# Impact of Caring for a Child With Cancer on Single Parents Compared With Parents From Two-Parent Families

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**Background.** It is currently unknown how the intensive and often prolonged treatment of childhood cancer impacts on the lives of single parents. Our aims were to determine whether single parents differ from parents from two-parent families in terms of caregiver demand (the time and effort involved in caregiving), and health-related quality of life (HRQL). **Procedures.** Forty single parents and 275 parents from two-parent families were recruited between November 2004 and February 2007 from five pediatric oncology centers in Canada. Parents were asked to complete a questionnaire booklet composed of items and scales to measure caregiver demand and HRQL (SF-36). The booklet also measured the following constructs: background and context

factors, child factors, caregiving strain, intrapsychic factors, and coping factors. *Results*. Single parents did not differ from parents from two-parent families in caregiving demand and physical and psychosocial HRQL. Compared with Canadian population norms for the SF-36, both groups reported clinically important differences (i.e., worse health) in psychosocial HRQL (effect size  $\geq -2.00$ ), while scores for physical HRQL were within one standard deviation of population norms. *Conclusion*. Our findings suggest that the impact of caregiving on single parents, in terms of caregiving demand and HRQL is similar to that of parents from two-parent families. Pediatr Blood Cancer 2012;58:74–79. © 2011 Wiley Periodicals, Inc.

Key words: caregiver; childhood cancer; quality of life; single parent; supportive care

#### **INTRODUCTION**

Given the additional challenges faced by single parent families [1], our study aimed to shed insight on whether single parents of children with cancer differ from parents in two-parent families. Our selection of factors studied was guided by a literature review [2] that organized findings according to a generic model of the caregiver stress process [3]. The Raina et al. model incorporates components of other caregiving theories [4–6] and measures the following constructs: background and context; child factors; caregiving strain; self-perception factors; coping factors; and caregiver health. Our hypotheses were that compared with parents from two-parent families, single parents would report spending more time and effort caring for their child with cancer, and would report poorer physical and psychosocial health-related quality of life (HRQL).

In Canada, parents raising children on their own represented 15.9% (n = 1,414,100) of all census families in 2006 and 34.8% of all census families with children, higher than any other recorded census figure in the last 75 years [7]. This figure compares with 29% of census families with children in the United States [8] and 25.6% of census families with children in the United Kingdom [9]. Although Canada reports the highest proportion, each country uses a different age cut-off to define a child in their calculations (up to 24 years of age (Canada), under 18 years of age (USA), 16 years of age or 16–18 years of age if in fulltime education (United Kingdom)).

Caregiver demand and HRQL are two important outcomes for parents of children with cancer. Pediatric oncology services are organized such that parents of children with cancer often provide much of their child's illness-related care at home. Parents administer medication, monitor for treatment side effects, travel back and forth from the hospital for medical care, and provide emotional support for the child with cancer and other family members. At the same time, parents must continue to financially provide for their family and accomplish all the routine tasks essential to the normal functioning of a household. In single-parent families, all of the day-to-day tasks associated with caregiving, in addition to regular household tasks, can be the responsibility of one parent alone. However, some parents from two-parent family may have minimal help from their partner or spouse, and some single parents may receive help and support from

friends, extended family members and their former partner or spouse. It is therefore important to explore whether time and effort involved in caregiving is higher for subgroups of parents so that appropriate interventions could be developed for those at higher risk of distress due to higher caregiving demand.

It is also important to determine whether single parents experience poorer health outcomes compared with parents from two-parent families. Single mothers appear to be a particularly vulnerable group due to being at increased risk for a variety of physical [10–12] and mental health problems [12–17]. Single mothers report lower levels of social support, social involvement and frequency of contact with friends and family compared with married mothers [14]. Furthermore, single-parent families, relative to other familial arrangements, are much more likely to experience social and economic disadvantage [13,18,19]. Canadian statistics for 2008 show that the gap between the average household incomes of single-parent and two-parent families is substantial (\$96,500 for two-parent families compared with \$39,400 for single-parent families) [20].

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Conflict of interest: Nothing to report.

