Infancy and Pediatric Cancer: An Exploratory Study of Parent Psychological Distress

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Abstract

Objective: Research on the psychological experiences of parents of infants within pediatric oncology is sparse. This study examined rates and indicative risk factors for psychological distress in parents where there is either an infant patient or infant sibling of a patient.

Methods: Participants were mothers (n=41) and fathers (n=25) of infants under two years, who either had a cancer diagnosis (n=37; infant patients), or was an infant sibling of an older child with cancer (n= 29; infant siblings), recruited from a single oncology center. There were 21 couple dyads. Parents completed the Depression Anxiety Stress Scales short form and the Posttraumatic Stress Disorder Checklist.

Results: Mothers (47.5%) and fathers (37.5%) reported elevated, cancer-related posttraumatic stress symptoms (PTSS). Rates of depression (12.2% of mothers and 12.0% of fathers) and anxiety symptoms (17.1% of mothers and 8.0% of fathers) were lower. Compared to parents of infant patients, parents of infant siblings reported significantly higher rates of depressive symptoms and trends towards higher rates of PTSS and anxiety symptoms. Parent anxiety was higher with increased time post diagnosis. No demographic or illness-related variables were associated with psychological distress with the exception of the number of children in the family.

Conclusions: Parent-child relationships are of fundamental importance during infancy. This study provides novel data highlighting the psychological impact for parents when a cancer diagnosis is made during this critical developmental period, including the contribution of family structure to parental distress. Results provide further support for applying a traumatic stress framework when exploring parent experiences of pediatric cancer.

Background

It is well established that parents of childhood cancer patients experience increased distress including posttraumatic stress symptoms (PTSS), anxiety and depressive symptoms [1]. Common to these parents is elevated distress associated with managing the emotional and practical requirements of cancer treatments [2, 3], and a heightened risk of longer-term psychological difficulties [4]. These findings are established across the wider childhood cancer population [5], however there is currently no research specifically exploring the impact of pediatric cancer on the parents of infants [6]. In healthy populations, infancy (birth to two years) is a time of significant adjustment for families, often resulting in increased psychological symptomatology for parents [7]. Further, the developmental importance of infancy on later social, psychological and physiological outcomes is paramount; environmental disturbances, such as disrupted caregiving or traumatic experiences during this time, can potentially have long-term impacts [8]. The paucity of research among infant cancer populations represents a notable gap; particularly given children are twice more likely to develop cancer in the first four years of life, compared to other developmental periods [10].

In addition to parents of infant cancer patients, the psychological experiences of parents of infant **siblings** who are dealing with a cancer diagnosis in an older **child** are yet to be explored. This is despite increased research into the experiences of siblings of pediatric cancer patients more generally [10], which has found parents report difficulties simultaneously meeting the needs of well siblings [11]. Although yet to be researched, the level of emotional and physical care required by infants [8], suggests that parents of infants face additional stressors in caring for their patient child and infant sibling.

Kazak and colleagues have proposed a medical traumatic stress model which conceptualizes stress symptoms across a spectrum from normal responses to a life threatening illness in a child through to more problematic and impairing symptoms [12]. Kazak and Baxt suggest this model may apply to parents of infants with cancer, particularly in terms of how parental emotional reactions may impact their

relationships with their infants and their infant's development [6]. However, this model is yet to be empirically tested.

In contrast to oncology, investigations of parental psychological distress in other infant illness populations is more common, particularly preterm or low birth weight infants, parents of infants admitted to a neonatal intensive care unit (NICU) and other life-threatening infant illness populations (e.g. congenital heart defects) [13, 14, 15]. Across these studies, significant proportions (20-56%) of parents consistently report elevated depressive symptoms, anxiety, PTSS, and PTSD [13-17].

Identified demographic risk factors for elevated psychological distress among parents within infant illness populations include: parents of younger age, lower education level and larger family size [18, 19]. Mothers typically report higher rates of distress [20]. However, there is increasing acknowledgement of the important role for fathers [21], whose psychological functioning significantly impacts family functioning [22]. Unlike demographic factors, psychological distress experienced by parents of unwell infants appears less dependent on factors associated with the nature and severity of an infant's illness [14, 18]. This finding is yet to be replicated in a cancer context.

