Published in final edited form as:

Qual Life Res. 2011 October ; 20(8): 1261–1269. doi:10.1007/s11136-011-9854-2.

Quality of Life among Parents of Children with Cancer or Brain Tumors: The Impact of Child Characteristics and Parental Psychosocial Factors

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Keywords

parental caregivers; caregiver burden; perceived stress; health-related quality of life; SF-12; childhood cancer; health; mental health

INTRODUCTION

Childhood cancer is the second leading cause of death among children ages 1 to 14 [1], afflicting 167 children per million each year [2]. In recent decades, improvements in treatment have dramatically increased survival rates [3]. However, survivors face long-term risks to their health and wellbeing [4], including recurrence or second cancers, early death, stunted development or cognitive function, and lower quality of life (QOL) [5].

These long-term consequences of childhood cancer may in turn negatively impact parental caregivers, who have been shown to experience greater stress and worse QOL than both parents of healthy children [6] and the general population [7]. Indeed, the present authors recently published a study [6] implicating stress as a mediator between caring for a child with cancer and poor parental QOL. This previous study, however, addressed only differences between parents of children with cancer and those without. As such, it did not assess potential sources of variation in parental QOL among parents of children with cancer. Specifically this study did not examine the role of child clinical characteristics and subsequent stress and burden in poor parental outcomes. It remains unclear, therefore, which specific factors of the diagnosis, treatment, or late sequelae of childhood cancer have a pronounced negative impact on parental QOL. Understanding these factors is vital to improving the health and QOL of both parents and their children with cancer.

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Disclosure: None of the authors has a conflict of interest with this research.

Much of the literature on the impact of child treatment and diagnostic factors evaluates the long-term adjustment and QOL of the *child* [8–11]. The literature on *parental* outcomes associated with diagnosis and treatment is limited, and conflicting. While some studies have implicated medical factors of treatment or diagnosis -- such as prognosis, type of treatment, or treatment intensity -- in poor parental psychosocial outcomes [7;12–14], others have found no effect for these factors [15–18]. Studies have also presented contradictory results on the impact of other variables, such as time elapsed since cancer diagnosis, survivor impairment, and whether the child is actively receiving treatment [13;15;17–21]. Given that these studies used diverse methodologies, variables, and sources, such inconsistent results are unsurprising. However, the lack of consensus among research into parental outcomes indicates a need for continued examination into how child disease characteristics impact the health and QOL of parental caregivers.

Theory suggests that caregiver burden, role-functioning, and stress may have deleterious effects on the health of caregivers [22–30] and that stress can reverberate throughout the family [31]. Little research, however, has examined the role of these factors in the relationship between the medical characteristics of a child with cancer and their parents' QOL. In extending the previous research, we sought to examine which specific cancer- and treatment-related factors are associated with adverse parental QOL outcomes, and whether caregiver burden and stress mediate these relationships. Understanding these associations will help identify parents at the greatest risk for poor QOL outcomes and potential pathways by which these outcomes occur. Such knowledge promises to improve our ability to support parents of children with cancer and may improve health and QOL outcomes for the entire family.

METHODS

Study Design, Population, and Data Sources

Our case-only sample was drawn from a larger longitudinal study of parents of children with or without cancer or a brain tumor, as described elsewhere [6]. The parent who was most involved in providing support and care to the child was recruited into the study. Parents in this study were defined as biological, step, adoptive or foster parents, grandparents, or legal guardians of the child.

Participants

Parents and their children living with cancer, including malignant brain tumors, or non-malignant brain tumors (hereafter “cases”) were invited to participate in our study. Cases were eligible to participate if the child had received cancer or brain tumor care at a local pediatric hematology and oncology clinic. Eligible families were invited to participate by clinical staff if they attended one of the following during the study period: 1) the child's cancer or brain tumor outpatient or inpatient visit; 2) a parent-provider advisory board meeting; 3) the hospital support groups for parents; or 4) a childhood cancer survivor reunion. In addition, clinical staff mailed an invitational letter to eligible families who could not be contacted in-person. Of the 162 case families invited to participate in the study, 46 declined participation, 24 did not respond to the invitation, 2 were ineligible, and 8 could not be scheduled to participate within the study timeframe. 80 (50% of those eligible) ultimately participated. Of those, 5 surveys were missing data and were removed from this analysis, resulting in a final sample of 75 cases.

