Predictors of Distress in Parents of Children With Cancer: A Prospective Study

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Objective: To investigate levels of psychological distress in parents of children with cancer and relationships between distress and measures of illness variables, appraisal, psychosocial resources and coping strategies. **Methods:** Questionnaires were completed by 68 mothers and 58 fathers at 6 (Time 1) and 18 (Time 2) months postdiagnosis. **Results:** High levels of distress for 51% of mothers and around 40% of fathers were apparent at both time points, with little change over time. For mothers, their appraisal of the strain of the illness, and their own ability to deal with it, and family cohesion were predictive of distress, both concurrently and prospectively, and, at Time 1, greater use of self-directed coping strategies was related to higher levels of distress. For fathers, risk factors of employment problems (Time 1) and the number of the child's hospital admissions (Time 2) were significant, along with appraisal and family cohesion. **Conclusions:** Continuation of high levels of distress over time points to the importance of identification of those at risk at an early stage and provision of ongoing support. Implications for such support are discussed.

Key words: *childhood cancer; parent adjustment; risk factors; stress; coping; mothers; fathers.*

The life-threatening nature of childhood cancer and its invasive treatment present both practical and emotional stresses for family members. High levels of parental distress have been found in many studies both at the time of the diagnosis and early stage of treatment (Kupst, 1992) and also persist over one or more years (Sawyer, Antoniou, Toogood, Rice, & Baghurst, 1993). The sources of such distress are varied and a number of potential stressors have been suggested. Kazak et al. (1995) note that parental distress regarding treatment procedures remained high over the course of the lengthy treatment for leukemia. The course and treatment of the illness varies

between different cancers and between different children. It may be expected that more lengthy treatment, more frequent and longer hospitalization, and relapse would all increase the risk of parental distress. The burden of care during the treatment phase can result in detrimental effects on employment and financial difficulties (Lansky et al., 1979; Sloper, 1996a). These effects may add to the strain on families. It has also been demonstrated that families of children with cancer have to deal with a number of other concurrent stressors, some linked to the illness and others independent of it (Kalnins, Churchill, & Terry, 1980). All these sources of stress are likely to act as risk factors, increasing the likelihood of high levels of parental distress during treatment. Even when treatment is completed,

parents have to face the difficulties of living with uncertainty and the possibility of recurrence over the longer term (Koocher & O'Malley, 1981). Recent studies have suggested that some parents and children show symptoms of posttraumatic stress disorder continuing a number of years after cessation of treatment (Kazak & Barakat, 1997; Stuber et al., 1994), but others find little evidence of distress after treatment (e.g., Brown et al., 1992).

However, not all parents of children with cancer show high levels of distress. Considerable variation within and between studies is apparent, and the relationship between potential sources of stress and outcome is by no means clear. The few prospective studies of the relationship between earlier sources of stress and problems continuing after treatment have often been based on small samples and a limited range of measures. Nevertheless, some interesting findings emerge. Kazak and Barakat (1997) found significant associations between parenting stress during treatment and anxiety after treatment was completed in mothers and fathers of children with leukemia. Stuber et al. (1994) found correlations between mothers' posttraumatic stress symptoms at an average of 5 years after cessation of treatment and children's appraisal of treatment intensity, duration of treatment, and mothers' trait anxiety. For fathers, only trait anxiety was a significant variable. It appears that both stresses associated with treatment and influences within the family system are important for longer term adjustment (Dolgin & Phipps, 1996).

Evidence on differences between mothers and fathers is inconclusive. Some studies report mothers to be more at risk of negative outcome than fathers (e.g. Dahlquist, Czyzewski & Jones, 1996; Sawyer et al., 1993), but others find no differences (e.g., Speechley & Noh, 1992). In a number of studies, tests of significance of any apparent differences are not reported (e.g. Kazak & Barakat, 1997; Stuber et al., 1994). Clearly, further investigation is needed to identify variables associated with varying levels of parental distress for both mothers and fathers and to ascertain the roles of risk factors and of potentially modifiable factors associated with resistance to distress for both mothers and fathers (Varni, Katz, Colegrove & Dolgin, 1996; Wallander & Varni, 1998).

