Psychological Distress and the Impact of Social Support on Fathers and Mothers of Pediatric Cancer Patients: Long-Term Prospective Results

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Objective To explore the effects of social support on psychological distress of parents of pediatric cancer patients using a prospective design over a 5-year period. Methods Parents of children diagnosed with cancer participated at diagnosis (T1), 6 months (T2), 12 months (T3), and 5 years later (T4). Instruments The General Health Questionnaire and the Social Support List (SSL) measuring amount of support, (dis)satisfaction with support, and negative interactions were administered. Results Psychological distress and amount of support received decreased significantly from diagnosis to T4. No significant change in (dis)satisfaction with support and negative interactions was found. Social support variables did not show any concurrent or prospective significant effect on mothers' distress at T4. Dissatisfaction with support showed a significant unique concurrent effect on fathers' distress at T4 and negative interactions had a prospective unique effect. Conclusions Dissatisfaction with support and negative interactions that fathers experienced significantly affected their levels of psychological distress. No such effect was found for mothers.

Key words parents stress; pediatric cancer; prospective longitudinal study; social support.

One of the focal points in studies on the psychological functioning of parents of pediatric cancer patients has been the role of social support in dealing with the experience of pediatric cancer diagnosis and treatment. Social support has been investigated in several ways ranging from focusing on the utilization of one’s social support network, that is, the number of contacts with persons in the network, to evaluating the quality of the social support one receives. An important aspect of defining social support is the need for assessment of perceived social support as an essential part of understanding the role social support plays in aiding parents to deal with the daily hassles that cancer diagnosis and treatment brings (Brown, Madan-Swain, & Lambert, 2003; Dockerty, Williams, McGee, & Skegg, 2000; Sloper, 2000; Speechley & Noh, 1992). Studies have shown that lack of perceived social support is associated with increased risk for development of posttraumatic stress symptoms (Best, Strehland, Catania, & Kazak, 2001; Kazak, Meeske, et al., 1997; Kazak, Stuber et al., 1998; Manne, Duhamel, & Redd, 2000). In addition, studies have shown that parents who have been able to adjust well to their child’s cancer have received better family or overall support (Hoekstra-Weebers, Jaspers, Kamps, & Klip, 2001; Kupst & Schulman, 1988; Kupst et al., 1995; Smith, Redd, Peyser, & Vogel, 1999). In contrast, at least one study has shown no effects for social support on PTSD symptoms (Pelcovitz et al., 1996).
The few studies that have included data for fathers have shown differences between mothers and fathers. One study found that the total support network provided a significant independent contribution to post-traumatic stress symptoms only for mothers of children who survived pediatric cancer (Barakat et al., 1997). For fathers, no significant contribution was found. In contrast, one study using the same instrument, found a unique significant contribution of social support to scores for anxiety and avoidance in fathers and not in mothers (Best et al., 2001). A larger affective response, defined in terms of anxiety and depression, was also found in fathers who made less use of perceived social support (Frank, Brown, Blount, & Bunke, 2001). In contrast, no significant association between affective response and perceived social support was found for mothers. In a prospective longitudinal study on prediction of distress in parents of children with cancer, a significant correlation was found between perceived social support and psychological distress for mothers but not for fathers (Sloper, 2000). Another prospective longitudinal study found that mothers continued to receive more social support than fathers over time. However, quantity of support had no effect on the distress of either fathers or mothers. Dissatisfaction with social support also predicted fathers’ psychological distress to a significant degree, whereas this was not found for mothers (Hoekstra-Weebers et al., 2001).

The results of the above referenced studies indicate differences existing between mothers and fathers on the effect of perception of social support on psychological functioning. Therefore, more information is needed to determine the specific effects of social support on fathers’ and mothers’ psychological distress. Also, because most studies have a cross-sectional design, more information is needed to provide insight into the role of social support during the process of dealing with pediatric cancer over time.

Therefore, the main focus in the present 5-year follow-up study is on the following questions:

1. Do parents report decline in quantity of support or changes in satisfaction with the support they receive 5 years after diagnosis (quality of support) as compared to during the first year after diagnosis, and do fathers and mothers continue to express this differently?
2. Do initial distress and social support have predictive value in relation to the amount of psychological distress parents report 5 years after diagnosis, and does change in social support over 5 years relate to change in reported distress?

