

children was influenced significantly by children's age but not affected by income or location of residence in Japan. Results of this study will be

useful for further delineation of health care-seeking behavior of children in the context of a health care system unique to Japan.

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Clinicians' perspectives on support for children with a parent who is diagnosed with breast cancer

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Abstract

Background There are few data on clinicians' perspectives regarding support for children who have a parent who has been diagnosed with breast cancer. The purpose of this study was to survey the attitudes of physicians and nurses regarding the care of children who had a parent diagnosed with breast cancer.

Methods A survey was mailed to 898 physicians and 135 nurses who were members of the Japanese Breast Cancer Society in 2009. They were asked to answer questions about their attitudes toward and current practice regarding care for children who had a parent with breast cancer.

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Results A total of 340 surveys (284 physicians and 56 nurses) were used in this analysis. The mean age of the respondents was 47.2 years, and their mean number of years of practice was 21.7 years. While 69.1 % of them reported that they felt it important for people in their roles to provide support for children, 84.4 % felt they could not provide sufficient support. The results also suggested that female gender in practitioners and nurses as opposed to doctor status seemed to be associated with preference for intervention, current practice of intervention, and recognition of difficulty to support.

Conclusions Physicians and nurses express a variety of opinions with regard to support for children with a parent who has breast cancer. It is important to cooperate with other specialists including physicians, nurses, and psychologists and allocate roles appropriately among them to improve outcomes for these children.

Keywords Parental cancer · Support for children · Physician and nurse preference

Introduction

The National Cancer Institute estimates that 24 % of adults with cancer are parenting children younger than 18 years of age [1]. Maternal cancer, particularly breast cancer, is most likely to affect families with children, because women in their 30s, 40s, and 50s are at higher risk of developing cancer than men [2]. Of more than 2 million women in the USA currently diagnosed with breast cancer, 35 % are younger than 55 years of age and are likely to have at least one child living in their home [3]. Similarly in Japan, it is expected that the incidence of breast cancer patients who have a child will increase over time [4]. As a

result, women with breast cancer often face the challenge of raising a family while undergoing intense treatment and coping with the psychological ramifications of having cancer, such as the fear of recurrence and/or physical incapacitation. They want to take good care of their children but are often too distressed, symptomatic, or overwhelmed by external pressures to be the parent they want to be [5]. Even though they are often aware of their children's emotional needs, mothers with cancer may knowingly place their children's needs second to their own, because they lack sufficient energy to listen [6]. This will further increase these mothers' levels of distress [7].

Children of a parent with breast cancer have been observed to be at increased risk of having psychosocial problems such as anxiety and depression as well as physical symptoms, such as headache, stomachache, dizziness, sleeping problems, and loss of appetite [7–9]. They may also face many changes in daily family routines because of repeated hospital admissions, hospital visits, and caring for their parent at home [8]. Some studies also indicate that when mothers with breast cancer are distressed, their children may be at risk of adjustment problems [7, 8].

On the other hand, studies have found that better psychological functioning of parents with breast cancer is associated with better psychological functioning of their children [10]. Parents battling cancer are encouraged by watching their children grow up healthy and happy. Therefore, psychosocial support for the children of parents with breast cancer is important from the viewpoint of total care of these parents. Although patients generally want their healthcare team to assist with their family's needs, many physicians do not have direct contact with their patients' children [11]. Little is known about the attitudes of healthcare providers regarding the care of children of parents who have been diagnosed with breast cancer. The purpose of this study was to survey these attitudes among physicians and nurses.

Participants and methods

Participants

Our study was a cross-sectional, anonymous, multicenter, nationwide survey of physicians and nurses in Japan. Questionnaires were mailed to all the medical specialists ($n = 898$) and certified nurses ($n = 135$) who were members of the Japanese Breast Cancer Society in 2009.

Survey instrument

The survey instrument was developed by the investigators (see Appendix). The survey included questions regarding

physicians' and nurses' attitudes toward, commitment to, and evaluation of children of parents with breast cancer. The survey also included demographic information about participants' age, gender, practice environment, and the number of years since they had completed their formal training.

Attitude toward psychosocial support for children whose parent has been diagnosed with breast cancer

Participants were asked about their attitudes toward psychosocial support for children whose parent had been diagnosed with breast cancer, using a 4-point Likert scale with the following options: (1) We should avoid intervening, (2) we should avoid intervening as much as possible, (3) we should try to intervene as much as possible, and (4) we should intervene. They were also asked to freely describe their reasons.

Current practice of psychosocial support for children of parents with breast cancer

Participants were asked about their current support practices for children whose parent had been diagnosed with breast cancer, using a 4-point Likert scale: (1) I do not intervene at all, (2) I hardly intervene, (3) I intervene as much as possible, and (4) I always intervene. They were also asked to freely describe their reasons.

Content of support and its evaluation

We asked only those participants with experience supporting children whose parent had been diagnosed with breast cancer to describe their interventions and successful and unsuccessful experiences. Participants were asked a multiple-choice question regarding intervention content, and were asked to describe their experiences in detail regarding successful and unsuccessful intervention experiences.

The survey was initially piloted on three physicians to examine the clarity and validity of the instrument. It was mailed to the participants after revisions were made following the pilot study. The survey questions were printed on both sides of a cardstock sheet and mailed with a cover letter explaining the study's purpose and how to return it.

Statistical analysis

All the survey data were coded and entered into a database using standard statistical software (SPSS version 17.0 for Windows). The descriptive statistics derived included the following: proportions, means, and standard deviations or medians and ranges. Preference to intervene or not was

entered into the analysis as a dependent variable, and associated factors were assessed by univariate and multivariate analysis. Socio-demographic factors were compared using Fisher's exact test and the *t* test. Socio-demographic variables that significantly correlated with a dependent variable in the univariate analysis were entered into the logistic regression analysis.

We also conducted descriptive analyses on the content and evaluation of support. Fisher's exact test was used to test group differences in the responses for each category. For comparisons between groups, an absolute value of standardized residual of more than 1.96 indicated statistical significance [12].

Qualitative data were coded and similar codes were grouped together into categories by two psychologists and one physician. These categories were then labeled on the basis of their content.

Results

Demographic data

Of the 933 questionnaires mailed to physicians and nurses, 316 physicians and 67 nurses returned questionnaires, amounting to a physician response rate of 35.2 %, and a nurse response rate of 49.6 %. Of the returned questionnaires, 32 physicians and 11 nurses were excluded because of missing data on the primary points of investigation. Respondent demographic characteristics are listed in Table 1. Physicians accounted for 83.5 % of respondents, and 71.5 % were men. The respondents' mean years in practice were long (physicians 23.0 years, nurses 15.2 years) because we surveyed

Table 1 Demographic data (*n* = 340)

	Physician (<i>n</i> = 284)	Nurse (<i>n</i> = 56)
Age		
Mean (SD)	49.1 (8.0)	37.6 (5.0)
Range	33–75	27–53
Years in practice		
Mean (SD)	23.0 (7.9)	15.2 (4.8)
Range	9–46	6–30
Gender		
Male	243	0
Female	41	56
Practice environment		
Cancer unit hospital	108	35
Usual hospital	68	3
University hospital	76	17
Clinic	29	1
Others	3	0

medical specialists and certified nurses, who require additional time to achieve their professional status.