In many cases, existing literature on adjustment in parents of pediatric cancer patients lacks a theoretical underpinning driving the investigation. A conceptual model that can encompass the varied factors affecting parents can enhance our understanding of the processes influencing the heterogeneity of response. Investigation of factors related to distress in a number of areas has been informed by Lazarus and Folkman's (1984) model of stress and coping, which emphasizes the role of the individual's appraisal of potential stressors, the availability and utilization of material, social and personal resources, and the coping strategies employed, in influencing the outcomes of stressful events. This model has been shown to have utility with a number of different groups of families dealing with childhood disability or chronic illness (e.g. Sloper & Turner, 1993; Thompson, Gustafson, Hamlett, & Spock, 1992; Wallander et al., 1989). The model has been further developed by Wallander et al. (1989) and Wallander and Varni (1998) in relation to families caring for children with chronic physical disorders. They delineate three categories of risk factors for this population: disease/disability parameters, functional dependence, and psychosocial stressors. Resistance factors are also defined in three categories: intrapersonal factors, such as personality and effectance motivation; socioecological factors, such as family environment and social support; and stress processing factors, such as cognitive appraisal and coping strategies. Although the specific risk factors related to the child's condition may vary, there is some consistency between studies of families of children with different conditions in parental and family variables that have been found to be related to outcome: socioeconomic factors, personality variables, family environment, and social support (Knussen & Sloper, 1992). Findings from studies utilizing this model suggest that the individual's perception of these factors, rather than their objective characteristics, is the most important determinant of outcome (Nolan, Grant, & Keady, 1996).

Specific studies of parents of children with cancer have also shown the importance of elements of this model. Social support and family relationships have shown significant relationships with parental adjustment in a number of studies (e.g., Kupst & Schulman, 1988; Morrow, Carpenter, & Hoagland, 1984; Speechley & Noh, 1992) and, as with more general findings on social support and stress outcome (Wethington & Kessler, 1986), perceived support appears to be a stronger influence than social network characteristics. Fewer studies have included measures of appraisal, but perceptions of illness-related stress have been shown to be related to adjustment problems (Kazak & Barakat, 1997).

The issue of which coping strategies are most likely to promote adaptation is unclear. Dahlquist et al. (1993) suggest that greater sensitizing or stimulus approach coping activity by both partners is related to greater marital distress in the early months after diagnosis, and that, at this time, greater use of avoidance strategies may be adaptive. However, no significant relationships were found 20 months after diagnosis (Dahlquist et al., 1996). In other areas of chronic childhood illness, it has been found that, in the longer term, greater use of palliative, emotion-focused coping strategies is related to poorer maternal adjustment (Thompson, Gil, Burbach, Keith, & Kinney, 1993).

Considerable work is needed to investigate the role of these many factors in parental distress at different stages of the illness and treatment, in order to inform interventions to prevent or reduce distress. In addition, greater clarity in specification of models to be tested is needed (Holmbeck, 1997). Wallander and Varni (1998) suggest that resistance variables moderate the relationship between risk factors and outcome, as well as directly affect outcome. However, the role of these variables as moderators is rarely tested statistically. "Moderation" implies an interactive effect between risk and moderator variables in relation to outcome; that is, outcome will be better for those at high risk with a resistance attribute than for those without it, whereas the attribute will make little difference to outcome for those at low risk. Main effects, on the other hand, imply that those with a resistance attribute do better than those without it, regardless of the level of risk factors.

Two problems affect the investigation of moderator effects in areas such as childhood cancer: first, the statistical problems of testing for interaction effects, especially with small samples (Luthar, 1993) and second, the problems of defining high- and low-risk populations, where delineation of particular risk factors remains unclear and the population as a whole could be deemed high-risk. In this case, the best test of moderator variables may involve comparison with control groups as the low-risk sample. Nevertheless, the main effects model is not necessarily less informative. It can still investigate the question of what distinguishes those who show good adjustment from those who show poor adjustment within a particular sample, and thus provide useful information for clinical practice and intervention.

This study aimed to address this question within a main effects model, investigating maternal and paternal levels of distress in the short and medium term, at 6 and 18 months after the diagnosis of childhood cancer, and the factors predictive, both concurrently and longitudinally, of high or low levels of distress. Selection of variables to measure risk and resistance was informed by the model of stress and coping and findings from existing literature. The analysis addressed three hypotheses:

1. Parents with higher levels of risk factors of longer and more frequent hospitalizations, relapse, negative effects on employment and family finances, and more concurrent life stresses will show higher levels of distress.

2. Higher levels of distress at both 6 (Time 1) and 18 (Time 2) months postdiagnosis will be significantly related to Time 1 measures of appraisal, resources, and coping strategies, concurrently at Time 1 and longitudinally at Time 2. High distress will be related to (a) appraisals of higher levels of strain from the illness and lower levels of self-efficacy in dealing with the illness; (b) lower levels of family and social resources; and (c) greater use of emotion-focused and less use of problem-focused coping strategies.

3. Psychosocial resources will be significant predictors of distress, independently of the effects of risk factors.

Method

Participants

Families were recruited from five hospitals in the north of England specializing in the treatment of childhood cancer. Families of children who had been diagnosed in the preceding 6 months were identified as eligible for the study ($n = 133$). As part of the study was concerned with sibling responses (reported elsewhere: Sloper & While, 1996), all families contained a sibling between 8 and 16 years of age. Ninety-nine families (75%) agreed to take part at Time 1. At Time 2, 70 of the 80 families of surviving children (87%) took part. There were no significant differences between participants and nonparticipants at Time 2 on any Time 1 demographic, illness, or parent measures.