**Method**

**Procedure**

During a period of 27 months, the parents of all newly diagnosed children with cancer in the University Medical Center Groningen, Beatrix Children’s Hospital, Division of Pediatric Oncology were invited to participate in this study. The parents of children with a life expectancy shorter than 6 months and the parents who spoke insufficient Dutch were not asked to participate. The pediatric oncologist first informed parents about the study and provided written information. They were subsequently asked to participate by the researcher. Informed consent as required by the medical ethics committee of the hospital was obtained. Participants completed questionnaires within 14 days from the time of diagnosis (T1), at 6 months (T2) and 12 months (T3). The original group of parents were again asked to complete questionnaires 5 years after diagnosis (T4). Fathers and mothers were instructed to complete questionnaires separately at all time points. T1 assessment took place in the hospital. All other questionnaires were completed at home. Results from the first year following diagnosis (T1, in comparison with T2 and T3) have been previously reported (Hoekstra-Weebers et al., 2001). This study reports on participants at T4 after 5 years have passed but also includes comparisons with data collected at T1–T3.

**Participants**

Of the 192 eligible parents at diagnosis (T1), 164 agreed to participate at that time (79 fathers and 85 mothers, total initial response rate 85.2%). At time of diagnosis (T1), six of these parents were single (one widow and five divorced), the rest were couples (158 parents). At T2 (6 months after diagnosis) and T3 (12 months after diagnosis), the parents of the children who had died during the course of the preceding months (n = 19) were not asked to participate (depending on when the child died). Five years after diagnosis, all parents who had participated at T1, including the parents of the children who had died during the course of treatment, were asked to participate in the final measurement (T4). Of the original 164 participants at T1 (diagnosis), six parents could not be traced, and three were deceased leaving 155 parents for potential participation at T4. Of these, 119 were parents of surviving children and 36 were parents who had children who died as a consequence of their cancer. Twenty-one of the 36 parents of deceased children participated at T4 (response rate of 58%), whereas 15 parents either refused to participate because they expected participation to cause too much emotional strain or they did not react at all.
Ninety-four of the 119 parents of surviving children participated (response rate of 79%). Twenty-five of the 119 parents of surviving children declined to participate at T4 either because they sought closure, they found the confrontation to be too emotional or their child had a recent relapse of the illness. Eight of the participating parents had a child who was experiencing a relapse of the cancer.

In total, 115 of the original 164 parents participated at the 5-year follow-up (response rate of 74% of the potential 155 respondents). Ninety-six of these 115 parents participated at all four measurement times.

Comparison of the participants with nonparticipants on demographic variables at the 5-year follow-up (T4) showed a significantly higher participation level from surviving children's parents than from deceased children's parents at T4 ($\chi^2 = 6.16, p < .05$). Also, more parents of older children who participated at T1 declined to participate at T4 ($t$ test $= -2.50, p < .05$). The mean age of T4 nonparticipant's children at diagnosis was 6.3 (SD = 4.6), for participant's children this was 5.7 (SD = 4.6) years. The mean level of education in the group of participating parents was higher than the level of the parents who did not participate at T4 ($t$ test 2.47, $p < .05$). No significant differences were found between the group of participants and the nonparticipants at T4 on gender of either parents or children; age of the parents; or marital status. Both the medical diagnosis and prognosis of the children at T1 had no significant effect on the decision to participate in the study at the 5-year follow-up (T4).

Fifty-seven (49.6%) fathers and 58 (50.4%) mothers participated at the 5-year follow-up. Almost all of the parents were married [109 (94.8%)], one was widowed, and five were divorced. No significant differences between the scores of the dyads and the single parents on the measurement variables were found at T4 [Mann–Whitney $U$, $z = −.955$, $p = .340$; Supportive interactions: Mann–Whitney $U$, $z = −.234$, $p = .815$; dissatisfaction with support: Mann–Whitney $U$, $z = −.782$, $p = .434$; negative interactions: Mann–Whitney $U$, $z = −.795$, $p = .426$]. The mothers had a mean age of 35 (range = 24–49, SD = 5.2) and fathers 37 (range = 22–53; SD = 5.4). The range in educational level ran from elementary school only to advanced university degree (1–7 levels) The mothers had a mean educational level of 3 (SD = 1.3) and fathers 4 (SD = 1.7). The parents of 41 boys (67.2%) and 20 (32.8%) girls participated at this time. The children's ages at time of diagnosis ranged from 0 to 16 years (40% under 4). They suffered from diverse forms of cancers of which leukemia was most prevalent (40%). Forty parents of children with leukemia, 12 parents of children with brain tumors, 18 parents of children with lymphoma's, 14 parents of children with Wilm's tumor, 18 parents of children with sarcoma's, five parents of children with neuroblastoma's, four parents of children with germ cell tumors and four parents of children with hepatoblastoma's participated at T4. The scores of the parents on the General Health Questionnaire did not vary according to type of cancer (nonparametric, $\chi^2 = 6.484$, $p = .49$). Therefore, no specific group was excluded from participation on the basis of the child's diagnosis.