Procedures

This study was approved by the Health Sciences Institutional Review Board of the University of Wisconsin-Madison. Written informed consent was obtained from all

participants. Parents provided written Health Insurance Portability and Accountability Act Privacy Rule (HIPAA) authorization for abstraction of the child's medical record. All participating parents completed an in-person interviewer-assisted survey that included items about sociodemographic characteristics, health behaviors, and a series of validated self-reported measures. Participants also completed a follow-up interviewer-assisted phone survey 3–6 months after their initial interview. Baseline interviews were completed between September 2008 and July 2009; follow-up interviews were completed between December 2008 and November 2009. Although data were collected at two time points, data were analyzed cross-sectionally in these analyses.

Measures

Outcome Measure—The *Short Form-12* (SF-12) version 2, a widely used measure of health status, was used to assess the overall health-related QOL of the parents [32–34]. The SF-12 has eight subscales which were condensed into two summary scales: the physical health component score and the mental health component score. The test-retest reliability for the summary scores is 0.89 and 0.76, respectively [33].

Independent Variables

Child clinical characteristics: Key diagnosis and treatment variables were abstracted from the child's medical record by a trained and licensed clinician. These factors included type of cancer (leukemia/lymphoma, Central Nervous System (CNS) tumor, or non-CNS tumor), treatment status at the time of the interview (active/maintenance treatment or off treatment), time since diagnosis (years between the date of diagnosis and date of interview), any type of treatment received (chemotherapy, radiation, surgery, and/or transplant), having one or more complications during treatment, and having a recurrence of the primary cancer. Children were grouped into categories for type of cancer by a trained physician based on their cancer diagnosis; these categories were chosen based on clinician consultation, and are similar to other studies of children with cancer [12;21]. Children's symptom severity during treatment was reported by parents during the baseline interview on a 5-point Likert scale, ranging from 0 (no symptoms) to 4 (very severe symptoms).

Children were considered to have an activity limitation if their parent indicated that the child was "limited or prevented in their ability to do the things most children of the same age can do" because of a medical, behavioral, or other health condition that had lasted or was expected to last for at least 12 months. This question was asked at the baseline and follow-up interviews.

Parental report of children's psychosocial problems was measured by the Columbia Impairment Scale (CIS), an instrument that includes 13 questions about a child's emotions, engagement in everyday activities, and ability to get along with others. The CIS has been shown to have good psychometric properties and to be highly correlated with mental health symptoms, service use, and other mental health measures [35–37]. This was measured at the baseline and follow-up interviews.

Parental psychosocial and behavioral factors: Parents' perceptions of stress symptoms in the week prior to the interview were measured using the 56-item Calgary Symptoms of Stress Inventory (C-SOSI) [38], which explores both physical and psychological manifestations of stress. Responses for the C-SOSI are recorded on a 5-point Likert scale ranging from 0 (never) to 4 (very frequently) and summed across subscales. Internal consistency for the subscales ranges from 0.80 to 0.92, with an overall Cronbach's $\alpha = 0.95$ for a validation population of adult cancer patients [38]. The C-SOSI was collected at the baseline and follow-up interviews.

Perception of stress over the last month was measured using the 4-item version of the *Perceived Stress Scale (PSS)*. Responses for the PSS 4 are recorded on a five point Likert scale ranging from 0 (never) to 4 (very often) and summed across the four items to provide a total score. Higher scores indicate higher perceived stress [39;40]. The PSS was collected at the baseline interview only.

Parent-reported caregiver burden was measured using the Caregiver Reaction Assessment (CRA), a 24-item multidimensional instrument designed to measure both positive and negative reactions to caregiving [41]. Responses for the CRA were recorded on a five point Likert scale ranging from 1 (strongly disagree) to 5 (strongly agree) and subscales were averaged across the respective items. Construct validity coefficients for this assessment's subscales range from 0.78 to 0.92 [42–44]. Internal consistency coefficients for the subscales ranged from 0.62 to 0.83 [45]. The CRA was collected at the baseline interview only.

Parent sleep quality and disturbance over the past month was measured using the Pittsburgh Sleep Quality Index (PSQI) [46;47]. A total score was derived by summing all items. Good reliability for the PSQI has been found across all diagnostic groups (Cronbach's $\alpha = 0.80$) [48]. The PSQI has been utilized in studies of caregivers of patients with cancer [49;50]. The PSQI was collected at the baseline interview only.