Mean age of the children at Time 1 was 9.3 years, range 9 months to 18 years; there were 46 boys (66%) and 24 girls (34%). There were 12 single-

parent families, 2 headed by fathers. Social class background was classified by occupation of the head of household (OPCS, 1991): 33 families (47%) were from nonmanual backgrounds and 35 (50%) from manual backgrounds, with 4 (3%) being unclassified. All mothers (68) and 58 fathers returned questionnaires; 2 fathers in two parent families failed to return questionnaires. Missing data on different measures reduced the numbers available for analyses to between 63 and 67 for mothers and 48 and 56 for fathers.

Procedure

The study was approved by local research ethics committees at the five hospitals concerned. Eligible families were contacted by letter to explain the study and invite them to participate. Written consent was obtained. Researchers then contacted families to answer any further questions about the study and arrange an appointment for an interview. Semistructured interviews focused on parents' reactions to the illness, effects on the family, and views of services. The majority of interviews were carried out in families' own homes. Parents were sent questionnaires by mail, which the majority completed before the interviews. With parents' consent, details of the child's diagnosis, hospital admissions, and prognosis were obtained from consultants and hospital records.

Measures

The measures utilized were mainly established scales of demonstrated reliability and validity contained in the questionnaires completed by mothers and fathers.

Parental psychological distress was measured at Time 1 and Time 2 on the Malaise Inventory (Rutter, Tizard, & Whitmore, 1970). This is a 24-item scale with a yes-no response format, adapted from the Cornell Medical Index and designed to access psychosomatic symptoms associated with emotional disorder. This general scale of psychological distress was chosen rather than a more specific measure of anxiety or depression for two reasons: first, it has been widely used in the United Kingdom (UK), both in national cohort studies (e.g., Power & Manor, 1992; Rodgers, Power, & Hope, 1997), and in studies of parents caring for children with chronic illness or disability (e.g., Quine & Pahl, 1991; Sloper & Turner, 1993); second, it has been

suggested that comorbidity of anxiety and depression makes broader measures appropriate in nonclinical samples (Feldman, 1993; Lindelow, Hardy, & Rodgers, 1997). Internal consistencies between .77 and .80 (Rodgers et al., 1997) and test-retest reliabilities between .91 and .94 (Quine & Pahl, 1985; Rutter et al., 1970) have been reported for the Malaise Inventory. It has been shown to discriminate between those with and without psychiatric disorder, rated on the basis of clinical judgment (Rutter et al., 1970), and between those who have or have not sought help for mental health problems (Rodgers et al., 1997). On the basis of such comparisons, a cutoff point of 6 or more is held to indicate high levels of emotional distress.

Demographic variables were social class and family composition (single- vs. two-parent family).

Potential stressors included information concerning *illness variables* obtained from the children's hospital records at both time points and comprising: diagnosis (leukemia and lymphoma; solid tumors; CNS tumors); number of hospital admissions; number of nights in hospital; prognosis at Time 1 (rated by doctors as good: survival chances $> 50\%$, and poor: survival chances $\leq 50\%$); relapse between Time 1 and Time 2; and whether the child was still under treatment at the time of the interview (see Table I). In order to investigate the effects of other potential stressors on parental distress, *recent life events* were measured at both time points on a 42-item checklist covering the occurrence of major life events over the last 12 months (Cheang & Cooper, 1984). The instrument also assesses the individual's perception of the strain of each event experienced on a 10-point Likert-type scale. Two scores are obtained: total number of life events and life events strain. A high level of agreement between mothers and fathers on the occurrence of events related to the family has been found in earlier studies, indicating a satisfactory level of interrater reliability (Sloper, Cunningham, Knussen, & Turner, 1988). In addition, *financial and employment problems* caused by the illness were investigated in Time 1 and Time 2 interviews with parents. Financial problems were rated as absent or present if such problems were reported by either parent, and employment problems were rated separately for each parent.

Psychosocial resources consisted of measures of family relationships, social support and locus of control completed by mothers and fathers at Time 1. *Family relationships* were assessed using the Cohesion and Expression subscales of the Family Envi-

Table I. Illness-Related Characteristics of Children ($n = 70$)

Variable	n (%)	M (SD)	Range
Diagnosis			
Leukemia/lymphomas	35 (50)		
Solid tumors	19 (27)		
Central nervous system			
tumors	16 (23)		
Treatment completed			
Time 1	29 (42)		
Time 2	42 (60)		
Relapsed			
Time 1	0 (0)		
Time 2	13 (9)		
Prognosis–survival chances at			
diagnosis			
< 50%	21 (30)		
> 50%	49 (70)		
Total number of hospital			
admissions			
Time 1		7.90 (5.71)	1–29
Time 2		9.39 (6.23)	1–29
Total number of nights in			
hospital			
Time 1		40.39 (23.81)	2–95
Time 2		47.25 (27.51)	3–125

ronment Scale (Moos & Moos, 1981). These nine-item scales assess individual family members' perceptions of their family environment, with a true-false response format, and have been widely used in studies of family functioning. Moos and Moos report internal reliabilities of .78 and .69, respectively, with test-retest reliabilities of .86 and .73 respectively over a 2-month period. In this study, alphas were .79 (mothers) and .66 (fathers) for cohesion, and .73 (mothers) and .61 (fathers) for expression. Mothers' and fathers' responses were significantly correlated: $r (49) = .64$, $p < .001$ for cohesion; $r (50) = .51$, $p < .001$ for expression.