Physicians' and nurses' attitudes towards supporting children

Physicians and nurses were asked to choose one of the four responses that best summarized their attitudes towards supporting children who had a parent diagnosed with breast cancer. As depicted in Fig. 1, 69.1 % preferred to intervene and 30.9 % preferred not to intervene. The results of the univariate analysis of demographic characteristics for preference with regard to intervention are shown in Table 2. The variables that were significantly associated with preference for intervention were age ($p = 0.019$), occupation ($p < 0.001$), and gender ($p < 0.001$). Using these significant factors in univariate analysis, we conducted a logistic regression analysis to identify independent factors for preference for avoiding intervention (Table 2). The results revealed gender to be significantly associated ($p < 0.001$) with preference for avoiding intervention. Occupation showed borderline significance ($p = 0.065$) in multivariate analysis.

The reasons why these professionals prefer to intervene or not intervene were examined through their free descriptions. We could only extract and categorize physicians' descriptions, because we did not receive any replies from nurses in this area. The categories are listed in Table 3. Physicians who preferred not to intervene cited problems such as medical system issues, positional constraints, and the lack of appropriate knowledge. On the other hand, physicians and nurses who preferred to intervene indicated the importance and benefit of support for children and their parents.

Current practice of support

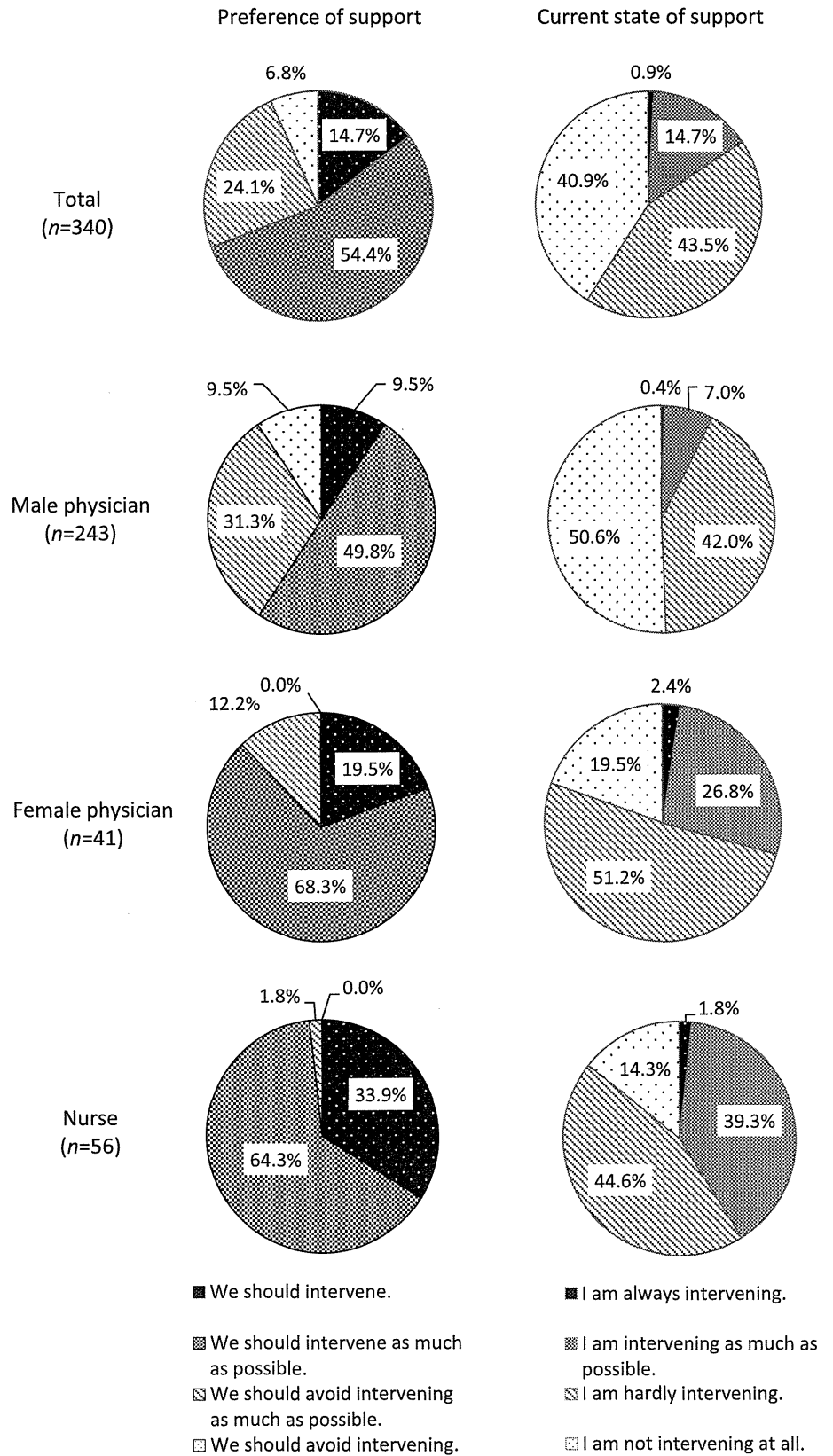
Regarding actual intervention, 84.4 % of all respondents reported that they did not or hardly ever intervened, and only a few physicians or nurses always intervened with children of breast cancer patients (Fig. 1).

Physicians and nurses who wanted to intervene but could not do so were queried on the reasons why they could not; they replied using free descriptions. The answers were as follows: "lack of opportunity to meet children," "support system issues," "anxiety of intervention," "low-priority category in daily context," "family issues," and "few requests for support from patients" (Table 4).

Content and evaluation of support

Physicians and nurses who were trying to intervene but could not were queried about their methods of support using multiple-choice questions. The results are shown in Table 5. Male physicians were less likely to give

Fig. 1 Attitude toward (*left column*) and current practice (*right column*) of psychosocial support for children who have a parent diagnosed with breast cancer. Many of the physicians and nurses reported that they felt it preferable to support children of breast cancer patients, but in practice they could not provide sufficient support



counseling to their patients ($p < 0.001$), whereas nurses were more likely to give counseling ($p < 0.001$) and/or provide brochures on support ($p = 0.010$).

Participants were also asked to evaluate the methods of support they provided and describe their experiences in detail. In terms of effectiveness, 52.4 % of all respondents

Table 2 Factors associated with preference of avoiding intervention (*n* = 340)

Characteristic	Univariate analysis			Multivariate analysis		
	Prefer to intervene (<i>n</i> = 235)	Not prefer to intervene (<i>n</i> = 105)	<i>p</i>	Odds ratio	95 % CI	<i>p</i>
Age	45.8 ± 8.9	50.5 ± 7.3	0.019	1.0	0.9–1.1	0.356
Years in practice	20.7 ± 8.2	24.2 ± 7.3		–	–	–
Occupation						
Nurse	55 (98.0 %)	1 (1.8 %)	<0.001	1	0.9–72.2	0.65
Physician	180 (63.0 %)	104 (36.6 %)		7.9		
Gender						
Female	91 (93.8 %)	6 (6.2 %)	<0.001	1	1.6–11.5	<0.001
Male	144 (59.3 %)	99 (40.7 %)		4.2		
Practice environment						
Cancer unit hospital	102 (71.3 %)	41 (28.7 %)	0.066	1		
Usual hospital	50 (70.4 %)	21 (29.6 %)		0.8	0.4–1.5	0.407
University hospital	60 (64.5 %)	33 (35.5 %)		1.3	0.7–2.4	0.417
Clinic	23 (77.0 %)	7 (23.3 %)		0.6	0.2–1.5	0.257

Logistic regression analysis used the respondents who prefer not to intervene as the dependent variable