Sociodemographic characteristics of children and parents: Child age and gender were reported by their parent in the survey. Parental age, gender, marital/partner status (married/partnered or unmarried/unpartnered), race (white or non-white), Hispanic heritage (yes or no), educational attainment (some college or less versus college graduate or higher), employment status (full-time work, part-time work, or not working outside the home), relationship to the child (biological parent versus adoptive, foster, or step parent or grandparent), number of people in the household, and family income were evaluated in the survey.

Analytic Approach

Sociodemographic characteristics, child clinical characteristics, and parental psychosocial and behavioral factors were summarized using descriptive statistics. Parental QOL was measured at up to two time points for each participant: baseline and/or 3 to 6 months later. For variables measured at both time points (child activity limitation, child psychosocial functioning, child active or maintenance treatment status, and symptoms of stress), covariate effects were assumed to be the same at both visits; interaction tests were performed to validate this assumption. For variables measured only at the baseline interview (perceived stress, caregiver burden, and sleep), covariate effects were allowed to vary by visit to account for the potentially different effects of contemporaneous and lagged variables on outcomes. In the results section, only the effects of contemporaneously assessed variables are presented and discussed.

For the regression analyses, we used generalized linear models (identity link, constant variance) with Generalized Estimating Equations (GEE) methods to account for correlation within subjects [51;52]. The models were fit to identify contemporaneous child factors associated with parental QOL at two time points, while adjusting for contemporaneous parental characteristics. The GEE approach efficiently uses all of the available information to estimate the effects of covariates measured at both visits on parental QOL. Based on our conceptual model, the aforementioned parent and child characteristics were included in the regression model by examining the statistical significance of each covariate to the outcome variable. Parent age was included in the regression model *a priori*.

A series of regression analyses were conducted to determine which specific cancer- and treatment-related factors were associated with adverse parental QOL outcomes, and whether caregiver burden and stress mediated these relationships. Model 1 examined only the relationship between child treatment factors and parental QOL, controlling for parental characteristics. For each outcome (mental health-related QOL and physical health-related QOL), caregiver burden was then added to Model 1 to test if burden impacted the relationship between child factors and parental QOL (Model 2). Finally, self-reported stress variables were then added to Model 2 to test if stress mediated the relationship between child factors and parental QOL (Model 3). Then, we examined Model 3 to assess if the coefficients for child activity limitation status and active treatment status were changed, as a result of the inclusion of the stress and burden variables.

In order to further assess the mediation, we used Sobel tests [53] to determine the statistical significance of the mediating effects on the relationship between the independent and dependent variables. Specifically, these tests were used to determine if and to what extent caregiver burden, symptoms of stress and perceived stress significantly mediated the relationship between child activity limitations and parental mental QOL, as well as between child's active treatment status and parental mental QOL.

RESULTS

The final sample included 75 children with cancer and their parent who was most involved in caregiving, of whom all but 3 were the child's biological parent. All parents were living with the child at the time of the interview (data not shown).

Table 1 describes the sociodemographic and psychosocial characteristics of the parents. Parents were between 22 and 52 years of age, with mean age of 41.1 years. They were mostly (over 90%) female, white (non-Hispanic) and married or partnered. Over half were college graduates, and nearly half were employed full-time. Mean annual income was \$83,611, ranging from \$8,000 to \$250,000. Over half of the parents experienced problems sleeping. Caregiver burden scores ranged from 28 to 87 points, with a mean of 48.9 points. Perceived stress scores ranged from 0 to 12 points, with a mean of 4.7; symptoms of stress ranged from 0 to 120 points, with a mean of 35.1. Compared to the national means for the US (standardized at a score of 50), parents reported worse mental health QOL (46.1), and better physical health QOL (54.4).

Table 2 depicts the children's characteristics, including age, gender, and clinical characteristics. On average children were 10.1 years old, and just over half were male. Time since diagnosis ranged from a few months to more than 14 years; nearly two-thirds of children were less than 5 years from diagnosis. Almost half had been diagnosed with leukemia or lymphoma, and nearly 40% were on active or maintenance treatment at the baseline interview. Most children (almost 90%) received chemotherapy while nearly 50% received surgery, 20% received radiation treatment and just under 7% received a transplant (treatment types are not mutually exclusive; many children received more than one type of treatment). 77% of the sample had experienced one or more complication during their treatment, and 10.7% had a recurrence of their cancer by the time of the baseline interview. The severity of the child's symptoms during treatment ranged from 0 (no symptoms) to 4 (very severe symptoms), with a mean of 2.6. More than half reported child activity limitations and 17.1% of children reported psychosocial problems.

