-02	.158	99.588						
47	6.726E-02	.135	99.723						
48	5.446E-02	.109	99.832						

Extraction Method: Principal Component Analysis.

Total Variance Explained

Component	Initial Eigenvalues			Extraction Sums of Squared Loadings			Rotation Sums of Squared Loadings		
	Total	% of Variance	Cumulative %	Total	% of Variance	Cumulative %	Total	% of Variance	Cumulative %
49	4.710E-02	9.421E-02	99.926						
50	3.707E-02	7.415E-02	100.000						

Extraction Method: Principal Component Analysis.

Rotated component matrix : YCPSS Stress Scale

Rotated Component Matrix[a]

	Component									
	1	2	3	4	5	6	7	8	9	10
S25	.734									
S23	.709		.307		.366					
S26	.688			.338						
S47	.569		.367							
S12	.562			.390	.430					
S41	.555									
S32	-.553	.423								
S8	.527		.441							
S13	.527		.387				.318			
S45	.504							.319		
S22	.495				.406			.340		
S49		.834								
S40		.783								
S46		.704								
S48		.696								
S14		.634								-.301
S15		.567								
S20	.331	.517			.371					
S27		.404						.401		
S6		.367			.341					
S19			.746							
S39			.699							
S11			.614							
S50		.304	.581							

Extraction Method: Principal Component Analysis.
Rotation Method: Varimax with Kaiser Normalization.

Rotated Component Matrix[a]

	Component									
	1	2	3	4	5	6	7	8	9	10
S33	.365		.490			.420				
S38	.395		.482				.349			
S37			.376	.354	.306					.308
S3				-.746						
S16	.338			.648						
S4				-.630						
S1			.356	.531					-.354	
S7	.319		.320	.446						
S24	-.330			-.436	-.383			-.393		
S31					.653					
S36			.343		.602			-.303		
S2			.338		.514					
S30					.458		.406			
S34						.749				
S21						-.716				
S44	-.334	.363				-.557				
S29						-.457			.390	
S35		.422				.448				
S10							.618			
S18							.554			
S9		.332					.538			
S43		.341					.378			
S5								.677		
S28									.774	
S17										-.666
S42	.315		.428							-.456

Extraction Method: Principal Component Analysis.
Rotation Method: Varimax with Kaiser Normalization.

Factor Analysis: What do you do to help?

Total Variance Explained

Component	Initial Eigenvalues			Extraction Sums of Squared Loadings			Rotation Sums of Squared Loadings		
	Total	% of Variance	Cumulative %	Total	% of Variance	Cumulative %	Total	% of Variance	Cumulative %
1	4.860	25.580	25.580	4.860	25.580	25.580	2.865	15.080	15.080
2	2.291	12.060	37.640	2.291	12.060	37.640	2.648	13.938	29.018
3	1.587	8.355	45.994	1.587	8.355	45.994	2.311	12.162	41.180
4	1.324	6.967	52.961	1.324	6.967	52.961	1.763	9.279	50.458
5	1.139	5.993	58.954	1.139	5.993	58.954	1.342	7.061	57.519
6	1.043	5.488	64.442	1.043	5.488	64.442	1.315	6.923	64.442
7	.902	4.747	69.190						
8	.810	4.264	73.453						
9	.775	4.076	77.530						
10	.683	3.597	81.127						
11	.608	3.201	84.328						
12	.550	2.894	87.221						
13	.492	2.588	89.809						
14	.468	2.463	92.272						
15	.414	2.178	94.450						
16	.360	1.892	96.342						
17	.274	1.441	97.783						
18	.253	1.331	99.114						
19	.168	.886	100.000						

Extraction Method: Principal Component Analysis.

Rotated Component Matrix[a]

	Component					
	1	2	3	4	5	6
H3	.735					
H4	.680			.373		
H5	.680					
H13	.626		.319			
H6	.460					.450
H12		.783				
H8	.334	.676				
H14		.673				
H18	.548	.570				
H15	-.318	.562				.441
H9		.522		.409	.463	
H2			.835			
H1			.820			
H11		.326	.662			
H19				.800		
H17				.670		
H7	.323			.448	.309	
H16					.845	
H10						.790

Extraction Method: Principal Component Analysis.
Rotation Method: Varimax with Kaiser Normalization.

a. Rotation converged in 11 iterations.