Table 3 Reasons why physicians and nurses prefer to intervene or avoid intervening to support children who have a parent diagnosed with breast cancer

Reasons to avoid intervening	Reasons to intervene
Intervention is not necessary	On an empirical basis
Uncertain about supporting children	The patients requested that I do so
I cannot determine whether intervention is suitable	I met many children who were worried
I do not know whether a physician/nurse should intervene	I felt that intervention was necessary
It may become excessive meddling	Scientifically proven
Depends on circumstances	Impact of cancer on patients
It changes with the patient's condition	Treatment is stressful for patients
It changes with their family	It takes a long time to treat their disease
Responsibility issues	Many patients who have a child are young and are women
We cannot have responsibility in a result of intervention	To improve the patient's quality of life
It is necessary to obtain parents' permission to intervene	To assess the needs
Support system issues	Impact of cancer on the patient's children
There is no medical treatment fee	Children feel anxiety, fear, and loneliness
It is difficult to find sufficient time to support children	Parental cancer will affect their child's development
The system for intervention is insufficient	There are few opportunities for children to express their fears
We should leave it to a specialist.	Children should be mentally prepared for their parent's death
Lack of knowledge about supporting children	Importance of support as a family
Family issues	The child is a member of a family
It is too private to intervene	Family issues have an impact on the patient's condition
We should leave it to the family	We should treat the entire family as a patient
Parents prefer not to tell their children the truth	Supporting children aids patient's medical treatment effectively
Intervention may have adverse effects on the children	

rated their support as effective, in that it positively impacted the patient, child, and family; 9.7 % ranked their intervention as ineffective, because nothing had changed; and 37.9 % replied “neither,” because it was difficult to

evaluate the interventional effect on the children or they did not have much experience in that area. There was no statistical difference among the responses of male physicians, female physicians, and nurses (Table 6). Regarding

difficulty, 24.3 % of respondents thought that support was difficult, in that it strayed from family policy, the child refused help, the provider lacked knowledge on how to support children of sick parents, or the provider had no opportunity to meet the patient's children; 36.9 % ranked their intervention as easy, because the child support provider offered their services at the parent's request; and 38.8 % replied "neither," because they did not have much experience in that area or it depended on the case. The results of Fisher's exact test (Table 6) show that male physicians were least likely to consider intervention difficult ($p < 0.05$) and nurses were most likely to consider it difficult ($p < 0.01$).

Table 4 Reasons why physicians and nurses who prefer to support these children cannot intervene sufficiently

Items
Lack of opportunity to meet children
Support system issues
It is difficult for me to find sufficient time to support children
The child-support system is limited
There are few specialists
Lack of understanding within the medical community
Anxiety of intervention
I am concerned about intervening in a half-hearted manner
I cannot take sufficient responsibility for intervention
Lack of knowledge about child support
Low-priority category in daily matters
Family issues
Parents prefer not to tell the truth to their children
I should leave it to the family
Few requests for support from patients

Discussion

Breast cancer has been the most frequently diagnosed form of cancer among Japanese women since the mid-1990s [13]. A rapid increase in the incidence rate of breast cancer was seen among middle and old age groups, especially 45- to 64-year-olds. In 2006, a clear peak in the incidence rate was seen in this age group [14]. Therefore, the incidence of breast cancer patients who have a child at the time of diagnosis will increase over time [4]. Studies show that parental cancer is associated with significant risk of developing various psychosocial problems in both patient and children [8, 15]. Our survey may be the first to examine physicians' and nurses' attitudes toward supporting children who have a parent diagnosed with breast cancer in Japan.

The data from this study include several notable findings. First, 69.1 % of the physicians and nurses in this study reported that they felt it preferable to support children of breast cancer patients, but many of them felt they could not provide sufficient support. These data indicate several difficult issues in the area of psychosocial support for children of sick parents. First are medical system issues such as shortage of people and resources, lack of understanding, and cost of medical care. In North America and Europe, there are some systematic programs of support for children of sick parents, such as the children of somatically ill parents (COSIP) project [16–18], and an adequate number of specialists in many hospitals in areas related to psychosocial support for children, such as CLSs and psychologists. However, in Japan there are few systematic programs or specialists in support for children, so that it is left to each physician's or nurse's discretion. It could lead to the introduction of a comprehensive care service in

Table 5 Responses to survey question about content of child support ($n = 111$)

	Physician						Nurse ($n = 41$)			p^a
	Male ($n = 50$)			Female ($n = 20$)						
	<i>N</i>	%	Standardized residual	<i>N</i>	%	Standardized residual	<i>N</i>	%	Standardized residual	
Provide counseling to their patients	29	58.0	-3.9**	16	76.2	0.5	39	95.1	3.7**	<0.001
Provide brochures on child support	20	40.0	-1.8	7	33.3	-1.4	28	68.3	3.0**	0.10
Counseling to the children	19	38.0	0.8	5	23.8	-1.0	14	34.1	0.0	0.585
Cooperate with specialists ^b	12	24.0	-1.4	10	47.6	2.1	12	29.3	-0.2	0.100
Have a seminar on support for children of cancer patients	4	8.0	-0.9	2	9.5	-0.1	6	14.6	1.0	0.593
Other	4	8.0	2.2	0	0.0	-1.0	0	0.0	-1.6	0.080

Multiple answers were allowed in response to questions. There were 90 missing responses

* $p < 0.05$, ** $p < 0.01$

^a Fisher's exact test was used to test group differences in the responses for each category

^b Specialists include doctors, nurses, child life specialists (CLS), medical social workers (MSW), and clinical psychologist (CP)

Table 6 Evaluation of support ($n = 103$)

	Physician						Nurse ($n = 38$)			p^a
	Male ($n = 44$)			Female ($n = 21$)			N	$\%$	Standardized residual	
	N	$\%$	Standardized residual	N	$\%$	Standardized residual				
Effectiveness										
I think it is <i>effective</i>	20	45.5	-1.2	12	57.1	0.5	22	57.9	0.8	0.819
I think it is <i>ineffective</i>	5	11.4	0.5	2	9.5	0.0	3	7.9	-0.5	
I think it is <i>neither</i>	19	43.2	1	7	33.3	-0.5	13	34.2	-0.6	
Difficulty										
I think it is difficult	6	13.6	-2.2*	6	28.6	0.5	13	34.2	1.8	0.015
I <i>do not</i> think it is difficult	24	54.5	3.2**	7	33.3	-0.4	7	18.4	-3.0**	
I think it is <i>neither</i>	14	31.8	-1.3	8	38.1	-0.1	18	47.4	1.4	

Survey question was as follows: please choose a single response that best summarizes your evaluation of support for children and describe the reasons. There were 98 missing responses

* $p < 0.05$, ** $p < 0.01$

^a Fisher's exact test was used to test group differences in the responses for category

which child care is part of the medical service provided to patients. Therefore, it is necessary to involve children when it comes to providing support for patients in medical institutions. In addition, not only hospital service, but also social welfare might be helpful in providing support for children. It is also necessary to develop an improved consulting system in local governments and community groups. The positional constraints of healthcare providers are also obstructive. Some physicians and nurses are concerned about their lack of knowledge or competence regarding support for children. A lack of appropriate knowledge and procedures to support children of cancer patients may increase work-related stress and exhaustion among healthcare workers [19]. Furthermore, we have to be aware of family issues. Many patients are conflicted about telling their children about their disease or condition. Given these issues, it is important to increase awareness of the importance of support for children of sick parents, and investigate what is necessary for the patient, the children, and families. In addition, we should organize a support system (i.e., a support program as well as brochures and other efforts to increase awareness of it) and support-training program, and improve communication between the patient, the patient's family, and healthcare providers.