Parental social support was measured for mothers and fathers using the Support Network Satisfaction Scale from the Social Support Resources Measure (Vaux & Harrison, 1985), as research has shown that satisfaction with social support is the aspect most strongly related to adjustment (Schwartzer & Leppin, 1991). The scale assesses satisfaction with five modes of support: emotional, socializing, practical, financial, and advice/guidance, on a 4-point Likert-type scale. The total score for satisfaction was selected for inclusion in analyses. Vaux and Harrison report internal reliability of .88. Alpha coefficients for this study were .81 for mothers and .70

for fathers. A high score indicates greater dissatisfaction.

Parental locus of control was measured using the Brief Locus of Control Scale (Lumpkin, 1985). This is a six-item measure, consisting of three items reflecting internality and three reflecting externality, scored on a 5-point Likert-type scale, with a high score representing greater internality. Lumpkin reported a coefficient of internal consistency of .68.

Stress processing variables, assessed at Time 1, consisted of measures of appraisal and coping strategies. *Parental appraisal* was measured using a scale developed by Thompson et al. (1992) to assess illness stress and efficacy in relation to four illness-related areas: dealing with the child's medical problems and symptoms; maintaining the child's emotional well-being; maintaining the parent's own emotional well-being; and preparing for an uncertain future. A further item, maintaining the emotional well-being of siblings, was added for this study. Parents rated the stress they experienced in relation to each area on a scale from 1 (not stressful) to 10 (very stressful), and their feelings about their ability to handle each task (efficacy) on a scale from 1 (very uncertain that they can handle it) to 10 (completely certain that they can handle it). Thompson et al. report internal reliability of .76 for each scale. In this study reliability was .84 (mothers) and .90 (fathers) for the stress scale and .84 (mothers) and .82 (fathers) for the efficacy scale. Addition of the item focusing on maintaining siblings' well-being in this study did not reduce the reliability of the scale: values without this item were .77 (mothers) and .86 (fathers) for stress and .82 (mothers) and .76 (fathers) for efficacy. Total scores were computed for stress and efficacy, and the difference (stress-efficacy) was used to give a measure of appraisal.

Parental coping strategies were measured at Time 1 using the Ways of Coping (Revised) Questionnaire (Folkman & Lazarus, 1985). This consists of 66 items representing thoughts and actions that can be used to deal with stressful situations. The respondent rates each item on a 4-point scale, from "not used" to "used a great deal." Adequate reliability and validity have been demonstrated for the use of the scale with parents of disabled children (Knussen, Sloper, Cunningham, & Turner, 1992). Parents in this study were asked to relate the items to "dealing with day-to-day problems and stresses caused by your child's illness." Other amendments to the scale followed those instituted by Knussen et al. (1992) in relation to parents dealing with problems related

to childhood disability. The scale used included 64 items. A number of studies have reported sets of subscales drawn from factor analyses of the Ways of Coping Questionnaire (Folkman & Lazarus, 1985; Knussen et al., 1992; Vitaliano, Russo, Carr, Maiuro, & Becker, 1985), and there are similarities between these sets. However, the solutions appear to be partly dependent on sample and context, and none of these studies relates to parents dealing with life-threatening illness in a child. Scales derived from factor analysis of the present data were therefore preferred for this study. Responses for mothers and fathers were pooled to maximize the number of respondents and subjected to principal components factor analysis, in line with methods described by Folkman, Lazarus, Dunkel-Schetter, DeLongis, and Gruen (1986). Five factors based on 50 items were obtained, accounting for 38.2% of the variance. All had eigenvalues of 2 or more. The factors were labeled "Problem solving" ($\alpha = .88$, 16 items, e.g., "I make a plan of action and follow it"); "Self-directed" ($\alpha = .76$, 9 items, e.g., "I criticize or lecture myself"); "Support seeking" ($\alpha = .78$, 8 items, e.g., "I ask relatives or friends I respect for advice"); "Wishful thinking" ($\alpha = .75$, 6 items, e.g., "I hope a miracle will happen"); "Distancing" ($\alpha = .71$, 11 items, e.g., "I don't let it get to me too much"). These factors correspond most closely with those of Vitaliano et al. (1985). Proportional coping scores for each factor were calculated by obtaining the mean score for the factor and dividing by the sum of the mean scores for all factors, and used in the analyses to take into account individual differences in relative use of ways of coping, as recommended by Vitaliano, Maiuro, Russo, and Becker (1987).