Appendix Jii
Data Analysis for main paper

Reliabilities for YCPSS

Reliability

R E L I A B I L I T Y A N A L Y S I S - S C A L E (A L P H A)

Statistics for	Mean	Variance	Std Dev	N of Variables
SCALE	81.6389	660.6441	25.7030	50

R E L I A B I L I T Y A N A L Y S I S - S C A L E (A L P H A)

Item-total Statistics

	Scale Mean if Item Deleted	Scale Variance if Item Deleted	Corrected Item-Total Correlation	Alpha if Item Deleted
S1	81.1481	646.7816	.3289	.8903
S2	79.5741	623.9290	.5641	.8870
S3	79.1111	667.9688	-.1417	.8957
S4	79.9722	680.0460	-.3312	.8979
S5	79.7037	637.7805	.3109	.8903
S6	79.7685	632.1422	.3765	.8894
S7	80.7500	638.6379	.3311	.8900
S8	80.2593	628.8107	.4793	.8881
S9	79.3611	626.7936	.5290	.8875
S10	80.1296	657.0858	.0302	.8938
S11	80.7315	633.1889	.4632	.8885
S12	80.5741	622.0786	.5402	.8871
S13	80.6574	629.7413	.5002	.8880
S14	79.3889	643.9034	.2301	.8913
S15	78.8611	620.1020	.5968	.8864
S16	80.7037	633.0329	.4042	.8891
S17	79.1852	668.6009	-.1376	.8965
S18	79.3981	629.4755	.5128	.8879
S19	80.6296	625.1886	.4743	.8880
S20	79.5463	627.3904	.5201	.8876
S21	79.3241	660.2772	-.0197	.8946
S22	80.0648	618.3229	.5669	.8866
S23	80.5926	626.4306	.4999	.8878
S24	79.1667	676.8131	-.2664	.8976
S25	80.6111	637.7539	.3405	.8899
S26	80.5463	629.4464	.4493	.8884
S27	78.5463	639.1848	.3555	.8897
S28	80.7778	645.3894	.2258	.8913
S29	80.1574	654.6012	.0674	.8934
S30	80.2315	632.4599	.4463	.8886
S31	80.3333	631.0654	.4191	.8888
S32	79.8426	647.2554	.1727	.8922
S33	80.0741	623.5272	.5272	.8873
S34	80.0278	639.0179	.2616	.8912
S35	79.4722	616.5132	.5446	.8868
S36	81.2407	648.9508	.2355	.8910
S37	80.8981	634.6905	.4478	.8887
S38	80.2500	623.4790	.5517	.8871
S39	80.7130	627.8888	.4593	.8883
S40	79.6852	631.6944	.4455	.8886
S41	79.8241	617.2865	.5735	.8865

R E L I A B I L I T Y A N A L Y S I S - S C A L E (A L P H A)

Item-total Statistics

	Scale Mean if Item Deleted	Scale Variance if Item Deleted	Corrected Item-Total Correlation	Alpha if Item Deleted
S42	80.1759	621.0996	.4831	.8878
S43	78.9259	616.8543	.5387	.8869
S44	79.1204	654.4807	.0611	.8938
S45	80.5926	632.2437	.4522	.8885
S46	79.5278	626.3450	.4867	.8879
S47	80.7130	632.7860	.4151	.8889
S48	79.6204	627.9200	.4776	.8881
S49	79.8241	628.2398	.4692	.8882
S50	79.9722	619.5600	.5210	.8872

Reliability Coefficients

N of Cases = 108.0 N of Items = 50

Alpha = .8917

****** Method 1 (space saver) will be used for this analysis ******

R E L I A B I L I T Y A N A L Y S I S - S C A L E (A L P H A)

		Mean	Std Dev	Cases
1.	S25	1.0192	1.2462	104.0
2.	S26	1.0962	1.3110	104.0
3.	S23	1.0288	1.3031	104.0
4.	S12	1.0769	1.3773	104.0
5.	S13	.9808	1.1740	104.0
6.	S22	1.6058	1.4239	104.0
7.	S41	1.8558	1.4509	104.0
8.	S47	.9135	1.2550	104.0

Statistics for	Mean	Variance	Std Dev	N of Variables
SCALE	9.5769	57.6639	7.5937	8