**Instruments**

The 12-item version of the General Health Questionnaire (Goldberg & Williams, 1988), a self-report measure of psychological symptoms commonly used for screening, was used in this study as a general measure for psychological distress. The scores range from 0 to 12. The psychometrical properties of the scale as used in the Dutch population are reported to be highly satisfactory (Koeter & Ormel, 1991). The alpha values in this study ranged from 0.86 to 0.91 for the various measurement points. The Dutch manual provides information on the norm group (a representative randomly selected community group of 1580 men and 1655 women, age range 18–65) as well as information on the reliability and validity of this instrument (Koeter & Ormel, 1991).

The concept of social support within this study was defined in terms of three aspects of experience within a social network: frequency of supportive interactions; frequency of negative interactions; and amount of dissatisfaction with support.

The following instruments were used to assess social support in relation to psychological functioning of the parents:

The Social Support List Interactions (SSL-I) and Discrepancies (SSL-D) was used to measure social support. This is a self-report questionnaire that was designed and validated in the Netherlands (Van Sonderen, 1993). It was developed on the basis of several well-known instruments such as the Inventory of Socially Supportive Behaviors (ISSB; Barrera, Sandler, & Ramsey, 1981) and the Social Support Questionnaire (SSQ; Sarason, Levine, Basham, & Sarason, 1983). The SSL has shown good construct validity and high reliability (Bridges, Sanderman, & van Sonderen, 2002; van Sonderen, 1993). The first and second series of 34 items consist of identical questions with different instructions. The first 34 items measure the number of supportive interactions the respondents
receive from their social support network (SSL-I). The 34 items are subsequently repeated to measure the amount of (dis)satisfaction with that support (SSL-D). In the first series of questions (SSL-I), the respondents answer questions about the support they receive. The questions begin with: “Do people ever...” and end with, for example: “show you affection; cheer you up; pay you a compliment; offer help during difficult times, such as with illness; call you out of the blue for a chat; give you constructive criticism.” Items are scored on a 4-point scale: very seldom/never; now and then; regularly; often (possible range is 34–136; the higher the score the more support received). In the second series of questions (SSL-D), the respondents are asked to evaluate the support they have received. Items are scored according to a 3-point scale: It is just right—I am satisfied; I do not really miss it but it would be nice if it happened more often; I really miss it (possible range is 34–102; the higher the score the more dissatisfied). In addition, seven items are included to measure the frequency of negative interactions (SSL-N). The higher the score, the more negative interactions the respondent has experienced (possible range 7–28). The questions read: “Do people ever treat you unjustly; blame you; make unreasonable demands etc.”

The Cronbach’s alpha for internal reliability of the scores varied between .92 and .94 for the SSL-I; .94 and .95 for the SSL-D; .78 and .84 for the SSL-N for all measurements.

**Analyses**

The results presented here pertain to the comparisons of all four measurement points for the 96 parents who completed questionnaires each time (results in Table I) and for the 115 who completed questionnaires at T1 and T4, 5 years later (results in Tables II and III).

Repeated measures analyses of variance were calculated to examine the effects of time and gender on psychological distress and social support. The parents who responded at all measurement points were included in this first analysis (n = 96).

Regression analyses were calculated to assess the concurrent predictive power of social support on psychological distress fathers and mothers experience at diagnosis (T1) and 5 years following diagnosis (T4). The inclusion criterion for the regression analyses was response at T4 (n = 115, 86 parents of surviving children, eight parents of relapsed children, and 21 parents of deceased children). Separate analyses were performed for fathers (n = 57) and mothers (n = 58). The relationship between psychological distress and social support is shown in a regression model in which the variables supportive interactions, dissatisfaction with support and amount of negative interactions were entered concurrently. Prospectively, the predictive effect of support received at diagnosis on psychological distress 5 years after diagnosis was examined using hierarchical regression analysis (while controlling for distress at diagnosis). The effect of change in support over time on psychological distress at T4 was analyzed while controlling for support and distress at diagnosis (T1).

