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Perceived Stress in Young Carers: Development of a Measure

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We report the development of a 5-factor, 31-item, Young Carers Perceived Stress Scale *(YCPSS) from an initial 50-item pool. The scale was developed and tested on 108 young carers aged between 12–18 years, and acceptable Cronbach Alpha values were obtained for the individual factors and the overall scale. In addition, both the overall scale and individual factors produced a pattern of correlations with social support, burden of care, psychological distress, and coping, supporting the initial validity and utility of the scale.*

KEY WORDS: *Young Carers Perceived Stress Scale*; young carers; stress; burden of care; coping.

It has always been the case that children in some deprived families have undertaken roles which would be considered more properly performed by adults. In addition, many children find themselves in the role of caring for parents, siblings or other relatives who have an illness or disability (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: p. 2). 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 et al., 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

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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. In many cases, caregiving responsibilities are taken on by adult family members or support services.

Research with 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 carer's rights by legislative bodies (Department of Health, 2000a; 2000b).

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

Two bodies of literature concerned with the psychological implications of children as carers are the literature on parentification and that on the roles and responsibilities of siblings with learning disabilities (for a review see Damiani, 1999). The former focuses on the adult nature of the responsibilities of a care giving role and the impact that this may have on the child's development and adjustment. The focus is on emotional care, usually provided to a parent, and studies are often retrospective in nature (Chase, 1999). Studies examining siblings as caregivers have focused on more task orientated care with a view to determining if siblings have increased responsibilities when compared with groups of children without a disabled sibling, and whether or not this responsibility impacts upon adjustment. Many studies in the area rely on parent reports which may produce a bias in responding as mothers could be inclined to underestimate their child's involvement in the home and, furthermore, neglects the child's appraisal of their situation. In studies using children's own self reports, the caregiving role has been shown to have an impact (McHale & Gamble, 1989; Stoneman, Brody, Davis, Crapps, & Malone, 1991). Appraisal has been shown to be an important factor in determining outcome, and studies suggest that children do perceive their family circumstances differently from parents (Kock-Hattem, 1986; Menke, 1987).

Studies investigating children as caregivers have suffered from a number of conceptual and methodological shortcomings (Damiani, 1999; Stoneman, 1989). The principal conceptual framework for considering the impact of informal family care giving in adult populations is the stress model (Biegel & Schulz, 1999). Research deriving from this model illustrates a link between care giving and both physical and mental health difficulties (Fuller-Jonap & Haley, 1995; Li, Seltzer, &

Greenberg, 1997; Pruchno, Peters, & Burant, 1995). Moreover, the social welfare literature has highlighted negative outcomes that are specific to young carers, including poor school attendance, loss of social opportunities, impact on future plans and independence, bullying, social stigmatization, and isolation (Aldridge & Becker, 1993; Meredith, 1992; White, 1989). These outcomes appear to be related to the conflicting demands from age-typical social and educational concerns and the additional responsibility of care giving.

One obstacle to clarifying the impact of competing demands on the development of young carers is the absence of a psychometrically sound scale to assess the specific problems faced by these children. 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 fail to take account of the wider social, educational and developmental issues. A plethora of measures exist to assess stress in adult carers (e.g., Robinson, 1983; Zarit, Reever, & Bach-Peterson, 1980) but 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 an apparent need for a measure of stress in adolescent young carers. Our sudy was therefore designed to develop a measure of the demands of the care giving role focussing specifically on young carers and taking into account the social and educational context within which they perform the role.

METHOD

Participants

The participants were 108 adolescents between the ages of 12 and 18, with a mean age of 13.6 years (SD = 1.5). Each was recruited from a network of young carer support groups–voluntary organisations that provide recreation and occasionally counselling support to young carers (Aldridge & Becker, 1998). A total of 28 support group managers were contacted, out of which 20 agreed to participate.