Item-total Statistics

	Scale Mean if Item Deleted	Scale Variance if Item Deleted	Corrected Item-Total Correlation	Alpha if Item Deleted
S25	8.5577	46.4627	.5679	.8553
S26	8.4808	44.4268	.6591	.8454
S23	8.5481	43.0656	.7542	.8347
S12	8.5000	44.5825	.6081	.8512
S13	8.5962	46.5926	.6048	.8518
S22	7.9712	44.3972	.5923	.8533
S41	7.7212	45.5428	.5114	.8632
S47	8.6635	44.8662	.6675	.8448

Reliability Coefficients

N of Cases = 104.0 N of Items = 8

Alpha = .8663

Reliability

R E L I A B I L I T Y A N A L Y S I S - S C A L E (A L P H A)

Statistics for	Mean	Variance	Std Dev	N of Variables
SCALE	11.3519	61.4264	7.8375	9

Item-total Statistics

	Scale Mean if Item Deleted	Scale Variance if Item Deleted	Corrected Item-Total Correlation	Alpha if Item Deleted
S39	10.4259	48.6019	.5877	.8059
S19	10.3426	46.9002	.6487	.7981
S11	10.4444	54.3801	.3490	.8302
S50	9.6852	48.6850	.5023	.8167
S33	9.7870	48.5430	.5930	.8053
S38	9.9630	48.6902	.6159	.8030
S42	9.8889	48.8660	.4717	.8211
S8	9.9722	49.9338	.5572	.8097
S45	10.3056	51.5226	.4985	.8161

Reliability Coefficients

N of Cases = 108.0 N of Items = 9

Alpha = .8294

R E L I A B I L I T Y A N A L Y S I S - S C A L E (A L P I

Statistics for	Mean	Variance	Std Dev	N of Variables
SCALE	12.0980	32.2279	5.6770	6

Item-total Statistics

	Scale Mean if Item Deleted	Scale Variance if Item Deleted	Corrected Item-Total Correlation	Alpha if Iter Deletec
S32	10.3039	24.2929	.4745	.8312
S49	10.2549	21.0433	.7873	.7647
S40	10.1176	23.5900	.6101	.8037
S14	9.8235	23.5131	.5581	.8140
S48	10.1078	23.3843	.5885	.8077
S46	9.8824	22.9761	.6157	.8021

Reliability Coefficients

N of Cases = 102.0 N of Items = 6

Alpha = .8318

R E L I A B I L I T Y A N A L Y S I S - S C A L E (A L P H A)

Statistics for	Mean	Variance	Std Dev	N of Variables
SCALE	6.5673	4.2090	2.0516	5

Item-total Statistics

	Scale Mean if Item Deleted	Scale Variance if Item Deleted	Corrected Item-Total Correlation	Alpha if Item Deleted
S3	4.0577	4.7733	-.3821	-.1298
S16	5.6154	3.5982	-.2143	-.5257
S4	4.8462	4.8693	-.3959	-.1038
S1	6.0769	3.6251	-.0124	-.8931
S7	5.6731	2.4358	.0623	-1.4815

Reliability Coefficients

N of Cases = 104.0 N of Items = 5

Alpha = -.7323

R E L I A B I L I T Y A N A L Y S I S - S C A L E (A L P H

Statistics for	Mean	Variance	Std Dev	N of Variables
SCALE	5.1759	10.3519	3.2174	4

Item-total Statistics

	Scale Mean if Item Deleted	Scale Variance if Item Deleted	Corrected Item-Total Correlation	Alpha if Item Deleted
S31	3.8704	5.2354	.5571	.4115
S36	4.7778	7.9128	.3173	.6044
S30	3.7685	6.9272	.3193	.6069
S2	3.1111	6.1745	.4227	.5308

Reliability Coefficients

N of Cases = 108.0 N of Items = 4

Alpha = .6190

R E L I A B I L I T Y A N A L Y S I S - S C A L E (A L P H A

Statistics for SCALE	Mean	Variance	Std Dev	N of Variables
	4.5185	4.4950	2.1201	2

Item-total Statistics

	Scale Mean if Item Deleted	Scale Variance if Item Deleted	Corrected Item-Total Correlation	Alpha if Item Deleted
S9	2.2407	1.3434	.5860	.
S18	2.2778	1.4922	.5860	.