**Results**

Both fathers and mothers reported significantly less psychological distress (GHQ) over the 5 years. A paired t test showed that distress at 5 years after diagnosis (T4)
was significantly lower than distress at 1 year after diagnosis (T3) for both mothers and fathers (two-tailed: fathers $t = 2.59$, $p = .013$; mothers $t = 2.37$, $p = .022$). Gender differences and interactive effects of time and gender were not found on the GHQ. The amount of supportive interactions also significantly decreased as time passed showing that parents received less support over time ($p < .001$). Again no interactive effect was found, but a significant gender effect was found on amount of support, mothers reported receiving more support. A paired t test showed no difference in amount of support received at 5 years after diagnosis (T4) and support received at 1 year after diagnosis (T3) for both mothers and fathers (two-tailed: fathers $t = .74$, $p = .466$; mothers $t = 1.16$, $p = .254$). No significant effects across time, between genders or interaction effects were found on the measure for (dis)satisfaction with support. No significant difference was found between scores on dissatisfaction with support at T3 and those at T4 for either fathers or mothers (two-tailed: fathers $t = -.456$, $p = .650$; mothers $t = -.345$, $p = .731$). No significant effect of time, gender nor an interactive effect of negative (interactions) support was found. No significant difference was found between negative interactions at T3 and T4 (two-tailed: fathers $t = -1.026$, $p = .310$, Table I).

Kruskal–Wallis (nonparametric) one-way analysis of variance between the scores of the three subgroups of parents ($n = 115$, 86 parents of surviving children, eight parents of relapsed children, and 21 parents of deceased children) at T4 showed no significant differences in scores on support variables (support received: fathers $\chi^2 = 169$, $p = .919$; mothers $\chi^2 = 2.806$, $p = .246$; dissatisfaction with support: fathers $\chi^2 = .052$, $p = .974$; mothers $\chi^2 = 2.735$, $p = .295$; negative interactions: fathers $\chi^2 = 2.089$, $p = .352$; mothers $\chi^2 = .231$, $p = .891$).

The percentage of variance in psychological distress of fathers and mothers at T1 explained by the T1 support variables was not significant. Nor did social support at T4 have predictive power on mothers’ distress at T4. None of the support variables included in these models appeared to have an independent effect. However, social support did significantly explain a proportion of the reported psychological distress for fathers at 5 years after diagnosis ($R^2 = .24$). Dissatisfaction with support had a unique effect on fathers’ levels of distress at T4 (Table II).

Initial distress at T1 significantly predicted fathers’ distress at T4. Inclusion of support variables at T1 did not account for a significant increment in explained variance. Negative interactions at T1 appeared to have an independent effect on fathers’ psychological distress at T4. Inclusion of support variables at T4 accounted for a significant increment of explained variance in fathers’ distress at T4. Dissatisfaction with support and negative interactions had significant independent effects on fathers psychological distress at T4 meaning that changes in dissatisfaction with support and negative interactions were associated with changes in distress. No significant predictive power was found for the variables included in the model for mothers distress at T4.

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**Table II. Multiple Regression Analyses of Psychological Distress and Support Variables, Concurrent**

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T1, measurement point at diagnosis; T4, measurement point 5 years after diagnosis. *$p < .001$.

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**Table III. Predictive Value of Psychological Distress and Support Variables for Distress at T4 (Hierarchical Regression Analysis)**

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<th>$\beta$</th>
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<tr>
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T1, measurement point at diagnosis; T4, measurement point 5 years after diagnosis. *$p < .05$. **$p < .001$. 

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Apparently, the distress mothers reported at T4 was not significantly affected by initial distress nor by initial levels of support or change over time in levels of support (Table III).

Discussion

This study aimed to increase our understanding of the effects of social support on the psychological distress of parents who have had to deal with pediatric cancer. Our study focused on social support using a self-report measure of perceived support defined in terms of supportive interactions, negative interactions, and dissatisfaction with support in relation to psychological distress over time. Our results show that psychological distress continued to decrease as time passed for both fathers and mothers of pediatric cancer patients. In addition, the amount of supportive interactions also decreased significantly as time passed, even though change in social support received between 1 year after diagnosis and 5 years after diagnosis (T3–T4) appeared insignificant. The initial amount of support received could therefore be seen as a type of crisis support, in which parents either mobilized or were offered the support they needed. This quantity of support then declined during the first year and stabilized at a somewhat constant level as we observed no significant change in quantity of support between 1 and 5 years after diagnosis. Parents did not become more dissatisfied with support, even though the perceived quantity of support declined as indicated by the lack of significant change in dissatisfaction over time. Lastly, the number of negative interactions showed no significant change over time.