To evaluate the impact of child clinical characteristics on parental QOL, regression models were fit separately for the mental health and physical health components of the SF-12. Multivariate analysis (Table 3) showed that both child and parent characteristics were

associated with parental mental QOL after controlling for confounders. Having a child with an activity limitation was associated with significantly worse mental health (5.4 points lower, $p<0.0001$), as was having a child on active or maintenance cancer treatment (4.4 points lower, $p=0.01$). Controlling for time since diagnosis and other treatment factors did not impact these results (data not shown). Being married or partnered was associated with significantly better mental QOL (7.2 points higher, $p=0.03$). Having a college degree or more education and reporting sleep problems were associated with significantly decreased mental QOL (4.8 points lower, $p<0.0001$ and 7.9 points lower, $p<0.0001$, respectively).

As a second step, we added caregiver burden to the model to determine if level of burden mediated the relationship between child characteristics and poor mental health. When burden was included in the model of poor mental health, the effect of having a child with an activity limitation was attenuated, but remained significant (3.8 points lower, $p=0.01$). The effect of having a child on active or maintenance treatment was approximately halved and was no longer statistically significant (2.2 points lower, $p=0.16$). A Sobel test for caregiver burden revealed this to be statistically significant mediation of the child's active treatment status on poor parental mental QOL (Z -value: -3.3 , $p=0.0009$). Including caregiver burden in the model also attenuated the effects of being married or partnered, being highly educated, and experiencing poor sleep.

As a final step, we added symptoms of stress and perceived stress to the model to determine if these further mediated the relationship between child characteristics and poor mental health. After adding stress to the model, the effect of having a child with an activity limitation was further attenuated, but remained marginally significant (2.3 points lower, $p=0.06$), while the effect of caregiver burden was completely explained. Sobel tests revealed that both symptoms of stress and perceived stress significantly mediated the relationship between child activity limitations and parental mental QOL ($Z=-2.5$, $p=0.01$ and $Z=-2.9$, $p=0.003$, respectively). The effect of poor sleep was also attenuated by controlling for stress.

Multivariate analysis showed that only children's symptom severity was associated with parental physical health QOL (2.0 points lower, $p=0.01$). This relationship was not mediated by parental psychosocial factors (data not shown).

DISCUSSION

To our knowledge, this is the first study to examine how parental burden and stress impact the relationship between child clinical characteristics and parental mental QOL among parents of children with cancer and brain tumors. Our results indicate that both caregiver burden and parental stress mediate this relationship. This supports our recent study comparing these parents with a control group which identified stress as a mediator of the relationship between being a caregiver for a child with cancer and poor parental QOL [6]. The present study adds to these findings by clarifying that stress also mediates the relationship between specific characteristics of a child's cancer diagnosis, treatment, or sequelae and poor parental QOL. These findings suggest a potential pathway by which child clinical characteristics may impact parental well-being and account for variation in QOL among parents of children with cancer. Specifically, increased burden due to caregiving may result in greater stress for parents, thereby negatively impacting parental mental QOL. This finding suggests possible points of intervention to help improve parental QOL through reducing caregiver burden and stress.

Child impairment has been shown to be significantly associated with distress among parents of children with chronic conditions [54], but has been understudied among parents of

children with cancer. Moreover, those studies that exist have provided conflicting results [17;55]. The findings for active treatment status are similar to previous research [15;18–20]. Our research, however, provides insight into the mediating mechanism by which the characteristics of a child's cancer may adversely impact parental outcomes.

Several parental factors remained significant predictors of parental mental QOL after controlling for confounders. Unsurprisingly, being married or partnered was associated with better QOL while poor sleep quality was associated with worse QOL. Being married or partnered may have a buffering effect against poor mental health outcomes, possibly through the protective effects associated with social support [56;57]. The findings on poor sleep quality support results from a recent study [7]. Since sleep habits are a modifiable behavior there may be promising avenues for improving sleep hygiene and potentially QOL outcomes.