In addition to these measures, the short 10-item version of the Marlowe-Crowne Social Desirability Scale (Strahan & Gerbasi, 1972) was used to measure *social desirability response bias*. Analysis of relationships between self-report measures from a single source can be affected by such response bias, increasing the strength of relationships between measures. In order to minimize this effect, social desirability scores were used as control variables in all multivariable analyses.

Interview data were analyzed using qualitative methods to identify themes and categories that reflected the perceptions of parents (Miles & Huberman, 1984). The results of this analysis are reported elsewhere (Sloper, 1996b), but, where appropriate, themes from interview material appear in the discussion to illuminate results of the quantitative analyses reported here.

Analysis

Separate analyses were carried out for mothers and fathers. In line with the importance placed on the individual's perception of appraisal and resources in the stress and coping model, mothers' measures of these variables were used in analysis of maternal outcome and fathers' measures in analysis of paternal outcome. The first step in each analysis was to investigate the bivariate relationships between outcome (Time 1 and Time 2 Malaise Inventory scores) and descriptor variables.

The distributions of Malaise Inventory scores for mothers and fathers at both time points were tested for normality (Kolmogorov-Smirnov test), and none was significantly different from normal. Therefore, one-way analysis of variance (ANOVA) was used for categorical descriptor variables and regression plots for continuous variables. Concurrent relationships between distress and potential stressors (illness events, life events, financial and employment problems) were investigated at Time 1 and Time 2, in order to take into account changes in these variables, such as the child coming off treatment or relapsing. Measures of appraisal, resources, and coping strategies at Time 1 were investigated as potential predictors of both Time 1 and Time 2 distress. The analyses included only those parents who were in the study at both times. For each outcome measure, a set of descriptor variables was identified for inclusion in multivariable analyses. In order to address problems in multivariable analysis of multicollinearity of the independent variables, correlations between descriptors were computed to identify whether any variables were confounded ($r > .59$). No variables significantly related to outcome were confounded. The linearity of all relationships was also examined to determine whether variables could be entered in multiple regression analyses. This indicated that all significant variables from bivariate analyses were suitable for entry into multiple regression. Dummy variables were created for categorical variables.

Variables related to the outcome at the 5% level in bivariate analyses were selected for inclusion in multivariate analyses. To control for Type 1 error, the Bonferroni method was used to determine per test significance for each family of variables. To reduce the number of variables entered in multiple regression and to take into account covariance between variables within the categories of stressors, resources, and coping strategies, a stage process of analysis was adopted (Cohen & Cohen, 1983). The

first analysis included potential stressors; the second included resource variables; and the third included coping strategies. Appraisal was treated as a separate category. For each analysis the significance of *t* for each predictor variable was examined, and only variables significant at the 5% level were selected for inclusion in the final stage of analysis. For these exploratory stages of the analysis, stepwise regression was used. Finally, to determine the most powerful combination of variables predicting Malaise Inventory scores and the independent effects of psychosocial variables, the significant variables from each analysis were entered into a hierarchical regression analysis, controlling for any significant stressors and demographic variables before stepwise entry of psychosocial resources, appraisal, and coping strategies. In each set of analyses, scores on the Marlowe-Crowne Social Desirability Scale were entered as a control variable.

Results

Scores on Malaise Inventory

The distributions of Malaise scores indicated a high level of stability in levels of distress over time. The mean score for mothers was 6.73 (SD = 4.75, range = 0–21) at Time 1 and 6.60 (SD = 4.83, range = 0–20) at Time 2; for fathers the mean score was 5.09 (SD = 3.98, range = 0–15) at Time 1 and 5.29 (SD = 4.50, range = 0–18) at Time 2. Time 1 and Time 2 scores correlated at r (67) = .83, p < .001, for mothers and r (56) =.70, p < .001, for fathers. Fathers' means were lower than mothers' at both times; the difference between scores for spouses was significant at Time 1, t (55) = 2.14, p < .05, but not at Time 2, t (55) = 1.42, ns. Fifty-one percent of mothers and 39% of fathers scored above the cutoff point at Time 1, with similar proportions at Time 2: 51% of mothers and 41% of fathers.

Bivariate Analysis

The next step in the analysis investigated the predictors of Time 1 and Time 2 scores. For this purpose Malaise Inventory scores were treated as continuous variables: the cutoff point is advisory only and categorizing the data in this way may lose valuable information with regard to variance in scores.

Potential Stressors and Demographic Variables. Current employment problems were significantly re-

lated to fathers' Malaise scores at Time 1: $F(2,54)$ = 10.37, p < .01. Significant differences were found between scores for those who did not experience problems (M = 3.32, SD = 3.30, n = 31) and both those who were unemployed at the time of diagnosis (M = 8.54, SD = 4.43, n = 11) and those who were employed but experienced problems as a result of the illness (M = 6.20, SD = 2.91, n = 15). For the purposes of entry into multivariable analysis, the latter two groups were combined. Illness variables showed no significant relationships with mothers' Malaise scores, but number of hospital admissions was significantly related to fathers' scores at Time 2: r (54) = .41, p < .05. Strain scores for life events in the preceding year were significantly related to fathers' Malaise scores at Time 2 only: r (49) = .40, p < .05. Demographic variables showed no significant relationships with mothers' or fathers' scores at either time.