Reliability Coefficients

N of Cases = 108.0 N of Items = 2

Alpha = .7383

APPENDIX Jiii
Data analysis for main research paper:

Anova examining differences between 'cases' and 'non cases'
Anova examining differences between genders

Oneway Anova: Cases

ANOVA

		Sum of Squares	df	Mean Square	F	Sig.
FRIENDS	Between Groups	2.580E-04	1	2.580E-04	.000	.998
	Within Groups	4216.916	106	39.782		
	Total	4216.917	107			
FAMILY	Between Groups	26.035	1	26.035	.525	.471
	Within Groups	5261.622	106	49.638		
	Total	5287.657	107			
HELP	Between Groups	198.132	1	198.132	1.099	.297
	Within Groups	19107.525	106	180.260		
	Total	19305.657	107			
devalued by others	Between Groups	1165.022	1	1165.022	24.918	.000
	Within Groups	4955.895	106	46.754		
	Total	6120.917	107			
value of caring	Between Groups	.868	1	.868	.027	.870
	Within Groups	3420.799	106	32.272		
	Total	3421.667	107			
Overload	Between Groups	1087.059	1	1087.059	21.006	.000
	Within Groups	5485.571	106	51.751		
	Total	6572.630	107			
social restrictions	Between Groups	2.867E-05	1	2.867E-05	.000	.998
	Within Groups	446.991	106	4.217		
	Total	446.991	107			

ANOVA

		Sum of Squares	df	Mean Square	F	Sig.
concern about care recipient	Between Groups	198.132	1	198.132	23.091	.000
	Within Groups	909.525	106	8.580		
	Total	1107.657	107			
Family cohesion stress	Between Groups	1.438	1	1.438	.401	.528
	Within Groups	380.636	106	3.591		
	Total	382.074	107			
vigilance stress	Between Groups	6.827	1	6.827	1.526	.219
	Within Groups	474.136	106	4.473		
	Total	480.963	107			
avoidance coping	Between Groups	243.251	1	243.251	11.341	.001
	Within Groups	2273.666	106	21.450		
	Total	2516.917	107			
attend to problem	Between Groups	230.236	1	230.236	5.510	.021
	Within Groups	4429.505	106	41.788		
	Total	4659.741	107			
socialising coping	Between Groups	30.353	1	30.353	1.477	.227
	Within Groups	2178.563	106	20.552		
	Total	2208.917	107			
STRESS	Between Groups	8269.013	1	8269.013	19.942	.000
	Within Groups	43953.061	106	414.652		
	Total	52222.074	107			

Oneway Anova: Gender

ANOVA

		Sum of Squares	df	Mean Square	F	Sig.
GHQ	Between Groups	23.341	1	23.341	.755	.387
	Within Groups	3216.819	104	30.931		
	Total	3240.160	105			
FRIENDS	Between Groups	326.456	1	326.456	8.769	.004
	Within Groups	3871.893	104	37.230		
	Total	4198.349	105			
FAMILY	Between Groups	39.228	1	39.228	.833	.363
	Within Groups	4895.650	104	47.074		
	Total	4934.877	105			
HELP	Between Groups	393.564	1	393.564	2.169	.144
	Within Groups	18868.021	104	181.423		
	Total	19261.585	105			
devalued by others	Between Groups	12.145	1	12.145	.219	.641
	Within Groups	5759.751	104	55.382		
	Total	5771.896	105			
Personal value of caring	Between Groups	9.233	1	9.233	.284	.595
	Within Groups	3383.757	104	32.536		
	Total	3392.991	105			
Overload	Between Groups	22.452	1	22.452	.374	.542
	Within Groups	6250.614	104	60.102		
	Total	6273.066	105			

3

ANOVA

		Sum of Squares	df	Mean Square	F	Sig.
social restrictions	Between Groups	1.516	1	1.516	.366	.547
	Within Groups	430.900	104	4.143		
	Total	432.415	105			
concern about care recipient	Between Groups	1.163	1	1.163	.112	.739
	Within Groups	1081.780	104	10.402		
	Total	1082.943	105			
Family cohesion stress	Between Groups	4.230	1	4.230	1.173	.281
	Within Groups	375.128	104	3.607		
	Total	379.358	105			
vigilance stress	Between Groups	1.863	1	1.863	.408	.524
	Within Groups	474.401	104	4.562		
	Total	476.264	105			
COPING	Between Groups	121.034	1	121.034	6.692	.011
	Within Groups	1881.117	104	18.088		
	Total	2002.151	105			
SUPPORT	Between Groups	592.012	1	592.012	4.304	.040
	Within Groups	14305.346	104	137.551		
	Total	14897.358	105			
STRESS	Between Groups	221.435	1	221.435	.462	.498
	Within Groups	49880.725	104	479.622		
	Total	50102.160	105			