Our results show that higher parental education is associated with worse QOL. Although this finding may be counter-intuitive, similar results have been reported among both parents of children with cancer [7] and caregivers of children with chronic illnesses [54]. Highly educated individuals prefer to be actively involved in the medical decision-making process [58]; in parents of children with cancer, this preference may increase their stress and negatively impact their QOL. Such parents may also be more likely to seek out information relating to their child's cancer, or be more familiar with the short- and long-term risks that their children face. This could potentially lead to increased fear or worry and worse QOL outcomes.

Although the parents in this study fared relatively well compared to national norms, the same population was recently shown to have significantly worse mental QOL than a control group [6]. As such, the findings of this study present a number of implications for clinicians and caregivers alike. Given that parental distress has been associated with child psychological maladjustment [59;60], self-care in parents of children with cancer is important in maintaining the health of the whole family. Pediatric practitioners and their patients will benefit from an awareness of the potential effect of treatment and activity limitation status on the child's caregiver. Parents' providers, too, should be cognizant of the potential impact of caregiving on the health and QOL of their adult patients. Screening parents for excessive burden, stress, or mental health problems, and assisting them to find appropriate support services or treatment may be essential in improving the health and QOL of both parents and children.

Parental caregivers themselves should be made aware that caring for a child with cancer, especially one on active treatment or with an activity limitation, could lead to poor QOL. Understanding the potential benefit of reducing burden, controlling stress levels, and seeking social support may help parents and their families cope with their caregiving role and improve their health and well-being. Future longitudinal research should examine these relationships among a larger cohort of subjects. This would facilitate further evaluation of the long-term, causal impact of child characteristics on parental health and QOL, and the impact of burden and stress on these relationships. In addition, future studies should examine whether interventions that target these factors have a salutary impact on parent or child outcomes.

This study has several limitations. First, a relatively small sample size limited our ability to fully evaluate the impact of child characteristics on parental mental and physical health. Although other studies were of similar size, future research should recruit a larger cohort of children in order to gain additional statistical power. Second, although child activity limitation status was based on parent reports (which may be influenced by parents' own

health and mental health status), parents are often the best source of information about their children's abilities. In addition, our participation rate was 50%. Unfortunately, due to our recruitment strategy we were unable to assess if and to what extent specific factors systematically influenced participation in our study. Although other clinic-based studies have reported similar participation rates [61–63], our results should nevertheless be interpreted with caution. Finally, the study sample was limited to cases receiving care at a local pediatric hematology and oncology clinic. Therefore, our results may not be generalizable to other populations.

This study also has important strengths. GEE methodology allowed us to evaluate the impact of child factors on parents at two time points. Moreover, this study provides important insight into the potential mechanisms by which caring for a child with cancer adversely impacts parental QOL. This information will be critical in designing and implementing effective and sustainable interventions to support parents who are experiencing excessive burden and stress, which may ultimately help prevent poor QOL outcomes.

CONCLUSION

In conclusion, this study extends previous research on the impact of childhood cancer on the family by examining the role of child clinical characteristics on parental QOL in a sample of parents of children with cancer and brain tumors. The findings show that caregiver burden and stress mediate the effect of caring for a child who is in active cancer treatment or has activity limitations on parental mental health-related QOL. This finding confirms that child treatment characteristics and long-term sequelae, as well as caregiver burden and stress, should be considered when evaluating caregiver QOL, and underscores the importance of understanding how burden and stress impact parental QOL outcomes. This information is critical in effectively intervening with families and could ultimately help improve health outcomes for children with cancer, reduce health disparities among these children, and address the health of parents and families of children with cancer.

Acknowledgments

We would like to thank the families who participated in this study. Special thanks go out to Hilary Spear for her assistance with the literature review for this manuscript and to Diane Puccetti, Peggy Possin, Kristin Casey, Beth Severson, and Peter Knight, who were instrumental in study recruitment. The follow-up portion of this study was administered by Survey Research Shared Services of the University of Wisconsin Carbone Cancer Center (UWCCC), with the help of Nathan Jones and Kathy Peck. This research was supported by a grant from the National Institute of Child Health and Human Development (HD049533, W.P. Witt, Principal Investigator and Waisman Center P30 HD03352, M.M. Seltzer, Principal Investigator), UWCCC Investigator Initiated Trial, and the University of Wisconsin Care for Kids Foundation. Thanks to colleagues Lauren Wisk, Erika Cheng, and Paul Creswell for their careful read and feedback on this paper. We would also like to thank Dr. Youngmee Kim and the two anonymous reviewers for their helpful comments.