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Received 5 February 2010; Accepted 8 November 2010

Given the evidence showing that single parents report more health and economic disadvantage compared with parents from two-parent families, and the caregiving impact that a diagnosis of cancer has on a family unit, research that seeks to understand how single parents adapt to the challenges of caring for an ill child while maintaining a home and family life is needed. Our study adds to the small literature that seeks to understand the caregiving experience of single parents of children with cancer. In a qualitative phenomenology study, Huang et al. [21] interviewed nine single parents caring for a child with cancer and described the nature by which single parents employ family resources to assist family adjustment and to maintain family function. Iobst et al. [22] found that negative affectivity and problemsolving abilities were similar when 87 single mothers were compared with 377 married/partnered shortly after the child has been diagnosed with cancer.

The purpose of this study was to better understand the unique issues facing single parents who need to care for a child with cancer.

### **METHODS**

### **Participants**

Data were collected as part of a large multi-institutional cross-sectional study of the health and well-being of parents of children receiving any type of active treatment for cancer [23]. The sample for this study was recruited during a 28-month period (November 2004 to February 2007) from five Canadian pediatric cancer tertiary centers: BC Children's Hospital (Vancouver), CancerCare Manitoba (Winnipeg), Children's Hospital of Eastern Ontario (Ottawa), The Hospital for Sick Children (Toronto), and McMaster Children's Hospital (Hamilton).

A convenience sample of parents from inpatient and outpatient settings were approached for participation. We included parents of children (18 years of age or younger) with any type of cancer, as long as the child was in active treatment, was 2 or more months postdiagnosis. Patients were considered eligible if the intent of treatment was curative, and considered ineligible if the intent of treatment was primarily for palliation rather than cure. The parent had to be the person most responsible for the day-to-day decision-making and care of the child, and able to read English. Only one parent was included per family. A total of 513 parents were asked to participate, and 501 agreed. We received completed questionnaires from 411 parents (80% response rate). In the current paper, from the 411 respondents, we excluded 96 families in order to focus the analysis on single parents (n = 40) and parents from two-parent families (n = 275). A single-parent family was defined as a family with one adult and one or more children living in the same household, and a two-parent family was defined as two adults living as married or common-law with one or more children in the same household. Of the 96 parents that were excluded from our analyses, 69 came from homes with more than two adults and one or more children, 15 had two adults whose marital status was other than married or common-law, 2 were single parents who reported having no children living at home, and for 10 there was missing data that prevented us from categorizing them.

#### **Procedure**

Ethical approval was obtained for each participating center and written informed consent from all participants. A research nurse, clinical research associate, or pediatric oncologist (depending on the

center) approached eligible participants to invite their participation Eligible parents were given a package that included a \$10 coffee card as a thank-you for considering the study along with a booklet to complete, which included items and scales that asked about the child, parent, and family. The booklet was returned in person or by mail. Nonrespondents were sent a second copy of the questionnaire booklet, a reminder letter and phone calls as needed. We collected the following measures for each of the constructs within the caregiver stress process model [3].

**Background/context.** Single parents and parents from two-parent families were compared in terms of annual household income, household income adjusted for family size and composition [24], family savings, and education level.

Child characteristics. Child characteristics included the following: age, gender, type of cancer, years since diagnosis, relapse status, type of treatment, prognosis, health status and HRQL. Prognosis (in terms of survival rate) was rated by 5 pediatric oncologists as good (> 80%), average (50 to 80%l), or poor (< 50%). Health status was assessed with the Functional Status II(R) (FS II(R)), a measure for children 0-18 years of age with ongoing illnesses [25]. Lower scores indicate worse health status related to the child's illness (in this case cancer). The FS II(R) has been shown to have excellent psychometric properties in children with and without chronic physical conditions [25]. HRQL was measured using the PedsQL 4.0 Generic Core Scales [26]. Versions are available for children 2–18 years of age. We used summary scores for physical and psychosocial health, with higher scores indicating better HRQL. The PedsQL 4.0 was shown to be reliable and valid in healthy populations and in children with cancer [26].

Caregiver strain. Caregiving strain was measured with the Impact on Family Scale (IFS) [27] which evaluates a parent's perception of the effects of an ill child's ongoing health problem on family life. The IFS has subscales that measure family impact and financial impact. Higher scores indicate more impact. This measure was shown to have excellent psychometric properties based on data from families of children with chronic health conditions [27].