The aim of this study was to examine rates of elevated PTSS/PTSD, depression and anxiety symptoms amongst mothers and fathers of infants with a pediatric cancer diagnosis (infant patients) and parents of infants with **an older child** who has a pediatric cancer diagnosis (infant siblings). A second aim was to investigate whether parent demographic factors (education, age and number of children in household) and illness-related factors (diagnosis, age at diagnosis and time since diagnosis) are associated with parental psychological distress symptoms.

Methods

Participants

Participants included mothers and fathers from **two-parent** families currently receiving treatment in the Children's Cancer Centre (CCC) of The Royal Children's Hospital (RCH) Melbourne, Australia. Either **both parents (complete parental**

dyads), or only one parent (incomplete parental dyads) filled out the study questionnaire package. Two groups were recruited for participation, including: 1) parents of infants (≤ 24 months) who had received a cancer diagnosis (infant patients), and; 2) parents of infant **siblings** (≤ 24 months) with an older **child** who had received a cancer diagnosis and were on active treatment (infant siblings). Potential participants were identified from a clinical database. Exclusion criteria were: insufficient English or cognitive functioning to complete measures, non-biological parents or involvement of child protective services. Single parents of infants and parents who were under 18 years were also excluded as these parents have been identified as having unique parenting challenges and higher risk of psychological symptoms [23]. Parents of infants born pre-term (< 32 weeks), with identified neurological or developmental conditions (e.g. Downs Syndrome), or who were considered palliative, were also excluded.

Procedure

The current study used a non-experimental cross-sectional design. Ethics approval for the study was obtained from The RCH Human Research Ethics Committee. Participant recruitment took place from April 2012 to August 2013. To minimize distress, parents were approached a minimum of 3 months post-diagnosis and during routine hospital visits. Consenting participants were provided with a questionnaire package and a pre-paid addressed envelope. Additional questionnaire packages were provided to participants whose partner/spouse was not present at the hospital. Mail-out recruitment was also used to recruit a small number of participants who could not be contacted at the hospital. Follow-up telephone calls were made 2 weeks post-recruitment. On average, at the time of questionnaire completion, children were 9 months post diagnosis and infants had a mean age of 18 months. See Table 1 for demographic information. **Participant recruitment is detailed in Figure 1.**

Measures

Demographics. Demographic data, including gender, age, ethnicity, education

and household constellation as well as the patient child's diagnosis and infants' age and gender, were collected using a questionnaire developed for the study.

Depression and Anxiety. The depression and anxiety subscales (7-items respectively) of the Depression Anxiety Stress Scales 21 (DASS-21) [23] were completed by participants. Parents completed each item on a 4-point scale ranging from 0) *did not apply to me at all*, to 3) *applied to me very much, or most of the time*. Items were summed and doubled to provide a total score for each scale. Scores of 14 and 10 or higher were used to indicate elevated (moderate or higher) depressive and anxiety symptomatology respectively [23]. Excellent reliability coefficients have been reported for the DASS 21; $\alpha = 0.90$ (anxiety) and $\alpha=0.95$ (depression) [24]. Cronbach alphas for the current study were 0.80 and 0.90 respectively.

Posttraumatic Stress Symptoms. The Posttraumatic Stress Disorder Checklist – Specific (PCL-S), is a 17-item questionnaire that corresponds to the PTSD symptoms in the DSM-IV [25]. Parents completed the questionnaire in relation their child's cancer diagnosis. Items were summed to provide a total cancer-related PTSS score between 17 and 85. A cut-off score of 30 was used to indicate elevated rates of PTSS [26]. A symptom-cluster (re-experiencing, avoidance and arousal) scoring method was also used to indicate participants who are likely candidates for meeting diagnostic criteria PTSD [28]. The PCL has very good internal consistency ($\alpha = 0.96$) and test-retest reliability [28]. For the current study $\alpha = 0.95$.