Abbreviations

QOL   Quality of Life

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Table 1

Characteristics of Parents of Children with Cancer or Brain Tumor and Childhood Cancer or Brain Tumor Survivors

Parental Characteristics	Mean (SD) or %
Total	75 (100%)
Age	41.1 (6.5)
Gender	
Female	90.7%
Male	9.3%
Race	
White	94.7%
Non-white	5.3%
Hispanic Heritage	
No	98.7%
Yes	1.3%
Marital/Partner Status	
Married/Partnered	93.3%
Unmarried/Unpartnered	6.7%
Education	
Some college or less	48.0%
College graduate or higher	52.0%
Employment	
Full-time	45.3%
Part-time	34.7%
Not working outside the home	20.0%
Household Size	
Less than or equal to 4	37.3%
More than 4	62.7%
Income	83,611 (44,778)
Sleep Problems	56.0%
<i>Psychosocial Factors</i>	
Caregiver Burden	48.9 (12.0)
Perceived Stress	4.7 (2.9)
Symptoms of Stress	35.1 (23.2)
Mental Health-Related Quality of Life	46.1 (9.7)
Physical Health-Related Quality of Life	54.4 (6.4)

Table 2

Characteristics of Children with Cancer or Brain Tumor and Childhood Cancer or Brain Tumor Survivors

Child Characteristics	Mean(SD) or %
Total	75 (100%)
Age	10.1 (4.8)
Gender	
Male	52.0%
Female	48.0%
Diagnosis	
Leukemia/lymphoma	49.3%
CNS tumor [§]	33.3%
Non-CNS tumor [§]	17.3%
Time since diagnosis	
<1 year	22.7%
1 to <2 years	17.3%
2 to <5 years	25.3%
5 to <10 years	22.7%
>10 years	12.0%
Treatment Status	
Active/maintenance	38.7%
Off treatment	61.3%
Type of Treatment [†]	
Chemotherapy	89.3%
Radiation	20.0%
Surgery	49.3%
Transplant	6.7%
Had 1 or more treatment complications	77.3%
Had a recurrence of cancer	10.7%
Symptom Severity	2.6 (0.9)
Activity Limitation	51.4%
Psychosocial Problems	17.1%

[†] Categories are not mutually exclusive[§] CNS: Central Nervous System

Table 3

Impact of Child Characteristics, Caregiver Burden, and Parental Stress on Mental Health-Related Quality of Life among Parents of Children with Cancer and Childhood Cancer Survivors[§]

	Model 1			Model 2			Model 3		
	Beta	SD	p-value	Beta	SD	p-value	Beta	SD	p-value
Intercept	49.35	3.99		49.40	3.69	<0.0001	48.22	3.13	
<i>Child Characteristics</i>									
Child Activity Limitation	-5.44	1.42	0.0001	-3.77	1.41	0.008	-2.32	1.23	0.06
On Active Treatment	-4.41	1.71	0.01	-2.21	1.57	0.16	-1.50	1.39	0.28
Received Radiation	3.53	2.22	0.11	1.81	1.94	0.35	0.14	1.63	0.93
<i>Control Variables</i>									
Parent Age [¥]	0.14	0.15	0.34	0.01	0.13	0.93	0.08	0.12	0.47
Married/Partnered	7.15	3.24	0.03	4.08	3.15	0.20	5.20	2.37	0.03
Highly Educated	-4.82	1.63	0.0032	-3.37	1.50	0.02	-3.40	1.26	0.007
Poor Sleep	-7.89	1.88	<0.0001	-6.40	1.79	0.0003	-3.87	1.58	0.01
<i>Parental Burden and Stress</i>									
Caregiver Burden [¥]	--	--	--	-0.32	0.07	<0.0001	0.00	0.06	0.99
Perceived Stress [¥]	--	--	--	--	--	--	-1.80	0.34	<0.0001
Symptoms of Stress [¥]	--	--	--	--	--	--	-0.09	0.04	0.01

[¥] Centered at median

[§] Controls for the interaction with interview stage (follow-up or baseline) for variables that were not measured at follow-up: poor sleep, caregiver burden, and perceived stress.