**Self-perception.** To measure mastery and self-esteem, we used scales included within the household component of the National Population Health Survey (NPHS), a multistage stratified survey of the health of Canadians (http://www.statcan.gc.ca/survey-enquete/household-menages/health-sante/nphs-ensp-eng.htm). The Life Orientation Test—Revised (LOT-R) [28] was used to measure dispositional optimism (i.e., a relatively stable expectation that good outcomes will occur across important life domains). The LOT-R is the most frequently used measure of optimism, and has been shown to be reliable and valid in research involving university students [28]. For all three intrapsychic measures, higher scores indicate more of the attribute.

Coping factors. Family function was measured using the Family Assessment Device (FAD) included in the National Longitudinal Survey of Children and Youth (NLSCY) [29]. Scores can range from 0 to 36, with higher scores indicative of greater family dysfunction [29,30]. Social support was measured with the MOS Social Support Scale [31], which assesses the availability of the following aspects of social support: emotional/informational (expression of positive affect, advice, information, guidance or feedback); tangible (provision of material aid or behavioral assistance); affectionate (expressions of love and affection); and positive social interaction (availability of another person to do fun things together). Higher scores indicate the perception of more social support. This measure

was shown to be valid and reliable in research with patients with chronic conditions [31].

Outcome measures. Caregiving demand was measured with the Care of My Child with Cancer (CMCC) questionnaire [32]. CMCC measures time and effort involved in providing care to a child with cancer in relation to 28 different tasks. Higher scores indicate more demand. This measure was shown to be reliable and valid in caregivers of children with cancer [32,33]. The Short Form 36 (SF-36) was used to measure adult HRQL in terms of a physical and psychosocial health summary score. SF-36 summary scores have a mean of 50 and standard deviation of 10, with higher scores indicating better health. The SF-36 has been shown to have high validity and internal consistency [34].

## **Data Analysis**

Bivariate analysis was used to compare single parent and parents from two-parent families across variables included to measure each construct in the caregiver stress process model. For categorical data, differences between single parents and parents from two-parent families were tested using the chi-square test. The *t*-test and Mann–Whitney *U*-test were used to test equality of mean scores and ranks (depending on the distribution of the data) for each of the stress-process constructs.

Bivariate analysis was also used to identify potential predictors of our outcome variables. Only variables that were associated with the outcome variables at P < 0.05 and r = 0.20 were included in the multiple regression models. The following predictor variables were examined in relation to our outcome variables: child age, child gender, type of cancer, years since diagnosis, relapse status, types of treatment, prognosis, health status, HRQL, parental age, parental gender, marital status, working (yes or no), education, household income, adjusted income, savings, financial impact on family, overall impact on family, mastery, self-esteem, optimism, family function and social support. Regression models for predicting caregiver demand and parental HRQL were then tested. The dichotomous variable for single/two-parent status was entered into the model on the first step, and the other significant bivariate predictors were then entered using stepwise regression. Statistical analyses were performed using SPSS 15.0 software.

Finally, we compared the mean scores for the SF-36 summary scores for single parents and parents from two-parent families with age- and sex-adjusted normative data gathered as part of a prospective cohort study involving 9,423 men and women 25 years of age or older from nine Canadian cities [35]. Effect sizes were calculated by dividing the mean difference in scores by the population standard deviation. We used Cohen's benchmarks for SD units to estimate the clinical importance of differences in mean scores (i.e., 0.20 is small, 0.50 is moderate, and 0.80 is large) [36].

#### **RESULTS**

Comparisons between single parent and parents from two-parent families across the variables included to measure each construct in the caregiver stress process model appear in Table I. Fewer single-parent families (15.8%) reported an annual household income over \$60,000 compared with parents from two-parent families (57.4%) (P < 0.001). Adjusted household income, which adjusts for the number of potential wage-earners in the family, also differed significantly (P < 0.001). Fewer single-parent families (27%)

reported having \$10,000 or more in savings compared with parents from two-parent families (52.2%) (P=0.004). Single parents reported that their child had worse health status (P=0.001) and psychosocial HRQL (P=0.025), and that they themselves experienced more caregiver strain on the financial subscale of the IFS (P=0.002), lower self-esteem (P=0.029), less optimism (P=0.035), lower social support (emotional/informational (P=0.035), tangible (P<0.001), affectionate (P=0.012) and positive social interactions (P<0.007)), and worse physical HRQL (P=0.019) than did parents from two-parent families.