Statistical Analysis

Dependent variables (**parental PTSS, depression and anxiety symptoms**) were analysed as either continuous (calculated as the sum of all relevant items) or dichotomous categorical (**'elevated' or 'non-elevated'**) using appropriate cut-scores: moderate levels or above of depression and anxiety symptoms on the DASS 21; and PTSS of 30 or above on the PCL-S. **PTSD symptom clusters (re-experiencing, hyperarousal and avoidance) were not explored as individual dependent variables due to sample size limitations.**

Independent variables for group comparisons of parental distress included group membership (mother/father and infant patient/infant sibling). Indicative risk factors for parental distress included: demographic variables (parent age, education level, marital status, infant age and number of children in the household); and illness-related variables (diagnosis, infant age at diagnosis, and time since diagnosis). Demographic and illness-related variables were compared between infant groups using independent t-tests and chi-square tests of independence.

Proportions of mothers and fathers meeting ‘elevated’ criteria for all dependent variables were identified for each group. Pearson’s correlations were used to examine relationships between continuous PTSS, depression and anxiety symptoms. Linear mixed model (LMM) analyses were conducted to determine the association between: i) parental role (mother or father); and ii) infant group membership (patient or sibling) with reported levels of PTSS, depression and anxiety symptoms.

Univariate LMM analyses were conducted to explore associations between demographic and illness-related variables with continuous PTSS and anxiety outcomes. To account for significant relationships found between infant group membership and depressive symptoms, multivariate LMM analyses were undertaken to investigate relationships between **demographic and illness-related** variables and depressive symptoms. In addition to each individual **demographic and illness-related** variable, infant group was included in all multivariate LMM analyses using depressive symptoms as the dependent variable. Additional multivariate analyses were not warranted to test models for dependent variables, as only one variable emerged as a significant predictor for each dependent variable.

Results

Demographics

There were no significant differences between the infant groups (patients and siblings) on demographic and illness-related variables except for diagnosis categories. Compared to the infant sibling group, there were significantly more solid tumors

(73.91% compared with 21.05%), and fewer diagnosed with leukaemia (13.04% compared with 78.95%) in the infant patient group. See Table 1.

Parent distress symptoms

Mean scores for cancer-related PTSS, depression and anxiety symptoms, by infant group and parental gender, are presented in Table 2. **Descriptive** rates of distress symptoms for mothers and fathers were identified. Using a cut-score of >30, 47.5% of mothers and 37.5% of fathers reported elevated cancer-related PTSS. Using the symptom-cluster scoring method 20.0% of mothers and 12.5% of fathers meeting criteria for ‘diagnostic’ cancer-related PTSD. However, an additional 17.5% of mothers and 12.5% of fathers met criteria for ‘partial’ cancer-related PTSD, defined as those meeting two of the three PTSD symptom clusters. A higher proportion of parents reported re-experiencing (51.6%) and arousal (39.1%) symptoms than avoidance symptoms (18.8%).

Twelve per cent (12.2%) of mothers and fathers (12.0%) reported elevated depressive symptoms and 17.1% of mothers and 8.0% of fathers reported elevated anxiety symptoms. See Table 3.

Group comparisons

Results of LMMs exploring group comparisons indicated that parental gender was not significantly associated with rates of cancer-related PTSS ($F=1.12$, $p=0.30$), depression ($F=0.01$, $p=0.92$) or anxiety ($F=0.51$, $p=0.48$) symptoms. Similarly, infant group membership was not significantly associated with cancer-related PTSS ($F=2.73$, $p=0.11$) or anxiety ($F=1.03$, $p=0.32$) symptoms. Infant group membership was however, significantly associated with depressive ($F=5.98$, $p=0.02$) symptoms. Parents of infant siblings reported higher rates of depressive symptoms than parents of infant patients.

Risk factors for parental distress

Results of LMMs exploring relationships between demographic variables and dependent variables indicated that the number of children in the household was significantly associated with rates of PTSS ($F=4.44$, $p=0.02$). Mean differences indicated rates of PTSS increased with the number of children in the household. Depressive symptoms also increased with the number of children in the household

($F=4.83$, $p=0.01$) and a significant relationship remained between infant group membership and depressive symptoms when included in this model ($F=5.95$, $p=0.02$). Parent age and education level were not significantly associated with any dependent variables.