Appendix Jiv
Data Analysis of Main Paper

Regression- Testing of Theoretical Model

Regression- Theoretical Model Validation:Step 1.

Variables Entered/Removed[a]

Model	Variables Entered	Variables Removed	Method
1	avoidance coping	.	Stepwise (Criteria: Probability-of-F-to-enter <= .050, Probability-of-F-to-remove >= .100).
2	socialising coping	.	Stepwise (Criteria: Probability-of-F-to-enter <= .050, Probability-of-F-to-remove >= .100).
3	STRESS	.	Stepwise (Criteria: Probability-of-F-to-enter <= .050, Probability-of-F-to-remove >= .100).

a. Dependent Variable: GHQ

Model Summary

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate
1	.382[a]	.146	.138	5.2644
2	.494[b]	.244	.230	4.9761
3	.543[c]	.294	.274	4.8320

a. Predictors: (Constant), avoidance coping

b. Predictors: (Constant), avoidance coping, socialising coping

c. Predictors: (Constant), avoidance coping, socialising coping, STRESS

Coefficients[a]

Model		Unstandardized Coefficients		Standardized Coefficients	t	Sig.
		B	Std. Error	Beta		
1	(Constant)	8.360	1.338		6.246	.000
	avoidance coping	.447	.105	.382	4.261	.000
2	(Constant)	12.795	1.744		7.336	.000
	avoidance coping	.553	.103	.473	5.358	.000
	socialising coping	-.407	.110	-.326	-3.693	.000
3	(Constant)	10.049	1.973		5.092	.000
	avoidance coping	.447	.108	.383	4.157	.000
	socialising coping	-.388	.107	-.311	-3.619	.000
	STRESS	6.160E-02	.023	.240	2.712	.008

a. Dependent Variable: GHQ

Regression:Step 2

Variables Entered/Removed[a]

Model	Variables Entered	Variables Removed	Method
1	attend to problem	.	Stepwise (Criteria: Probability-of-F-to-enter <= .050, Probability-of-F-to-remove >= .100).
2	FAMILY	.	Stepwise (Criteria: Probability-of-F-to-enter <= .050, Probability-of-F-to-remove >= .100).
3	STRESS	.	Stepwise (Criteria: Probability-of-F-to-enter <= .050, Probability-of-F-to-remove >= .100).

a. Dependent Variable: avoidance coping

Model Summary

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate
1	.397[a]	.157	.149	4.4733
2	.456[b]	.208	.193	4.3576
3	.500[c]	.250	.228	4.2610

a. Predictors: (Constant), attend to problem

b. Predictors: (Constant), attend to problem, FAMILY

c. Predictors: (Constant), attend to problem, FAMILY, STRESS

Coefficients[a]

Model		Unstandardized Coefficients		Standardized Coefficients	t	Sig.
		B	Std. Error	Beta		
1	(Constant)	5.615	1.457		3.854	.000
	attend to problem	.291	.066	.397	4.447	.000
2	(Constant)	8.217	1.739		4.725	.000
	attend to problem	.384	.073	.522	5.248	.000
	FAMILY	-.178	.069	-.258	-2.589	.011
3	(Constant)	6.619	1.825		3.627	.000
	attend to problem	.311	.078	.423	4.002	.000
	FAMILY	-.172	.067	-.250	-2.564	.012
	STRESS	4.963E-02	.021	.226	2.412	.018

a. Dependent Variable: avoidance coping

Regression:Step 3.