Second, while 52.4 % of the respondents who said that they make efforts to support children think that their support is effective, 37.9 % think that there is no way to evaluate whether it is effective. This finding might reflect the fact that a good method to measure the effectiveness of support is not yet firmly established. Some studies reported positive changes in children's cancer-related worries and

adjustment, and a significant decrease in depression. Parents with cancer also reported positive changes in the level of depression, state of anxiety, and self-efficacy. Although previous intervention studies have reported positive outcome [20, 21], these were experimentally based interventions; the obtained results were based on facilitators' impressions and participants' verbal feedback, elicited by self-constructed, non-validated questionnaires [8]. With the acquisition of more structured and well-grounded knowledge, an instrument that specifically measures the effectiveness of support should be developed. Furthermore, we should examine children's response to support efforts. It is difficult for healthcare providers to evaluate the responses of children, because they do not commonly deal with children who have had a parent diagnosed with cancer. We should gather self-reported information from children to obtain an accurate picture of support needs for children of parents with breast cancer.

Finally, gender and occupation seem to be associated with preference regarding intervention, current practice, and difficulty of support. The results of this study indicate that male gender and the status of physician as opposed to female gender and the status of nurse seem to be associated with the tendency to prefer not to support children. This tendency might be due to professional, cultural, biological features or nurturance or maternal feeling that women and nurses feel in dealing with children of sick parents, or the length of time they are in contact with patients and their children [22]. It is important to decide on a course of support in cooperation with various specialists and allocate roles appropriately. Furthermore, our study showed that the

younger staff preferred intervention more than the older ones. It may reflect differences related to the position. Experienced doctors and nurses, especially those in managerial positions, have multiple functions and responsibilities for managing their ward such as leading a team, coaching subordinates, and attending a hospital staff meeting [23]. Therefore, it may be hard for them to actively promote child support. Further research is needed to verify the effectiveness of child support, and we have to work systematically toward establishing an efficient method of child support.

In consideration of our findings, it is important to remember several limitations. First, we surveyed only physicians and nurses. The results indicate that cooperation with various other specialists is necessary to provide appropriate support to children. Additional studies should be undertaken to explore the attitudes of these other healthcare providers toward supporting the children of their cancer patients. Second, the respondents of this study belong to the Japanese Breast Cancer Society. Some of the experiences and situations they reported might be specific to breast cancer patients. Thus, further research is needed to estimate the current state of support for children of patients among other physicians and nurses who care for patients diagnosed with various cancers.

In conclusion, our study suggests that most physicians and nurses feel the need to support children who have a parent with cancer, but many of them feel that they could not provide sufficient support. Spreading the awareness of the need to care and sufficient specialists and their cooperation are needed for successful intervention or sufficient support for these children, and it should be done as a national project. Our findings should provide a foundation for additional research and possible targeted interventions to improve support systems for children who have a parent with cancer.

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Appendix

(A) What do you think about psychosocial support for children whose parent had been diagnosed with breast cancer? Please choose one answer from the following and describe the reason in your own words:

(1) We should avoid intervening. (2) We should avoid intervening as much as possible. (3) We should try to intervene as much as possible. (4) We should intervene.

(B) How do you support children whose parent had been diagnosed with breast cancer in routine care? Please choose one answer from the following and describe the reason in your own words:

(1) I do not intervene at all. (2) I hardly intervene. (3) I intervene as much as possible. (4) I always intervene.

(C) If you have had some experience in psychosocial support for children whose parent had been diagnosed with breast cancer:

(C-1) What did you do? Please check all that apply.

(1) Provide counseling to their patients. (2) Provide brochures on child support. (3) Counseling to the children. (4) Cooperate with specialists (i.e., Dr, Ns, CLS, MSW, CP). (5) Have a seminar on support for children of cancer patients. (6) Other (What?) —

(C-2) How effective do you think this support is? Please choose one answer from the following and describe the reason in your own words.

(1) I think it is effective. (2) I think it is ineffective. (3) I think it is neither.

(C-3) How difficult is it to provide this support? Please choose one answer from the following and describe the reason in your own words.

(1) I think it is difficult. (2) I do not think it is difficult. (3) I think it is neither.

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ONLINE FIRST

RESEARCH LETTER

Association Between Parental Preference and Head Computed Tomography in Children With Minor Blunt Head Trauma

Natale et al¹ recently reported that race/ethnicity is independently associated with head computed tomography (CT) use among children with minor blunt head trauma. They showed parental anxiety as an important factor influencing head CT orders in non-Hispanic white children regardless of brain injury risk.¹ In a Japanese pediatric cohort of patients with minor blunt head trauma, we conducted a study with similar objectives attempting to identify factors that influence a physician's decision to order a head CT in children.

Methods. As part of a larger hospital quality improvement activity, we conducted a cohort study comprising children younger than 15 years seen at the St Luke's International Hospital outpatient emergency clinic after experiencing a minor blunt head trauma between October 2007 and July 2012. Inclusion was limited to patients with available quality improvement data recorded by the physician onto a data collection template regarding the parents' preference for a head CT examination (deferred to physician's decision, strongly preferred, favored, and opposed) and relevant clinical data that were used to classify patients into brain injury risk categories (low, intermediate, and high) based on a validated prediction rule.² Electronic medical records were accessed to obtain data on whether a head CT scan was performed within 12 hours of being seen, child's age and sex, time of visit (working hours, evening, and night), and department of attending physician (pediatrics, emergency department, and other). Complete data for all variables were available for 2020 patients. This series of patients showed similar demographic characteristics and proportion of head CT examination as those patients who were not included. We used Poisson regression specifying a robust error variance and calculated relative risks (RRs) and 95% confidence intervals to evaluate factors associated with head CT order and, additionally, used a recursive partitioning method, Chi-squared Automatic Interaction Detection (CHAID),³ to explore and visualize potential higher-order relationships that are often difficult to detect with traditional regression procedures. SPSS statistical software version 20.0 (IBM Japan Ltd) was used.

Results. Of 2020 patients, 310 (15.3%) underwent head

CT scan. Using multivariate Poisson regression, head CT scan was independently associated with older age (age ≥ 7 years vs < 2 years: RR=2.01; 95% CI, 1.57-2.57), strong parental preference (vs deferred to physician: RR=4.39; 95% CI, 3.43-5.60), high brain injury risk classification (vs low: RR=6.61; 95% CI, 4.85-9.01), and emergency department attending physician (vs pediatrics: RR=1.54; 95% CI, 1.21-1.97) (eTable, <http://www.jamapediatrics.com>). Complementary to these results, recursive partitioning based on CHAID first selected parental preference as providing the most evidence in discriminating whether a head CT scan was performed (**Figure**). Stratification also showed that nearly 40% of children in the low injury risk group underwent a head CT scan if their parents "favored" one, in contrast to only 2% of children in this risk group if the decision was deferred to the physician (**Figure**). Evidence suggesting higher-order interactions with child's age was observed.

Comment. The overuse of cranial CT in children,⁴ even for minor blunt head trauma, is a concern particularly in light of a recent report⁵ that showed CT scans in children delivering cumulative doses of about 50 mGy and 60 mGy might almost triple the risk of leukemia and brain cancer, respectively. Our results indicate that medically irrelevant factors such as parental preference may affect physician decision making and can result in unnecessary exposures to children. Furthermore, CHAID analysis suggested interaction between parental preference, injury risk classification, and child's age, but a tendency for overfitting the data is a possibility with this algorithm. Thus, additional studies would help to clarify these higher-order relationships.