When considering the decline of psychological distress in the light of social support parents have received across time, we found surprising differences between fathers and mothers in how social support affected their experience of psychological distress. Our results show that social support seems to have had a negligible effect on mothers’ psychological functioning, although they continued to receive more social support than fathers did. Indeed, for mothers, the results of the concurrent and prospective regression analyses we performed showed no unique significant contribution of social support (either in number of interactions or amount of (dis)satisfaction with support received) to distress for mothers at diagnosis nor at 5 years after diagnosis. The changes in support they experienced over time seemed to have no effect on the changes in distress they reported. This lack of effect on psychological distress for mothers is in line with studies that found no significant associations of scores on social support with either PTSD symptoms or anxiety and avoidance (Best et al., 2001; Pelcovitz et al., 1996). However, our findings are in contrast with several studies that found significant effects of social support on mother’s psychological distress (Barakat et al., 1997; Manne et al., 2000; Sloper, 2000). Other factors we have not measured in this study such as parenting stress, child behavior, or general family functioning could be more important to mothers than social support for maintaining a sense of psychological well-being.

Remarkably, social support plays an unexpected role for fathers in this study. Predictors of fathers psychological distress at 5 years following diagnosis were dissatisfaction with support and negative interactions. Concurrent and prospective effects were found for these two support variables. In addition, increased dissatisfaction with support and increased negative interactions were associated with higher levels of distress. On similar lines, it is interesting to note that Speechley and Noh (1992), in their cross-sectional study on parents of childhood cancer survivors, found a more pronounced generalized elevated risk for psychological distress in relation to low levels of social support in fathers. Though we found no significant relationship with low levels of social support we did find dissatisfaction with support and increased levels of negative interactions to be significantly associated with fathers’ psychological distress even after 5 years. One could expect the effect of social support on distress to be largest at diagnosis because of the initial confrontation with the cancer diagnosis. However, the concurrent predictive value of social support was much smaller than its counterpart at 5 years after diagnosis in this group. Dissatisfaction with support and, to a lesser degree, the number of negative interactions experienced by fathers showed a uniquely significant contribution to the explained variance in distress at 5 years following diagnosis. This could be interpreted to mean that fathers who were less effective in mobilizing a support network also continued to experience more psychological distress. For fathers, the quality of support seemed to be more important than the quantity. In line with our results, one study has found a greater affective response (defined in terms of anxiety and depression) in fathers who made less use of perceived social support while no significant association between affective response and perceived social support was found for mothers (Frank et al., 2001).

An explanation for the different effects social support has on the psychological distress of mothers and fathers as measured in this study may also be found in a difference...
in types of relationships with the persons that form one’s social network. Women have been reported to rely on family and friends for support, whereas men rely on contact with colleagues (Due, Holstein, Lund, Modvig, & Avlund, 1999; Fuhrer, Stansfield, Chemali, & Shipley, 1999). Family and friends may offer a more intimate type of support that is more in harmony with the support and expectations parents need when dealing with pediatric cancer and therefore naturally more in tune with the type of support mothers need. Fathers, on the other hand, must rely on support from colleagues which may be of a more formal and distant nature and may not satisfy the needs and expectations fathers have in a situation that disturbs their emotional balance such as that of pediatric cancer.

Clinicians should be alert to the needs fathers have for continued proper social support especially when fathers indicate they have experienced negative interactions and are dissatisfied with the support they have received. Negative interactions experienced at the time of diagnosis appear to have long-term consequences for fathers. More research is needed to specify the exact needs fathers who are distressed may have and to specify the type of support that would be most helpful not only in alleviating present distress but also in preventing future distress.

In summary, social support seemed to be the greatest at diagnosis and to further decline as time passed for both mothers and fathers. Mothers continued to experience more supportive interactions than fathers. No gender or time effect was found on amount of negative interactions and dissatisfaction with support. However, we did find a difference in the effects of support on the psychological functioning of fathers and mothers both concurrently and prospectively 5 years after diagnosis. Dissatisfaction with support and negative interactions that fathers experienced significantly affected their levels of psychological distress. No such effect was found for mothers.

One general source of concern, when considering our results, is the fact that we have not included measures for personality as control variables. Studies on social support and psychological distress within the general population have shown that personality characteristics such as neuroticism have strong direct effects on the perception of social support and especially so when considering negative social exchange (Finch, Okun, Pool, & Ruehlman, 1999). These could be mediating factors that influence the responses of the fathers and mothers participating in this study. Future research should include measures of personality to tease out the effects of these variables on social support and in association with dealing with cancer treatment and survivorship.

Other limitations to this study can be found in the small numbers of participating parents in the groups with relapsed or deceased children. Our groups of bereaved parents and parents of relapsed children were much too small to justify any far-reaching conclusions about the needs of parents who are faced with bereavement or relapse after a long period of time. However, the results of this study do underline the need for research that focuses on both parents when considering the role social support plays in dealing with psychological distress. We were fortunate to be able to retain a large number of participants, especially fathers, during the course of this study.

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