Examination of illness-related variables indicated a significant association between time since diagnosis (months) and anxiety symptoms ($F=5.58$, $p=0.02$), with anxiety increasing with time since diagnosis. Diagnosis type and child age at diagnosis were not significantly associated with PTSS, anxiety or depressive symptoms. A significant relationship remained between infant group membership and depressive symptoms in all other models including other demographic and illness-related variables. See Table 4 for descriptive statistics of significant categorical independent variables.

Discussion

This is the first pediatric oncology study to investigate parent psychological distress **specifically** amongst parents of infant patients and infant siblings of patients. The study results are consistent with existing pediatric oncology research that suggests that trauma reactions are commonly experienced by parents in response to their child's diagnosis and treatment [12] and provide important and novel data on parents of infants impacted by cancer.

Almost half the mothers and more than one third of fathers reported elevated rates of cancer-related PTSS, with a subset meeting criteria for 'diagnostic' PTSD (20.0% of mothers, 12.5% of fathers), and a further subset meeting criteria for 'partial' PTSD. Consistent with previous oncology studies [3, 29] and other infant illness populations [30], parents reported higher rates of re-experiencing and hyperarousal symptoms than avoidance symptoms. This is expected given ongoing treatment requirements make it difficult for parents to avoid stimuli (e.g. attending hospital appointments) associated with their child's illness [4].

The high rates of psychological distress indicated in this study suggests that parents of infant cancer patients **may potentially** be considered as an important

subgroup of the broader infant illness population. Rates of parental elevated cancer-related PTSS in the current study were higher compared to studies of parents of medically fragile and hospitalised infants [13]. There may be unique factors contributing to the traumatic experience for these parents, including witnessing invasive and prolonged treatment regimes and often debilitating treatment side-effects, in addition to the associated life threat [6, 31].

In contrast to elevated cancer-related PTSS, rates of elevated symptoms of anxiety (17% mothers; 8% father) and depression (12% mothers and fathers) were comparable to those reported in the general population (6% depression, 14% anxiety, 12 month prevalence) [32]. Elevated anxiety symptoms were lower than those reported among parents of hospitalised infants [21], but comparable to those reported among parents of premature infants [15]. Rates of elevated depressive symptoms for both mothers and fathers were also lower than available studies of other infant illness populations (e.g. premature infants), which report rates as high as 40% [17]. These results are difficult to interpret as they may reflect differences in sampling and measurements tools between studies and the small sample size in the current study. Despite this, the current rates of anxiety and depressive symptoms are consistent with pediatric oncology studies generally [2, 33]; parents of pediatric cancer patients do not report high levels of anxiety and depressive symptoms, despite experiencing high rates of trauma symptoms. The current study therefore lends support to the contention that a trauma framework **may have** greater utility in conceptualising parental distress [34] and therefore better inform evidence-based support.

Parental gender was not found to be a significantly associated with rates of reported cancer-related PTSS, depression or anxiety symptoms, despite a trend towards higher rates of anxiety and cancer-related PTSS among mothers. Fathers reported comparable rates of elevated depressive symptoms to mothers, which is in contrast to evidence from both childhood illness literature [35] and the general population [32]. This result may reflect the small number of fathers within the infant sibling group. Notwithstanding, these results **suggest** that fathers also experience heightened distress in response to their child's cancer diagnosis, and highlight the

importance of their inclusion within both pediatric research and clinical interventions [36]. This may be particularly important in families of infants, as fathers play an important supportive role for mothers during this time, particularly in terms of mitigating significant disruption to family functioning and relationships associated with childhood cancer [22, 37].

Parents of infant siblings reported significantly higher rates of depressive symptoms than parents of infant patients. There was also a non-significant trend towards higher rates of anxiety symptoms and cancer-related PTSS among parents of infant siblings. Given the small sample sizes, differences between infant patient and sibling groups need to be interpreted with caution. It is possible that there are real differences between the two groups, potentially reflecting the difference in prognosis and treatment regimes experienced by parents of older compared to infant cancer patients [38]. Significant differences in the distribution of diagnoses between infant groups lends support to this, however, diagnosis was not found to be a significant predictor of depression in the current study. Alternatively, as families of infant siblings tended to have more children than families of infant patients, differences may reflect increased cumulative burden on parents of infant siblings. This lends support to family systems theories, which highlight the cumulative stress experienced by families coping with additional burdens, and concomitant increases in anxiety and depression [6]. Further research with larger samples is indicated.