Although clinical benefits likely outweigh the small risks in most cases, radiation doses from CT should be kept as low as reasonably achievable,⁶ and alternative procedures should be considered, when appropriate.

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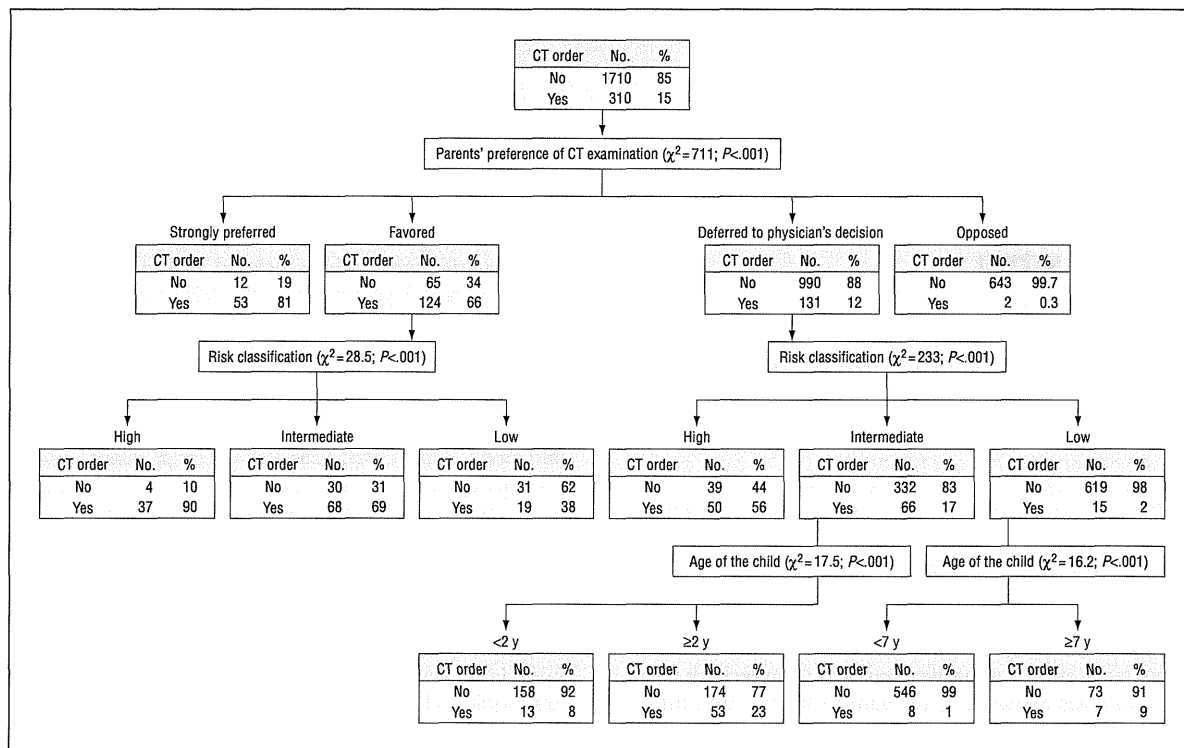


Figure. A graphical representation of the Chi-squared Automatic Interaction Detection (CHAID) analysis. Through a process of recursive partitioning based on degree of statistical significance of the χ^2 tests for independence, the CHAID algorithm evaluated which explanatory variables (eg, parental preference and brain injury risk categories), if split, most “explain” the dependent variable (head computed tomography [CT] scan). Cut points for child’s age were selected by the CHAID algorithm.

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Factors influencing self- and parent-reporting health-related quality of life in children with brain tumors

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Abstract

Purpose Health-related quality of life (HRQOL) is not only a degree of health but also reflects patient perceptions and expectations of health. For children with brain tumors, better understanding of HRQOL requires the use of complementary reports from parents and interviewer-administered reports for children. Here, we aimed to test whether

or not the trait anxiety of children and the psychological distress of their parents influence children's and parents' responses to HRQOL questionnaires, and whether or not the report-administration method for children influences children's responses to HRQOL questionnaires.

Methods One hundred and thirty-four children aged 5–18 with brain tumors and one of their parents completed the Pediatric Quality of Life Inventory™ (PedsQL™) Brain Tumor Module questionnaires. In addition, the children also completed the State-Trait Anxiety Inventory for Children (STAIC), and the parents also completed the

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Kessler-10 (K10) and health and sociodemographic characteristics questionnaires. The child questionnaires were administered either by the child (self-administered) or an interviewer. Rater-dependent perceptions about HRQOL were derived from the subscales scores of the PedsQL™ Brain Tumor Module using structural equation modeling based on a multitrait-multimethod model. The STAIC trait-anxiety score, K10 score, report-administration method, and other health and sociodemographic factors related to each child's or parent's perceptions were identified through multiple linear regression analyses of the questionnaire responses. We used a path analysis to estimate the change in a PedsQL™ child-reported score that occurs when interviewer-administration changes the child's perception about HRQOL.

Results Surveys for 89 children were self-administered while those for 45 were interviewer-administered. The perceptions of the children and parents were calculated by fitting data to the model (chi-squared $P = 0.087$, normed fit index = 0.932, comparative fit index = 0.978, standardized root mean squared residual = 0.053, and root mean square error of approximation = 0.054). The children's perception of HRQOL was affected by their STAIC trait-anxiety score ($b = -0.43$, 95% CI [-0.60, -0.25]). The parent's perception was affected by their child's treatment status ($b = 0.26$, 95% CI [0.09, 0.43]), the parent's K10 score ($b = -0.21$, 95% CI [-0.37, -0.04]), and by education level ($b = 0.17$, 95% CI [0.00, 0.34]). The change in the child-reported PedsQL™ score in relation to the method of administration ranged from -1.1 (95% CI: -3.5, 1.3) on the procedural anxiety subscale to -2.5 (95% CI: -7.6, 2.6) on the movement and balance subscale.

Conclusion Child-reporting of HRQOL is little influenced by the method of administration. Children's perception about HRQOL tended to be influenced by their trait anxiety, while parents' perception was influenced by their psychological distress, academic background, and their child's treatment status.

Keywords Brain neoplasms · Child · Observer variation · Parents · Quality of life · Questionnaires

Abbreviations

AMOS	Analysis of moment structures
CCAJ	The Children's Cancer Association of Japan
CFI	Comparative fit index
CHQ	Child Health Questionnaire
CI	Confidence interval
HRQOL	Health-related quality of life
K10	Kessler-10
MID	Minimum clinically significant difference
MTMM	Multitrait-multimethod
NFI	Normed fit index

PedsQL™	Pediatric Quality of Life Inventory™
RMSEA	Root mean square error of approximation
SD	Standard deviation
SEM	Structural equation modeling
SPSS	Statistical package for social sciences
SRMR	Standardized root mean squared residual
STAIC	State-Trait Anxiety Inventory for Children
TACQOL	TNO/AZL Child Quality of Life

Introduction

Children with brain tumors often show symptoms, such as pain, nausea, and lack of energy [1]. Even after treatment has ended, they may experience neurological, endocrinological, and cognitive problems and difficulties with psychosocial adjustment [2–6]. Appropriate care of children with brain tumors can be enhanced by assessing the child's health-related quality of life (HRQOL).