Information packets were distributed by support group managers to approximately 137 families. Families were selected for inclusion on the bases that the child carer was living at home, attending full time education and caring for a family member with a physical illness or disability who was resident in the household. Families were excluded if recipients of care had mental health difficulties, drug and alcohol problems, or HIV/Aids. The information packets included an explanation of the study, a parental consent form, and an information leaflet for the carer. These materials made it clear to both parents and carers that participation in the study was voluntary and would have no impact on access to support services.

Table I. 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

Accurate records were not kept by group managers regarding the total number of families to whom packets were distributed, although we estimate the number to be 137. Therefore, the approximate response rate was 50%. Table I provides descriptive information about the composition of the sample with respect to gender, disability/illness precipitating care, care recipient's relationship to the young carer, and ordinal position of the carer. All of those being cared for were physically challenged and the illness/disability category in Table I indicates the main source of the illness or disability. The chronically ill group were suffering from a debilitating ongoing illness (mainly cancer patients) which made them dependent on a carer; the learning disability group were mainly Down's Syndrome and had a learning disability which was associated with elements of physical challenge; the physical disability group had a physical challenge which was not a consequence of chronic illness or associated with any learning impairment (mainly malformed or absent limbs); the acquired intellectual impairment group were children with brain damage which also caused physical challenge; the sensory impairment group were either blind or deaf children; and the combination group were children whose impairment crossed the other categories (e.g. a sensory impaired Down's Syndrome child). The sample is comparable to a recently obtained statistical profile of 2,303 young carers (Dearden & Becker, 1998), although the present sample contained a greater percentage of females, and also a greater percentage of mothers as care recipients.

Procedure

Drawing on the focus group work (Early, Cushway, & Cassidy, in press) and the literature, a set of categories and a pool of 50 items was constructed. The categories were labelled as follows: social restrictions, school-caring conflict, family tensions, identity issues (problems with developing independence), vigilance, burden, concern for relative, victimisation, devaluation of role (described as a lack of understanding of young carers' pressures by others), and the positives of caring. The 50 items were constructed to reflect these categories. The items were presented in a questionnaire format on a 5-point Likert scale which was then combined with the other measures outlined above.

Questionnaires were administered by one of the research team members (a clinical psychologist) to the participating adolescents in small groups of between 5–10 carers. The researcher explained the study to each carer and was on hand to assist with any difficulties in completing the questionnaires. Questionnaires took approximately 40 min 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 debrief. In addition, individual time was offered by the researcher to all participants if they wished to discuss any issues relating to the research. Two participants took that opportunity. A telephone number was also made available should any of the participants wished to make contact regarding the research at a later date.

Measures

In order to test the utility of the scale the following measures were also used.

Perceived Social Support

Perceived levels of social support received from family and friends were measured by the Perceived Social Support Scale (Procidano & 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. 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). In the current study, the Cronbach alpha values were: family support ($\alpha = 0.81$) and support from friends ($\alpha = 0.83$). This compares favorably with previous reported alpha values; for example family support ($\alpha = 0.87$) and support from friends ($\alpha = 0.88$) (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 the scale has been shown to be correlated with a range of other relevant variables such as social competence (Procidano & Heller, 1983).

Coping Style

Coping style was measured by the Adolescent Coping Scale- short form (ACS) (Frydenberg & Lewis, 1990). 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 described in the preceding 18 items. This measure was selected because it is brief, covers a comprehensive range of coping strategies, and has been specifically developed for use with adolescents. The Cronbach alpha value for the scale in this study was 0.85 which is in line with the data reported by Frydenberg and Lewis (1990) and Frydenberg (1997).

Psychological Distress

The General Health Questionnaire (GHQ) (Goldberg, 1978) 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 ($\alpha = 0.79$). The GHQ has also been employed with younger school age adolescent populations (Houlihan, Fitzgerald, & O'Regan, 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 2000 English speaking children in Singapore.

Care Giving Responsibility

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 that have been identified in the literature as being commonly carried out by young carers. The scale showed good internal consistency in this study with a Cronbach alpha of 0.84.