# Contribution of Single-Parent Status to Caregiver Demand

Significant bivariate predictors of caregiver demand included the following: child health status ( $r=-0.488,\,P<0.001$ ); child physical HRQL ( $r=-0.444,\,P<0.001$ ), child emotional HRQL ( $r=-0.536,\,P<0.001$ ); financial impact ( $r=0.386,\,P<0.001$ ); family impact ( $r=0.558,\,P<0.001$ ); mastery ( $r=-0.222,\,P=.001$ ); and family functioning ( $r=0.209,\,P=0.002$ ). Results of the final stepwise regression analyses appear in Table II. After entering into the model the significant predictors of caregiver demand, we found no difference between single parents and parents from two-parent families. Three variables were, however, significant predictors of caregiver demand (child health status, child emotional HRQL and impact on family) combining to account for 49% of the variance in scores ( $R^2=0.491,\,P<0.001$ ).

# Contribution of Single-Parent Status to Caregiver Physical HRQL

Significant bivariate predictors of parents physical health included the following: family savings (r=0.306, P<0.001); adjusted household income (r=0.290, P<0.001); child health status (r=0.281, P<0.001); financial impact (r=-0.268, P<0.001); family impact (r=-0.232, P<0.001); mastery (r=0.210, P<0.001); and tangible social support (r=0.224, P<0.001). Results of the stepwise regression analyses (see Table II) show that after adjusting for these predictors, there was no difference in parental physical health comparing single parents with parents from two-parent families. Four predictors of caregiver physical health (child health status, financial impact on family, adjusted household income, family savings) accounted for 17% of the variance in scores ( $R^2=0.171$ , P<0.001).

# Contribution of Single-Parent Status to Caregiver Psychosocial HRQL

Significant bivariate predictors of parents' psychosocial health included the following: child health status (r = 0.371, P < 0.001); child physical HRQL (r = 0.314, P < 0.001); child emotional HRQL (r = 0.375, P < 0.001); financial impact (r = -0.310, P < 0.001); family impact (r = -0.538, P < 0.001); mastery (r = 0.486, P < 0.001); self-esteem (r = 0.317, P < 0.001); optimism (r = 0.397, P < 0.001); family functioning (r = -0.339, P < 0.001); emotional/informational support (r = 0.320, P < 0.001); affectionate support (r = 0.295, P < 0.001); and positive social interaction (r = 0.391, P < 0.001). Adjusting for significant predictors, we found no difference in psychosocial health comparing single parents with parents from two-parent families (Table II).

TABLE I. Parent and Child Characteristics Comparing Single and Two-Parent Families