HRQOL is a patient-based outcome measured as a continuum of the quality of health experienced by a patient in a variety of aspects, including physical, emotional, social, and cognitive domains. Each of these domains can be measured in two dimensions: by an objective assessment of function or health status and by a subjective perception of health [7]. As such, HRQOL is not only a degree of health but also reflects a patient's personal perception and expectations.

HRQOL questionnaires for children often use both child- and parent-reports, respectively, reflecting the child's and parent's perception of the child's HRQOL; as a result, scores on these reports may differ. Child- and parent-reports provide complementary interpretations of HRQOL [8, 9], and neither is clearly superior to the other [10].

Several standard HRQOL questionnaires have been established for use with children, including the Pediatric Quality of Life Inventory™ (PedsQL™) [11], the TNO/AZL Child Quality of Life (TACQOL) [12], and the Child Health Questionnaire (CHQ) [13]. Several factors need to be considered when choosing a questionnaire, but clinical practice requires that the HRQOL instrument chosen for children with brain tumors reflects the impact of the disease and treatment.

We chose the PedsQL™ because this questionnaire includes generic core and disease-specific modules suitable for use in assessing pediatric chronic health conditions. Further, the PedsQL™ can be administered by an interviewer, a particularly essential factor, as child-reporting by children with brain tumors may occasionally be constrained by complications, such as visual impairment, motor dysfunction, or cognitive deficit. In addition, the

PedsQL™ is the only questionnaire presently available in Japanese and has been used before for children with brain tumors.

Having selected an HRQOL instrument, we then addressed two further questions affecting the feasibility and interpretation of the HRQOL scores: First, what are the causes of any differences between child- and parent-reported scores derived from standard questionnaires? Second, are there any significant differences between self- and interviewer-administered child-reports?

Previous studies have found that questionnaire responses may vary with the personality of the child [14] or their parent's mental health [15]. Jurbergs et al. [14] indicated that children with lowered trait anxiety and elevated defensiveness reported a higher CHQ score for themselves than did their parents. In effect, the personality of the child influences his/her perception about HRQOL, such that the score for the child differs from that perceived by the parent. With regard to parents' reports, Davis et al. indicated that increased maternal psychological distress, as measured by the Kessler-6 questionnaire, lowered the mother-proxy reported PedsQL™ score. These authors further indicated that reduced income of the caregiver resulted in a lowered mother-proxy reported, but not father-proxy reported score [15]. Although these reports suggest that the gender and income of parents may also influence parent-reports on the child-HRQOL, these authors did not compare the parent and child self-reports, and no studies have been conducted on differences between child- and parent-reports for children with brain tumors.

Studies in other medical fields have also confirmed that perceptions of HRQOL are dependent on the reporter. For example, Tamim et al. [16] used a visual analog scale to compare agreement between the HRQOL reported by older people discharging from emergency departments with that reported by their caregivers. The agreement between reported HRQOL was significantly lower for caregivers who had less contact with their patients than for those who lived with or were in daily contact with older people. Similarly, Hays et al. [17] found that the degree of agreement between HRQOL self-assessed by adult epilepsy patients and proxy-reports (by a relative, friend, or other significant person) was related to educational attainment of the patients and the reporters.

HRQOL is also influenced by several factors. Predictors of HRQOL in children with brain tumors include the child's age, age at diagnosis, gender, tumor location, tumor malignancy, relapse, treatment intensity, treatment status, and time since diagnosis [18–22]. Several demographic characteristics (child's age, age at diagnosis, gender) may affect the child's personal perception and expectation about HRQOL but not their HRQOL directly. Similarly, current life status (treatment status, time since diagnosis) may

affect the child's or parents' personal perception and expectation about HRQOL but not the child's HRQOL directly.

These studies indicate that reported HRQOL can be influenced by physical, psychological, and sociodemographic characteristics, which may be unrelated to the condition. Further, rater-dependent (of each child's and parent's) perceptions of HRQOL can be influenced by health and sociodemographic characteristics.

We define "children's or parents' perception about the child's HRQOL" as each child's or parent's reporting bias, which is measured as a rater-dependent variance of reported HRQOL scores. Children's or parents' perception is their personal tendency to score an HRQOL questionnaire higher or lower than their parents or child, irrespective of objective measures of the child health. As a result, a child or a parent may score the child's HRQOL differently, even though the child's health condition is the same.

However, which predictors influence the child's or the parent's perception about HRQOL in children with brain tumors remains unclear. A better understanding of the influence of perception would enable more relevant interpretation of the HRQOL score reported by children and parents.

At present, little data are available on the differences between self- or interviewer-administered child-reports for children with brain tumors. Ideally, a person surveying children should be able to choose freely between either method of administration: while self-administered child-reporting may be less expensive, interviewer-administered child-reporting may be useful for children with complications from brain tumors. If these methods can be shown not to differ, then either can be selected for use in measuring HRQOL.

In a previous study using the PedsQL™ Brain Tumor Module, Palmer et al. [23] found no statistically significant difference between self- and interviewer-administered PedsQL™ scores or between parent scores of self-administered children and interviewer-administered children. However, whether or not this finding was clinically significant remains unclear, as Palmer's study was not primarily aimed to compare self- and interviewer-administered scores. It is important to describe the difference between the PedsQL™ self- and interviewer-administered reports.

Here, we investigated the influence of child and parent health, parent socio-demographic characteristics, and report-administration method on the child and parent perceptions about HRQOL (Fig. 1). We hypothesized that a child's perception about their own HRQOL was related to trait anxiety, a parent's perception about their child's HRQOL was related to psychological distress, and a child's perception was not related to the report-administration method (child self- or interviewer administered-reporting).

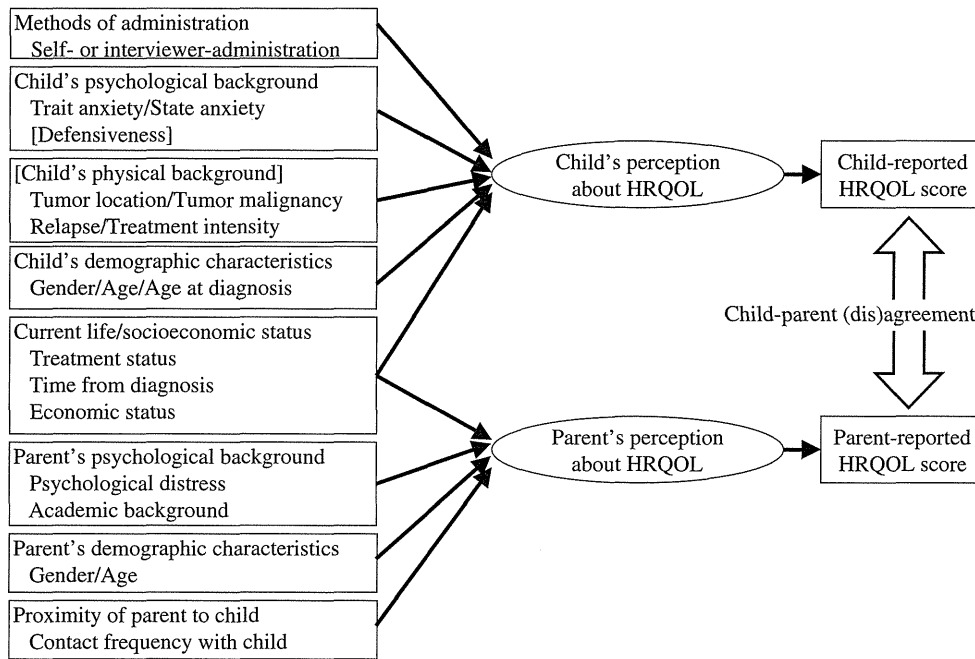


Fig. 1 Conceptual framework for organizing the factors that influence child and parent agreement. [Bracketed factors] were not measured in this study. *HRQOL* health-related quality of life

The following variables were considered as covariate to the above relationships: child's interviewer, state anxiety, age, gender, age at diagnosis, time from diagnosis, treatment status, and parent's age, gender, academic background, time with child per day, and subjective opinion regarding their economic status.