Time since diagnosis was the only illness-related variable to emerge as significantly associated with anxiety symptoms, with anxiety symptoms increasing over time since diagnosis. Similar trends were identified for PTSS and depressive symptoms which also tended to increase with time since diagnosis, although not significantly. These results are in contrast to declines over time in distress symptoms reported by longitudinal pediatric oncology studies [5] and suggest parents may experience fluctuations in distress associated with their child's ongoing treatment [39], rather than a stable trajectory of distress symptomology. Further research would be beneficial in determining if distress trajectories across the cancer process are noticeably different for parents of infants.

Limitations of the current study need to be considered. Parental distress symptomatology was collected using self-report measures rather than clinical interviews, which represent the gold standard for diagnosis of clinical symptoms [40]. With this in mind, diagnostic criteria have been interpreted as indicative only. As with all studies limited to a single institution, generalizability of results is limited. Further, participants in the current study opted into the study, which may have biased the sample towards parents who are less distressed or more willing to seek help. In addition, parents of children who were in palliative treatment, who likely experience heightened distress [29], were not included. Finally, the unequal and small sample sizes limited the generalizability of comparisons between rates of distress symptoms reported by mothers and fathers.

Despite these limitations, results of the current study provide an **important** first exploration into the experiences of parents of infant pediatric cancer patients and infant siblings of patients. High rates of elevated cancer-related PTSS and ‘partial’ or ‘diagnostic’ cancer-related PTSD reported in this study provide further evidence of the traumatic nature of the pediatric cancer experience for parents. Results also provide a **preliminary** indication that parents of infant cancer patients **may** experience high rates of PTSS compared with parents of other infant illnesses, highlighting the confronting nature of pediatric cancer treatments. Parents of infants within a pediatric oncology context may therefore be at heightened risk for psychological difficulties, indicating the importance of identifying parents who would benefit from psychosocial support and clinical interventions.

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Table 1. Demographic Information of Participants

Demographic	Infant patient group		Infant sibling group		<i>p</i>
	Mothers	Fathers	Mothers	Fathers	
N (%)	22 (60.00%)	15 (40.00%)	19 (65.52%)	10 (34.48%)	
Mean parent age, years (<i>SD</i>)	33.82 (4.94)	38.99 (7.28)	36.00 (3.68)	38.70 (3.23)	0.42
Education (%)					0.55
Year 12 or below	6 (27.30%)	4 (26.70%)	3 (15.80%)	3 (30.00%)	
Higher education	16 (72.70%)	11 (73.30%)	16 (84.20%)	7 (70.00%)	
Participant family demographics*	Infant patient group		Infant sibling group		<i>p</i>
N	23 (54.76%)		19 (45.24%)		
Marital status					0.33
Married	15 (65.22%)		15 (78.9%)		
Defacto	8 (34.78%)		4 (21.1%)		
Diagnosis					>0.001
Leukaemia	3 (13.04%)		15 (78.95%)		
Solid tumors	17 (73.91%)		4 (21.05%)		
Brain/CNS	1 (4.35%)		1 (5.26%)		
Non-Hodgkin's lymphoma	0 (0.00%)		1 (5.26%)		
Ewing's sarcoma	1 (4.35%)		0 (0.00%)		
Neuroblastoma	7 (30.43%)		1 (5.26%)		
Rhabdomyosarcoma	0 (0.00%)		1 (5.26%)		
Wilms' tumour	2 (8.70%)		0 (0.00%)		
Other solid	6 (26.09%)		0 (0.00%)		
Other	3 (13.04%)		0 (0.00%)		
Mean infant age, months (<i>SD</i>)	18.39 (6.59)		17.95 (8.26)		0.85
Mean infant age at diagnosis, months (<i>SD</i>)	9.78 (5.74)		6.37 (13.28)		0.31
Mean time since diagnosis, months (<i>SD</i>)	7.57 (5.65)		10.74 (9.01)		0.17
					0.10
Number of children in household					
One	5 (21.74%)		0 (0.00%)		
Two	9 (39.13%)		10 (52.63%)		
Three or more	9 (39.13%)		9 (47.37%)		