Psychosocial Variables: Appraisal, Resources, and Coping Strategies. Table II presents the results of analyses of relationships between psychosocial variables, measured at Time 1, and Malaise scores at both times. Significant relationships with appraisal scores were found for mothers and fathers at both time points. For mothers, resources of social support satisfaction, family cohesion and expression, and locus of control were also significant at both time points. For fathers, there were no significant relationships between Time 1 outcome and resource variables. At Time 2, social support satisfaction and family cohesion were significant. Use of coping strategies of problem solving and self-directed coping showed significant relationships with maternal distress at both times. For fathers, self-directed coping was significantly related to distress at Time 2 only.

Multiple Regression Analysis

Mothers. Intermediate stages of the analysis reduced the number of variables for entry into the final regression. The significant variables for regression on Time 1 Malaise scores were appraisal scores, family cohesion, social support satisfaction, locus of control, and self-directed coping. For Time 2 Malaise scores, the significant variables were appraisal scores, family cohesion, and self-directed coping. The final analyses produced similar models at Time 1 and Time 2 (see Table III). At both times, higher levels of distress were associated with lower levels of family cohesion and appraisal of high strain and low efficacy in relation to ability to handle the ill-

Table II. Correlations Between Time 1 Psychosocial Variables and Mothers' and Fathers' Malaise Scores at Time 1 and Time 2

Variable	Mothers T1 r (n)	Mothers T2 r (n)	Fathers T1 r (n)	Fathers T2 r (n)
Appraisal				
Appraisal score	.47 (67)***	.42 (67)***	.39 (54)**	.34 (52)*
Psychosocial resources				
Social support	.52 (65)***	.40 (65)**	.29 (52)	.41 (50)*
Family cohesion	−.56 (66)***	−.52 (66)***	−.32 (53)	−.50 (51)***
Family expression	−.44 (67)***	−.41 (67)**	−.15 (53)	−.19 (52)
Locus of contrast	−.41 (67)***	−.31 (67) *	−.18 (56)	−.11 (54)
Coping strategies				
Problem solving	−.40 (63)**	−.36 (63)*	−.13 (49)	−.13 (48)
Self-directed	.58 (63)***	.48 (63)***	.32 (50)	.38 (49)*
Support seeking	−.25 (63)	−.29 (63)	−.25 (49)	−.15 (48)
Wishful thinking	.25 (63)	.26 (63)	.16 (50)	.16 (49)
Distancing	−.08 (63)	.00 (63)	.02 (49)	−.14 (48)

*$p < .05$.
** $p < .01$.
*** $p < .001$, with family-wise Bonferroni correction.

ness. At Time 1, high use of self-directed coping was associated with higher levels of distress.

Fathers. Only two variables showed significant bivariate relationships with Time 1 Malaise scores: appraisal scores and employment problems. Both were entered into multiple regression. Intermediate stages of analysis on Time 2 Malaise scores indicated the following variables for entry into the final analysis: number of hospital admissions, life events strain in the past year, family cohesion, appraisal, and self-directed coping. Table III gives the results of the final multiple regressions for Time 1 and Time 2 scores.

In contrast to the analysis for mothers, fathers' results showed that both risk variables and psychosocial variables were significantly related to outcome. At Time 1, unemployment or negative effects of the illness on fathers' employment and appraisal of high strain and low efficacy in dealing with the effects of the illness continued to show significant relationships with Malaise scores when controlled for each other. At Time 2, risk factors of hospital admissions and life events strain were entered first, before stepwise entry of psychosocial variables. Family cohesion was the significant psychosocial variable to enter the equation. Appraisal and self-directed coping lost significance when controlled for risk factors. Life events strain scores lost significance after the entry of cohesion scores, leaving number of hospital admissions and family cohesion as the significant variables.

Discussion

The findings of high levels of distress, both in the short and medium term, for a substantial number of parents (half the sample of mothers and 4 out of 10 fathers) are consistent with some recent studies of parents of children with cancer (Hoekstra-Weebers, Heuvel, Klip, Bosveld, & Kamps, 1996; Sawyer et al., 1993). The mean Malaise scores found in this study are also comparable with those found in UK studies of parents of severely disabled children (e.g., Quine & Pahl, 1991: mothers M = 6.0; Sloper & Turner, 1993: mothers $M = 7.4$, fathers $M = 4.8$). In contrast, findings on representative populations samples have shown lower scores. For example, Richman, Stevenson, and Graham (1982) found that 20% of mothers of nondisabled preschool children scored above the cutoff point and, in the National Cohort Study, Rodgers et al. (1997) found mean scores of between 1.85 and 2.89 for men and 2.61 and 3.45 for women at age 33 (with the higher means for those who experienced parental divorce before age 16).