Methods

This study was conducted as part of the development of the Japanese version of the PedsQL™ Brain Tumor Module [24].

Study population

Children with brain tumors and their parents were recruited from six hospitals across Japan and from the Children's Cancer Association of Japan (CCAJ), a non-profit organization established in 1968, which supports children with cancer and their families, between September and December 2008. A child and one parent were included if the child was aged 5–18 years (age range covered by PedsQL™). Families were included if at least 1 month had passed since the child's brain tumor diagnosis and excluded if hospital doctors or social workers of the CCAJ determined that the family found the subject of the child's condition too uncomfortable to discuss.

Procedure

Researchers presented information about the study to 101 families in participating hospitals orally and in writing. Of these, 98 families elected to participate. At the CCAJ, a written description of the study was given to all families invited to a meeting regarding brain tumors, to which 45 families responded. In total, questionnaires were accordingly distributed to 143 families.

Parents were asked to determine, when providing informed consent, whether their child was able to self-administer the questionnaire. In accordance with the PedsQL™ administration guidelines [11], children aged 5–7 years and those determined to be incapable of self-administration were given the questionnaire by an interviewer, who was either a researcher or, if the child wanted the questionnaire to be administered at home, one of their parents. The parent-report questionnaires were self-administered by one of the parents, but we asked parents and children not to report in concert. If a child was administered the questionnaire by the parent, we asked the parent to complete the parent-report and then administer the child-report.

After distribution, 138 of the 143 families returned questionnaires. The background of the five families who did not respond is unknown. We excluded questionnaires from four families (four children and one parent) who answered less than 50% of items in one or more subscales.

The missing subscales were as follows: cognitive problems subscale for one child, pain and hurt for two children, movement and balance for two children, procedural anxiety for two children, nausea for two children and one parent, and worry for two children and one parent. Therefore, answers from a total of 134 families were analyzed. The children from the four excluded families were 3 boys and 1 girl aged 6–8 years who had been off treatment for 12–53 months.

Ethical considerations

This study was approved by the review boards of all seven participating institutions. For children aged 13 or over, informed consent from both the child and the parent was required prior to participation. For children aged 12 or under, informed verbal assent from the child and informed written consent from the parent was required.

Measurements

Child HRQOL was measured by the PedsQL™ Brain Tumor Module. The PedsQL™ Brain Tumor Module [23, 24] measures disease-specific HRQOL and comprises 24 items in six subscales: cognitive problems, pain and hurt, movement and balance, procedural anxiety, nausea, and worry. Children and parents were asked, on separate questionnaires, to describe the extent to which each item had troubled the child over the previous 7 days. For example: Item 1 of the child questionnaire stated “It is hard for me to figure out what to do when something bothers me,” with the possible responses of 0 = never, 1 = almost never, 2 = sometimes, 3 = often, 4 = almost always. All subscale scores were calculated in reverse and linearly transformed so that the minimum score was 0 and maximum score was 100, with higher scores indicating a higher HRQOL. Cronbach’s alpha coefficients [25] for the subscales for child- and parent-reports in the current study were 0.83 and 0.92 (cognitive problems), 0.52 and 0.78 (pain and hurt), 0.77 and 0.91 (movement and balance), 0.82 and 0.95 (procedural anxiety), 0.84 and 0.94 (nausea), and 0.75 and 0.86 (worry), respectively. Internal consistency in most subscales was considered sufficient, as Cronbach’s coefficient alpha values exceeded 0.70 [25].

Global HRQOL was measured by the PedsQL™ Generic Core Scales [11, 26]. The instructions and scoring method are identical to the PedsQL™ Brain Tumor Module. Cronbach’s alpha coefficients for the child- and parent-reports were 0.91 and 0.93, respectively.

State- and trait-anxiety of children were measured using the State-Trait Anxiety Inventory for Children (STAIC) [27, 28]. Children aged 8 years or over were asked to complete the questionnaire, with a higher score indicating

increased anxiety. Cronbach’s alpha coefficients for state- and trait-anxiety scales were 0.89 and 0.89, respectively.

Psychological distress of a parent was measured by the Kessler-10 (K10) questionnaire [29, 30]. The parent was asked to describe the frequency with which they experienced mood or anxiety symptoms over the past 30 days, with higher scores indicating higher psychological distress in relation to depression and anxiety. Cronbach’s alpha coefficient for this questionnaire was 0.92.

The parent was also asked to describe their child’s age, gender, tumor pathology, age at diagnosis, experience with treatment, their economic status, age, relationship to the child, academic background, and time spent with the child per day.

Statistical analyses: model for analysis

In the first step of the analysis, each child’s perception, and each parent’s perception about the child’s HRQOL, was calculated by a multitrait-multimethod (MTMM) model [31].

MTMM models are used for quality of life research [32, 33] to test the validity of measures of multiple traits assessed by multiple raters. Here, we used a MTMM model to identify how child- and parent-reported scores of all six PedsQL™ Brain Tumor Module subscales differed. The MTMM model is known to be capable of separating variation in child- and parent-reported HRQOL scores into variation derived from the method and that derived from a trait [32]. The MTMM model also enables the division of HRQOL scores into rater-dependent perception and rater-independent condition. For example, a previous study of HRQOL using the TACQOL questionnaire with seven subscales found that children and parent scores were determined by rater-independent (38–73%) and rater-dependent (0–30%) latent factors [32].

In the present study, the HRQOL of each child was assessed by two raters: the child and one parent. The score for each HRQOL subscale was determined by two elements (Fig. 2) based on the perception of the child or the parent as well as the child’s condition. Given that perceptions can differ between the child and parent, the child’s perception is one element determining the child-reported scores of the six HRQOL subscales, while the parent’s perception is one determining the parent-reported scores for the HRQOL subscales. The other element that determines both child-reported and parent-reported scores is the rater-independent condition, that is, a part of the child’s function or health status that is recognized by both the child and the parent. These two elements—each rater’s perception about HRQOL and the rater-independent condition of each aspect of HRQOL (for example, pain and hurt)—determine the rater reported score for each of the six subscales (Fig. 2).