RESULTS

Statistical Analysis

The process of analysis involved exploring the pool of items comprising the proposed Young Carers Perceived Stress Scale (YCPSS) to identify whether these items represent a single dimension or a number of underlying factors. The next stage was to explore the internal consistency of the identified factors in order to produce a reliable set of factors. These factors were then tested in terms of their relationship to perceived levels of support, coping and psychological distress in the young carer group.

Principal Component Analysis and Reliability of the YCPSS Item Pool

An exploratory principal component analysis, using varimax rotation into simple structure, was performed on the initial 50 items. Ten factors were found to have eigenvalues greater than 1 and accounting for 61% of the variance. Of these only seven could be identified between them accounting for 53% of the variance. Two further factors had very poor internal consistency and were removed. Two items did not load on to any factor. There is some agreement with the original categories; however, several items loaded onto different factors suggesting that they were interpreted by the young carers' to have a different meaning from that originally suggested. 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. Two of the 7 factors identified had quite low Cronbach alpha scores (0.65 and 0.54) and were removed, leaving 5 factors for further analysis. The final five factors, the Cronbach alpha for each factor, the individual items for each factor and their factor loadings are shown in Table II. Internal consistency for the total YCPSS is quite high ($\alpha = 0.89$).

Correlations

Values for the correlations of all measures and YCPSS factors are displayed in Table III and described below. The significance value was set at $p < 0.01$.

The overall YCPSS score correlated significantly with perceived psychological distress, burden of care, avoidance coping, and approach style as a coping focus. The direction of the relationship is that the higher the perceived stress, the higher the level of psychological distress and the greater the perceived tendency to use both approach and avoidance coping.

Table II. Factor Loadings and Cronbach's Alphas for the Identified Factors

	Factor loadings
Factor 1: Devaluation of role (Cronbach's alpha)	0.87
It bothers me that people never say they are pleased with my caring	0.73
It bothers me that I don't know where I belong in the family	0.71
It bothers me that I can't have a life of my own	0.69
I feel left out in my family	0.57
Feeling different from other kids is a problem for me	0.53
I worry about what I will do in the future	0.56
It bothers me that caring takes over everything in my life	0.53
It bothers me that other people don't understand what I do to help my family	0.50
Factor 2: Personal value of role (Cronbach's alpha)	0.83
I feel closer to people in my family because of the caring I do	0.84
Caring for my relative helps me feel important in my family	0.78
Having an ill or disabled relative helps me think about the good things in life	0.70
Caring helps me to feel better about my relatives illness or disability	0.70
Caring makes me feel trusted by my family	0.63
My family let me know how pleased they are with the work I do as a carer	0.42
Factor 3: Overload (Cronbach's alpha)	0.83
It bothers me what other kids will say if I take time off school	0.70
I am bothered that I have missed too much school	0.75
I worry that if I wasn't caring I wouldn't know what to do with myself	0.61
It bothers me that the teachers don't understand about my caring	0.58
I feel tired because of the caring I do	0.49
It's hard to get a rest from caring	0.48
It bothers me what teachers will say if I fall behind at school	0.43
I feel there is no break from caring	0.44
Factor 4: Social restrictions (Cronbach's alpha)	0.74
I have plenty of energy for doing other things	−0.75
Caring can get in the way of having a boy or girlfriend	0.65
I find looking after my relative easy	−0.63
Getting teased about being a carer is a problem for me	0.53
It bothers me that I can't take part in clubs or activities after school	0.45
Factor 5: Family Cohesion (Cronbach's alpha)	0.80
It bothers me that my family argues	0.75
My family get on well together	−0.72
I get extra money like treats or privileges because of the caring that I do	−0.46
I feel I know more about how to look after myself than other people my age	0.45

Looking at the individual factors of the YCPSS, Factor 1 (devaluation of role) and Factor 3 (Overload) correlated significantly with psychological distress. The more devalued and overloaded the higher their perceived levels of psychological distress. The only factor correlated with support was Factor 2 (personal value of the role) which was positively related to support from family. All but Factor 4 (social restrictions) were all positively correlated with burden of care. Factors 1 and 3 were correlated positively with avoidance style coping. Factors 2 and 3 were positively correlated with approach style coping. The only factor that correlated at the .01 level with overall coping score was Factor 1. This suggests that it is more effective to measure separate factors of coping.