The distribution of Malaise scores indicated that high levels of distress were by no means inevitable for these parents of children with cancer. The analysis aimed to investigate what factors distinguished those with high distress from those without. The high correlations and similar means between Time 1 and Time 2 Malaise scores indicate consistency over time, despite changes in the children's treatment and illness status. Parents whose children had

Table III. Hierarchical Regression Analysis for Variables Related to Mothers' and Fathers' Malaise Scores at Time 1 and Time 2

Variables	B	SE B	β
Mothers, T1[a]			
Step 1			
Social desirability	−.63	.30	−.26*
Step 2			
Social desirability	.23	.26	.10
Appraisal	.08	.03	.25*
Family cohesion	−1.01	.25	−.41***
Self-directed coping	24.76	9.03	.33**
Mothers, T2[b]			
Step 1			
Social desirability	−.75	.30	−.30*
Step 2			
Social desirability	−.20	.28	−.08
Appraisal	.10	.04	.31**
Family cohesion	−1.01	.28	−.47***
Fathers, T1[c]			
Step 1			
Social desirability	−.23	.27	−.11
Employment problems	4.05	.99	.51***
Step 2			
Social desirability	−.17	.25	−.08
Employment problems	3.45	.99	.43**
Appraisal	.07	.03	.27*
Fathers, T2[d]			
Step 1			
Social desirability	.33	.33	.14
Life events strain	.07	.03	.35*
Hospital admissions	.26	.10	.36*
Step 2			
Social desirability	.33	.30	.13
Life events strain	.04	.03	.20
Hospital admissions	.24	.09	.33*
Family cohesion	−1.07	.38	−.38**

[a]R^2 = .07 for step 1; R^2 = .45 for step 2.
[b]R^2 = .09 for step 1; R^2 = .29 for step 2.
[c]R^2 = .25 for step 1; R^2 = .07 for step 2.
[d]R'' =.29 for step 1; R'' =.12 for step 2.
*$p < .05$.
**$p < .01$.
***$p < .001$

completed treatment were not significantly less distressed than those whose children were still receiving treatment or those whose children had relapsed. On the face of it, this result is surprising. However, Dahlquist et al. (1996) also found that parents of children still in treatment did not differ from parents of children who were off treatment at 20 months postdiagnosis. As Eiser (1998) notes, the fear of recurrence can remain high, and this fear was apparent in our interviews with parents 18 months after diagnosis. Parents' accounts in these interviews also showed that the transition from the active phase of treatment and attempts to return to normal routines were often problematic; parents felt that they had received little preparation for the problems encountered and little support in the posttreatment phase. Some parents described feeling that they had had to cope during the active phase of treatment and their own feelings had been set aside. Once they returned home after this phase, these feelings may erupt. These descriptions, and the levels of distress found, support recent suggestions (Kazak & Barakat, 1997; Stuber et al., 1994) of posttraumatic stress disorder in some parents of children with cancer after the end of treatment. Further investigation of this issue on a longitudinal basis would be helpful to our understanding of parental reactions.

For mothers, the results show that hypotheses regarding the effects of illness events and risk factors related to life events, employment, and financial problems were not supported: none of these variables was significantly related to Malaise scores. The hypotheses regarding the effects of psychosocial variables and appraisal, derived from the model of stress and coping, were supported. In multivariate analyses, Time 1 measures of these variables were related to levels of distress at both time points. Thus, specific aspects of the illness situation did not strongly affect mothers' distress; rather, their ability to deal with the illness without deleterious effects on mental health was affected by psychosocial resources and stress processing.

Family cohesion was an important resource for mothers and fathers. High levels of family cohesion have been found to relate to adjustment of parents and children in other studies (e.g., Horowitz & Kazak, 1990; Mastroyannopoulou, Stallard, Lewis, & Lenton, 1997) and interviews with parents in this study suggest that families with strong relationships were more likely to become closer as a result of the illness, in contrast to those who felt that the illness had caused problems in relationships. Dolgin and Phipps (1996) suggest that the construct of family cohesion is related to the idea of centripetal and centrifugal forces, which operate around events in the normal family life cycle to draw families together or pull them apart. Serious illness is generally seen as producing centripetal forces (Rolland, 1987), but if this occurs in families who are already undergoing centrifugal forces, greater family disengagement may result. In this context, it is significant that Time 1 measures of family cohesion predicted distress at Time 2.

Mothers' appraisals of the strain of illness-related demands and their confidence in their own ability to deal with these were related to distress, both concurrently at Time 1 and predictively for Time 2. Both this and the strong relationship between distress scores at the two time points indicates that problems are likely to continue, regardless of changes in the illness situation, for those mothers who find most difficulty in dealing with the situation in the early stage. Early identification of and intervention to support such parents are indicated. At Time 1, more use of self-directed coping, which encompasses self-blame, was related to higher levels of maternal distress. This suggests that investigation of parental perceptions in the early stages could be useful in helping parents to gain a greater understanding of their situation and avoid self-blame.