Variable	Single-par	ent $(N = 40)$	Two-parer	it $(N = 275)$	P-value
Background/context					
Parent age in years, mean (SD)	39.1	(6.6)	38.6	(6.1)	0.618
No. male (%)	3	(7.5)	38	(13.8)	0.325
No. working (%)	17	(43.6)	110	(40.7)	0.735
No. university education (%)	10	(25)	93	(34.2)	0.248
No. household income $\geq$ \$60,000 (%)	6	(15.8)	152	(57.4)	< 0.001
Adjusted household income in dollars, median (IQR)	15,767	(21,875)	32,500	(27,935)	< 0.001
No. savings $\geq $10,000 \ (\%)$	10	(27)	129	(52.2)	0.004
Child characteristics					
Child age in years, mean (SD)	9.3	(4.4)	8.1	(4.8)	0.145
No. male gender (%)	19	(47.5)	163	(59.3)	0.159
No. cancer type (%)					
Leukemia/lymphoma	32	(80)	188	(68.4)	0.325
Solid tumor	5	(12.5)	55	(20)	
Brain tumor	3	(7.5)	32	(11.6)	
Years since diagnosis, median (IQR)	0.54	(1.17)	0.50	(0.9)	0.534
No. relapse (%)	3	(7.5)	24	(8.7)	1.000
No. surgery to remove cancer (%)	8	(20)	69	(25.1)	0.484
No. bone marrow transplantation (%)	1	(2.5)	30	(10.9)	0.150
No. received radiation (%)	8	(20)	55	(20)	1.000
No. prognosis good (%)	21	(52.5)	144	(52.4)	0.987
Health Status, mean (SD)	64.3	(17.6)	74.0	(16.4)	0.001
Physical HRQL, mean (SD)	47.7	(24.8)	55.6	(25.1)	0.067
Psychosocial HRQL, mean (SD)	56.7	(17)	63.3	(17.2)	0.025
Caregiver strain		. ,		. ,	
Financial impact, mean (SD)	16.8	(3.6)	15.1	(3.7)	0.002
Overall family impact, mean (SD)	44.7	(7.6)	42.5	(7.7)	0.091
Self-perception, mean (SD)		(****)		(***)	
Mastery, mean (SD)	22.7	(5.1)	23.7	(5.3)	0.262
Self-esteem, mean (SD)	23.3	(4.5)	24.7	(3.7)	0.029
Optimism, mean (SD)	19.5	(5.6)	21.4	(4.9)	0.035
Coping factors		( )		( '- /	
Family function, mean (SD)	12.9	(6.8)	11.3	(5.7)	0.124
Social support, mean (SD)		()		()	
Emotional/informational	54.2	(27.2)	62.7	(23)	0.035
Tangible	41.6	(32.8)	61.2	(27.9)	< 0.001
Affectionate	63.5	(33.7)	78.1	(25.2)	0.012
Positive social interactions	55.0	(31.6)	67.6	(26.7)	0.007
Outcome measures		(- 1.0)		(=0.7)	0.007
Caregiving demand, mean (SD)	67.5	(16.3)	66.7	(17.8)	0.815
Caregiver health, mean (SD)	07.0	(10.0)	· · · · · · · · · · · · · · · · · · ·	(17.0)	0.015
Psychosocial health	31.5	(14.1)	33.5	(13.2)	0.380
Physical health	50.1	(9.6)	53.4	(8.1)	0.019

Individuals with unknown values not considered in the calculation of percentages.

Significant predictors of caregiver psychosocial HRQL included mastery, self-esteem, family impact, and the child's emotional HRQL scores. These predictors combined accounted for 44% of variance in parental psychosocial health ( $R^2 = 0.438$ , P < 0.001).

### **Parental Health Compared with Population Norms**

Compared with age- and sex-standardized scores for the two SF-36 summary scales for Canadians, both groups' mean scores for psychosocial HRQL were substantially lower and represent large and clinically important differences (i.e., effect sizes =-2.22 for single parents and -2.00 for parents from two-parent families). The mean score for physical health for both groups of parents did not differ substantially from population norms.

Pediatr Blood Cancer DOI 10.1002/pbc

### **DISCUSSION**

It is currently unknown how the intensive and often prolonged treatment of childhood cancer impacts on the lives of single parents. We attempted to address this question in a multi-centered cross-sectional Canadian study of parents of children receiving chemotherapy.

Contrary to our hypotheses, we did not find any difference in our three outcome measures when scores for single parents were compared with scores for parents from two-parent families. For caregiving demand, our expectation was that the primary caregiver from two-parent homes would report spending less time and less effort caring for their child with cancer because their partner would be helping them out. A possible explanation for our finding of no

TABLE II. Predictors of Caregiving Demand and HRQL

Predictors	β (SE)	P-value	
Caregiving demand			
Single parent	0.086 (0.051)	0.094	
Child emotional HRQL	-0.387(0.063)	< 0.001	
Impact on family	0.329 (0.057)	< 0.001	
Child health status	-0.165(0.064)	0.011	
Physical HRQL			
Single parent	-0.041 (0.058)	0.481	
Child health status	0.206 (0.059)	0.001	
Savings	0.160 (0.071)	0.026	
Adjusted income	0.150 (0.070)	0.033	
Financial impact on family	-0.134(0.061)	0.030	
Psychosocial HRQL			
Single parent	-0.074(0.049)	0.130	
Impact on family	-0.335(0.057)	< 0.001	
Mastery	0.302 (0.064)	< 0.001	
Child emotional HRQL	0.168 (0.052)	0.001	
Self-esteem	0.116 (0.059)	0.050	

difference is that it in two-parent households, one parent may take on virtually all the burden of care or, alternatively, that some single parents may have received help and support from friends, extended family members or the child's other parent. A limitation of our study is that we did not measure the extent of involvement of the other parent in the caregiving process and we are not able to determine the amount of help the primary caregiver received either from within or outside the family to fully explore this possibility. Future research to understand the role that each parent plays in caring for a child with cancer for different family structures is warranted.