Table III. Pearson Correlations Between the YCPSS Factors and the Other Variables

	Psychological distress	Support from friends	Support from family	Burden of care	Avoidance coping	Approach coping	Social coping	Overall coping score
Devaluation of role	.48**	.09	−.00	.25**	.35**	.21*	−.09	−.09
Personal value of role	−.12	.15	.39**	.35**	−.02	.52**	.30**	.30**
Overload	.38**	.07	.05	.31**	.30**	.28**	−.07	−.07
Social restrictions	.06	−.05	.09	.16	.24*	.05	.00	.00
Family cohesion	−.00	.08	.15	.26**	.15	.20*	.20*	.20*
Overall YCPSS score	.37**	.12	.18	.42**	.36**	.42**	.04	.04

*$p < .05$; **$p < .01$.

DISCUSSION

We develop a measure of stress in adolescent young carers. From an initial pool of 50 items, five factors were identified. The identified factors were labelled and scores were calculated in order to test their relationship with perceived psychological distress, perceived burden of care, perceived social support and perceived coping. Taking the overall YCPSS scores, it is clear that higher scores correspond with greater perceived psychological distress, a greater perceived tendency to use both avoidance and approach style coping, and a greater overall perceived burden of care. What is interesting here is the tendency to use both approach and avoidance style coping. This does support some previous research which has demonstrated the need to view these as separate dimensions rather than opposite ends of a single dimension (Cassidy & Long, 1996). In this case, it appears that a young carer who is experiencing both high levels of stress and a high burden of care may be trying to tackle the problem while simultaneously avoiding some of the issues. It would appear that their role as the main carer leaves no option but to try and deal with the problem, while at the same time they may wish for a miracle and try to mentally distance themselves from the problem. It would be useful to explore this in future research.

This relationship with perceived avoidance and approach style coping is further explicated in correlations with the separate factors of the YCPSS. Factor 3 has a strong relationship with both avoidance and approach style coping. Individuals who perceive themselves as overloaded seemed to have both approach and avoidance tendencies in regard to coping. It appears that if high scores on Factor 3 are combined with a perception of the role being devalued, the carer is more likely to use an avoidance style. When Factor 3 is combined with higher perceived Factor 2 the carer is more likely to use an approach style. This demonstrates the importance of considering the YCPSS as a multidimensional measure.

The overall YCPSS score correlates significantly in a positive direction with burden of care so that children who perceive their burden as greater report higher levels of perceived stress. In addition, all of the separate dimensions except Factor 4 show significant positive correlations with burden of care. Where the burden is greater one can see how stress from overload, feeling that the role is undervalued, and family conflict would occur. The relationship with the personal value of the role is less obvious and may relate to the tension between valuing the role on one hand whilst feeling that it is a burden on the other.

The initial findings from this study suggest that the relationship between the young carer and the care recipient involves tension between opposing motivations. The child feels an obligation to their charge and even values the role of caring while at the same time experiencing the burden imposed by the role. In addition the child may wish to be helped and supported but is wary of participating in research because the very act of participation may expose them to social service intervention which in turn may do more harm than good. It is interesting that level of burden is not significantly correlated with social restriction in this sample and this is an area that would be interesting to explore further.

Given the sensitivity of the target sample it was not possible to obtain a larger sample for this study and the ratio of participants to items was just over 2:1. This is low, although Kline (1993) argues convincingly that a ratio of 2:1 produces clear factors and that increasing the ratio above this produces no improvement. In addition, it is important to acknowledge that there was an element of self-selection in the sample and that the response rate was around 50%. Information was not available on the 50% who did not participate hence one must be wary of assuming that the sample was totally representative of this group of carers. On the other hand the distribution did correspond to that produced by Dearden and Becker (1998) in their statistical profile of 2,303 young carers suggesting that the potential range of young carers was included. Clearly it is important that further testing of the factor structure, reliability, and validity of the scale is undertaken.

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