Note: *Participant family refers to parental dyads from the same family unit

Table 2. Cancer-related PTSS (PCL-S), Depression and Anxiety Symptom Scores (DASS 21) for Mothers and Fathers by Infant Group

	Infant patient group				Infant sibling group			
	Mothers (n=22)		Fathers (n=15)		Mothers (n=19)		Fathers (n=10)	
	<i>M</i> (<i>SD</i>)	95% CI	<i>M</i> (<i>SD</i>)	95% CI	<i>M</i> (<i>SD</i>)	95% CI	<i>M</i> (<i>SD</i>)	95% CI
PTSS	30.14 (11.70)	25.14 - 35.14	25.71 (13.56)	18.61 - 32.81	34.53 (14.13)	28.18 - 40.88	33.80 (13.83)	25.23 - 42.37
	Mothers (n=21)		Fathers (n=14)		Mothers (n=19)		Fathers (n=10)	
	<i>M</i> (<i>SD</i>)	95% CI	<i>M</i> (<i>SD</i>)	95% CI	<i>M</i> (<i>SD</i>)	95% CI	<i>M</i> (<i>SD</i>)	95% CI
Depression symptoms	3.82 (5.62)	1.47 -6.17	2.27 (3.45)	0.52 - 4.02	6.21 (6.56)	3.26 - 9.16	9.20 (10.34)	2.79 - 15.61
Anxiety symptoms	3.55 (4.45)	1.69 - 5.41	2.93 (6.36)	-0.29 - 6.15	5.16 (6.05)	2.44 - 7.88	3.60 (5.64)	0.10 - 7.10

Table 3. Proportions (%) of Mothers and Fathers Reporting PTSS, Depression and Anxiety Symptoms Using Cut Scores

		Infant patient n (%)		Infant sibling n (%)	
		Mother (n=22)	Father (n=15)	Mothers (n=19)	Fathers (n=10)
Depression	Normal	20 (90.9)	13 (86.7)	16 (84.2)	6 (60.0)
	Mild	0 (0.0)	2 (13.3)	0 (0.0)	1 (10.0)
	Elevated	2 (9.1)	0 (0.0)	3 (15.0)	3 (30.0)
Anxiety					
	Normal	19 (86.4)	13 (86.7)	14 (73.7)	8 (80.0)
	Mild	1 (4.5)	1 (6.7)	0 (0.0)	1 (10.0)
	Elevated	2 (9.1)	1 (6.7)	5 (26.3)	1 (10.0)
		Infant patient n (%)		Infant sibling n (%)	
		Mother (n=21)	Father (n=14)	Mothers (n=19)	Fathers (n=10)
PTSS	Re-experiencing	10 (47.6)	4 (28.6)	12 (63.2)	7 (70.0)
	Avoidance	3 (14.3)	1 (7.1)	6 (31.6)	2 (20.0)
	Hyperarousal	8 (38.1)	3 (21.4)	8 (42.1)	6 (60.0)
	‘Partial’ PTSD	4 (19.0)	2 (14.3)	3 (15.8.0)	3 (30.0)
	‘Diagnostic’ PTSD	3 (14.3)	1 (7.1)	5 (26.3)	2 (20.0)
	Elevated (>30)	9 (42.9)	4 (28.6)	10 (52.6)	5 (50.0)

Table 4. Estimated Marginal Means and Standard Deviations of Significant Categorical Predictors of Distress Symptoms

	PTSS M(SD)	Depression M(SD)	Anxiety M(SD)
Infant group			
Patient	28.25 (2.53)	3.16 (1.11) *	3.32 (1.01)
Sibling	34.48 (2.79)	7.26 (1.25) *	4.85 (1.13)
Number of Children in the household (HH)			
One	20.37 (5.41) *	2.82 (2.45)	1.23 (2.14)
Two	28.50 (2.60) *	3.21 (1.12)	2.86 (1.05)
Three or more	36.43 (2.68) *	7.85 (1.14)	5.82 (1.07)

* P<0.05

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