Variables Entered/Removed[a]

Model	Variables Entered	Variables Removed	Method
1	attend to problem	.	Stepwise (Criteria: Probability-of-F-to-enter <= .050, Probability-of-F-to-remove >= .100).
2	STRESS	.	Stepwise (Criteria: Probability-of-F-to-enter <= .050, Probability-of-F-to-remove >= .100).

a. Dependent Variable: socialising coping

Model Summary

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate
1	.555[a]	.308	.302	3.7972
2	.594[b]	.353	.341	3.6890

a. Predictors: (Constant), attend to problem

b. Predictors: (Constant), attend to problem, STRESS

Coefficients[a]

Model		Unstandardized Coefficients		Standardized Coefficients	t	Sig.
		B	Std. Error	Beta		
1	(Constant)	5.855	1.237		4.734	.000
	attend to problem	.382	.056	.555	6.870	.000
2	(Constant)	7.327	1.319		5.555	.000
	attend to problem	.450	.060	.654	7.552	.000
	STRESS	-4.815E-02	.018	-.234	-2.704	.008

a. Dependent Variable: socialising coping

Regression:Step 4.

Variables Entered/Removed[a]

Model	Variables Entered	Variables Removed	Method
1	FAMILY	.	Stepwise (Criteria: Probability-of-F-to-enter <= .050, Probability-of-F-to-remove >= .100).
2	STRESS	.	Stepwise (Criteria: Probability-of-F-to-enter <= .050, Probability-of-F-to-remove >= .100).

a. Dependent Variable: attend to problem

Model Summary

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate
1	.488[a]	.238	.231	5.7886
2	.595[b]	.354	.341	5.3557

a. Predictors: (Constant), FAMILY

b. Predictors: (Constant), FAMILY, STRESS

Coefficients[a]

Model		Unstandardized Coefficients		Standardized Coefficients	t	Sig.
		B	Std. Error	Beta		
1	(Constant)	9.488	2.118		4.479	.000
	FAMILY	.458	.080	.488	5.750	.000
2	(Constant)	4.718	2.247		2.099	.038
	FAMILY	.400	.075	.426	5.338	.000
	STRESS	.103	.024	.346	4.339	.000

a. Dependent Variable: attend to problem

Regression: Step 5

Variables Entered/Removed[a]

Model	Variables Entered	Variables Removed	Method
1	FRIENDS	.	Stepwise (Criteria: Probability-of-F-to-enter <= .050, Probability-of-F-to-remove >= .100).

a. Dependent Variable: FAMILY

Model Summary

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate
1	.624[a]	.389	.384	5.5192

a. Predictors: (Constant), FRIENDS

Coefficients[a]

Model		Unstandardized Coefficients		Standardized Coefficients	t	Sig.
		B	Std. Error	Beta		
1	(Constant)	7.839	2.234		3.509	.001
	FRIENDS	.699	.085	.624	8.221	.000

a. Dependent Variable: FAMILY

Regression:Step 6

Variables Entered/Removed[a]

Model	Variables Entered	Variables Removed	Method
1	HELP	.	Stepwise (Criteria: Probability-of-F-to-enter <= .050, Probability-of-F-to-remove >= .100).

a. Dependent Variable: FRIENDS

Model Summary

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate
1	.295[a]	.087	.079	6.0261

a. Predictors: (Constant), HELP

Coefficients[a]

Model		Unstandardized Coefficients		Standardized Coefficients	t	Sig.
		B	Std. Error	Beta		
1	(Constant)	21.364	1.431		14.925	.000
	HELP	.138	.043	.295	3.182	.002

a. Dependent Variable: FRIENDS

Regression:Step 7

Variables Entered/Removed[a]

Model	Variables Entered	Variables Removed	Method
1	STRESS	.	Stepwise (Criteria: Probability-of-F-to-enter <= .050, Probability-of-F-to-remove >= .100).

a. Dependent Variable: HELP

Model Summary

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate
1	.416[a]	.173	.165	12.2725

a. Predictors: (Constant), STRESS

ANOVA[b]

Model		Sum of Squares	df	Mean Square	F	Sig.
1	Regression	3340.434	1	3340.434	22.179	.000[a]
	Residual	15965.223	106	150.615		
	Total	19305.657	107			

a. Predictors: (Constant), STRESS

b. Dependent Variable: HELP

Coefficients[a]

Model		Unstandardized Coefficients		Standardized Coefficients	t	Sig.
		B	Std. Error	Beta		
1	(Constant)	14.851	3.462		4.290	.000
	STRESS	.253	.054	.416	4.709	.000

a. Dependent Variable: HELP