For parental physical and psychosocial HRQL, we expected that single parents would report poorer health compared with parents from two-parent families, in line with the research showing that single mothers are at increased risk for physical and mental health problems. While this was not the case in our study, it is important to note that the mean scores for psychosocial HRQL for both groups of parents were substantially lower than population norms for the SF-36. This finding of poor psychosocial health of parents of children with cancer is in agreement with other research using the SF-36 to study mothers of children with cancer in England [37] and in Japan [38]. Our findings are also in agreement with the only other study to examine psychological distress in single parents of children with cancer compared with parents from two-parent families [22]. Iobst et al. found that single mothers and mothers from two-parent families did not differ in terms of negative mood, and perceived post-traumatic. Single mothers did report more symptoms of depression, but these differences disappeared when age and education level were controlled for in the analysis. In addition, all mothers' depressive symptoms scores, regardless of marital status, were elevated compared to normative data. Scores for physical HRQL, on the other hand, indicated that physical health problems were not an important issue for parents in either group.

Although we did not find differences between single parents and parents from two-parent families in our three measures of outcome, our regression analysis helped to identify a number of important predictors of caregiving demand and parental HRQL for parents of children with cancer. Unsurprisingly, we found that greater caregiving demand was associated with having a sicker child (poorer health status) and with the child's health problem having a greater

impact on family life. We found that poorer physical HRQL of parents was associated with lower family savings and adjusted household income, as well as greater financial impact on family. Even though all medically necessary services provided by physicians or received in hospitals in Canada (including most prescription chemotherapy) are covered by a government administered, tax-financed health insurance plan, having a child with cancer generates substantial costs to families. In a clinical setting, team members need to ensure that parents, and especially single parents who are higher risk of financial strain, are made aware of all possible financial resources available to them.

We also found that poorer psychosocial HRQL of parents was associated with higher impact on family, and lower scores for mastery and self-esteem. Self-perception is important in highly stressful circumstances, like dealing with childhood cancer, because of the role it plays in coping and adjustment. More research is needed on the topic of optimism, resilience and other supportive factors.

We also found that poorer physical and psychosocial HRQL of parents was related to their child's health status and emotional HRQL. These findings go along with literature showing a relationship between parental health and the health of their child with cancer. More specifically, parents who reported higher levels of psychological distress had children with more behavioral problems, greater emotional distress, poorer quality of life, and increased feelings of hopelessness [2]. These findings also fit into the broader literature showing that caregivers of children with health problems have greater odds of health problems than do caregivers of healthy children [39,40].

Our study has a number of limitations. First, non-English readers were excluded given the nature of our study (questionnaire survey). Second, our sample represents a convenience sample of parents. While our aim was to recruit as many eligible parents as possible during our 28-month recruitment phase, we cannot discount the possibility that we may have missed some families and that our results could vary if a truly consecutive sample of parents been recruited. Third, it should be noted that 69.8% of children in our sample had leukemia. This proportion is much higher than the incidence rate for childhood leukemia in the general population, which makes up 33% of all childhood cancers [41]. Given that our analyses included all types of cancers, we considered length of time since diagnosis as a variable rather than phase of illness (e.g., new diagnosis, consolidation) as the latter is only relevant to the leukemia group. Fourth, we recognize that our sample of single-parent families was heterogeneous and composed of parents who at the time of the survey reported being divorced, separated, widowed, or never married. As these are very different experiences, they may also be associated with different levels and types of risk. Fifth, we aimed to provide a comprehensive description of the study sample because little is known about single parents of children with cancer. Since this necessitated making multiple statistical comparisons, the possibility of a Type 1 error cannot be discounted. Finally, a cross-sectional study provides only a snapshot of the relationships between caregiving factors. Longitudinal research is needed to determine the impact of caregiving on single parents' health and well-being over time.

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