Results for fathers were similar to those for mothers in showing that appraisal and family cohesion were predictors of distress. Some studies have suggested that fathers are less affected than mothers by serious childhood illness (Sawyer et al., 1993). However, it is not clear whether the difference between mothers and fathers in this study at Time 1 indicated different reactions to the illness or was related to general population differences between men and women. Nevertheless, there were different predictors of fathers' distress scores, with stronger effects of risk factors, both those related to and outside the immediate illness situation. At Time 1, the significant risk factor was fathers' employment situation, with unemployed fathers and those experiencing employment problems due to the illness being at greater risk. Unemployment and job insecurity have been shown to be risk factors for psychological health (Fryer, 1995), and the results may reflect a number of factors: already raised levels of distress before the illness, greater vulnerability for unemployed fathers, and the impact of employment problems caused by the illness on current levels of distress. For unemployed fathers and those experiencing problems at work, the role of work in providing a focus and distraction outside the family and the illness may not have been available.

At Time 2, the significant risk factor for fathers was the total number of hospital admissions experienced by the child in the 18 months since diagnosis. In the majority of families, mothers stayed in the hospital with their children, and frequent hospital admissions were disruptive of family life. In the longer term, this may have a cumulative effect on fathers' well-being. Interviews with mothers indicated that they often obtained support from other parents and staff while staying at the hospital. This may have helped to reduce the effects of such disruption on mothers' well-being. However, such support was not generally available outside the hospital; thus, fathers may lack the means to obtain support, a situation compounded by the frequent absence of their wives.

The results of the multivariable analysis suggested that for fathers, unlike for mothers, the effects of higher levels of stressors combined with lower levels of family support were additive. This points to the importance of service providers' awareness of the ways in which both parents are affected by the illness and other events in their lives and recognition that responses of different family members will vary.

Finally, the amount of variance explained in the multivariate analyses was only moderate, and it is apparent that other factors not measured in this study influence parental adjustment. Other personal resources, reflected in measures of aspects of personality and beliefs, are also likely important (Sloper & Turner, 1993). Equally, more sensitive measures of illness and treatment variables than those obtained in this study may show significant effects.

The continuation of high levels of distress over time for a number of parents points to the importance of interventions to identify those at risk in the early treatment stages and of the provision of ongoing support. Such support could usefully focus on the important resources that can help parents withstand the stresses of the illness: family relationships and appraisal, that is, their feelings about the demands of the illness and their confidence in their ability to deal with these demands. It was clear from our interviews that fathers in particular found it difficult to access support at all stages, and both parents felt that they received little support once treatment was completed. Making the transition from the active phase of treatment to the off-treatment phase is identified as a problem by Ostroff and Steinglass (1996), who suggest that parents need support and guidance to help them to return to normal routines.

In general, the results of this study are similar to those found for many different groups of individuals dealing with stressful life events (e.g., Holahan & Moos, 1987), and there are few indications of stressors specific to childhood cancer. However, both the

generalizability of these findings and the ability of the analysis to detect differences in relation to predictor variables are limited by the small sample. While the study recruited from a number of different centers and the response rate was relatively good, the low incidence of childhood cancer makes accrual of large samples difficult. The small sample size, and the lack of a control group to form a low-risk sample, precluded the investigation of moderator effects, and thus the testing of models such as those of Wallander and Varni (1998). The analysis of main effects shows that variables such as family cohesion or employment problems are associated with more distress, and this can alert clinicians to be aware that the presence of such factors indicates the need for early intervention to support families. However, this analysis cannot tell us whether these factors pose risks for all families or only for parents facing the stress of childhood illness. Whereas comparison with research on other samples suggests that these are general risk factors, research that investigates moderator effects could usefully indicate to what extent such risk is increased under the stress of childhood illness.

Although theoretical models emphasize the importance of the individual's perceptions in the stress and coping process, there are problems in interpretation of analyses of variables obtained from a single self-report source. Efforts were made to minimize such problems statistically by controlling for social desirability response bias and investigation of multicollinearity of descriptor variables before multivariable analysis. However, studies that obtain data from multiple sources, including staff who are closely involved with families, could help to increase our understanding. In addition, the study investigated only one dimension of emotional distress: that reflected in psychosomatic symptoms. This may underestimate the incidence of distress that manifests itself in other ways, such as anxiety, helplessness, or difficulties in social functioning. Studies using a wider range of measures could provide a clearer picture of the extent of distress. Further longitudinal research focusing on multicenter samples, and using a range of measures and informants, is needed. Such research also needs to extend the period of follow-up and to investigate the effects of targeted family-focused interventions to reduce distress.

Acknowledgments

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