Fig. 2 **a** Two latent variables that determine the score on a health-related quality of life (HRQOL) subscale. **b** Example of two latent variables that determine parent-reported score on the Worry subscale in the Pediatric Quality of Life Inventory Brain Tumor Module

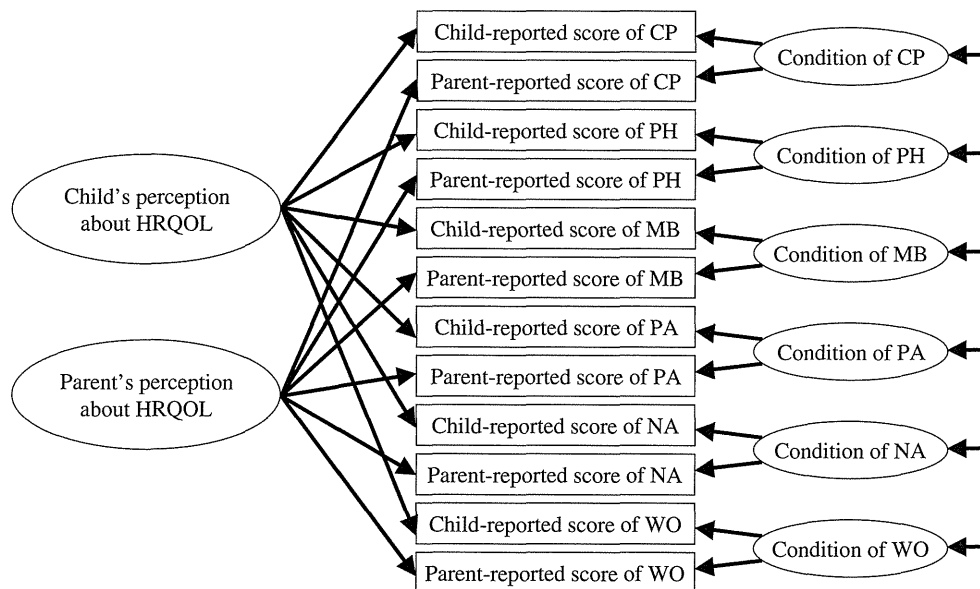
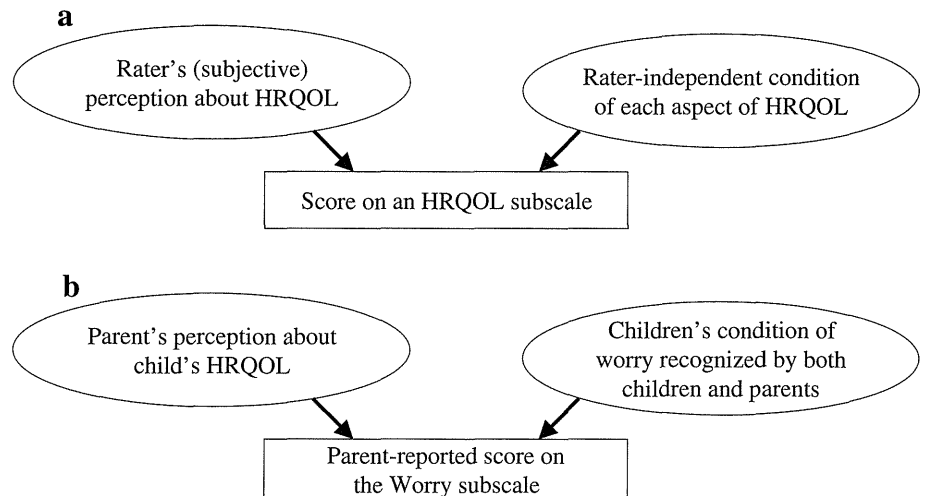


Fig. 3 Multitrait-multimethod model for Pediatric Quality of Life Inventory (PedsQL) Brain Tumor Module. Unique factors are not displayed. Pediatric Quality of Life Inventory (PedsQL) Brain Tumor

Module has six subscales: *CP* cognitive problems, *PH* pain and hurt, *MB* movement and balance, *PA* procedural anxiety, *NA* nausea, *WO* worry

The MTMM model combines each subscale score (Fig. 3) into an independent element as either child's or parent's perception, thereby enabling calculation of perception from either child- or parent-reported scores. The MTMM model was tested via structural equation modeling (SEM) using a maximum-likelihood approach to derive parent and child perceptions from all six subscales in PedsQL™ Brain Tumor Module.

In previous research using an HRQOL measurement with seven subscales (the TACQOL), SEM confirmed that the MTMM model adequately explained child- and parent-reported scores [32]. We believe that SEM can also be used to validate the MTMM model for child- and parent-reported HRQOL scores and to calculate child- and parent-

perception scores derived from the PedsQL™ Brain Tumor Module. Here, we tested the validity of the MTMM model via goodness-of-fit indices: model chi-squared $P > 0.05$, normed fit index (NFI) > 0.90 , comparative fit index (CFI) > 0.90 , standardized root mean squared residual (SRMR) < 0.06 , and root mean square error of approximation (RMSEA) < 0.06 [34].

The latent scores of the child's and parent's perception about HRQOL were then estimated from the reported scores of each subscale and the factor score weight derived from the SEM. We decided to calculate the perception scores using PedsQL™ Brain Tumor Module. An exploratory factor analysis found that HRQOL derived from the PedsQL™ Brain Tumor Module may be separated into six

factors corresponding to the six subscales [24], and the total score of the brain-tumor subscales cannot be calculated. It follows then that the calculated perception scores indicate whether parents or children tend to score HRQOL high or low rather than the absolute value of children's HRQOL resulting from brain-tumor symptoms. In other words, the calculated perception scores are measuring perception, not HRQOL.

To confirm that the model effectively discriminates perception and condition, we assessed convergent and discriminant validity using the global HRQOL score of the PedsQL™ Generic Core Scales. Both the child- and parent-reported global HRQOL will be correlated with the children's HRQOL resulting from brain-tumor symptoms. The child-reported global HRQOL will also be correlated with child's reporting tendency, but uncorrelated with parent's tendency. Parent-reported global HRQOL will be correlated with parent's reporting tendency about their child's HRQOL, although uncorrelated with their child's tendency.

In the present study, the correlation of the calculated perception scores with the PedsQL™ Generic Core Scales (child's perception and self-reported global HRQOL; parent's perception and the parent-reported global HRQOL) was assessed using Spearman's rank correlation coefficient. We expected a correlation between the child's perception and the child-reported global HRQOL and a correlation between the parent's perception and the parent-reported global HRQOL, but did not expect a correlation between the parent's perception and the child-reported global HRQOL, or between the child's perception and the parent-reported global HRQOL. If there is a correlation between either reporter's (child or parent) calculated perception and the other reporter's (child or parent) reported HRQOL, we should conclude that the calculation cannot be estimating perception because the calculated scores may depend on the absolute value of the HRQOL.

Statistical analyses: regressions of perceptions about HRQOL

In the second step of the analysis, the factors that influence each child's or parent's perceptions were analyzed by multiple linear regression. Factors related to each child's perception about HRQOL and the parent's perception about their child's HRQOL were then identified by bivariate and multivariate correlation. The bivariate correlations were tested by Spearman's rank correlation coefficient, and the multivariate correlations were tested by the standardized partial regression coefficient from multiple linear regression analysis. A child's perception was treated as a dependent variable, and the following variables were treated as independent: method of administration, interviewer; child's trait anxiety, state anxiety, age, gender, age

at diagnosis, time from diagnosis, and treatment status; and parent's subjective opinion regarding economic status and life. Given that we did not measure trait- or state-anxiety of children under 8 years of age, these data were not included in the multiple regression analysis, and regression for perception about children aged 5–7 years was recalculated excluding method of administration, child's trait anxiety, and state anxiety from independent variables.

In a second regression analysis, parents' perception was treated as a dependent variable, and the following variables as independent: parent's psychological distress, age, gender, academic background, time with child per day, subjective opinion regarding economic status and life, and child's treatment status. Missing values in the regression analyses were considered by list-wise case deletion, and independent variables were selected by a step-down procedure, mounted in SPSS software. This procedure was considered necessary, as when all independent variables were selected, the variables were multi-collinear and therefore regression could not be feasibly interpreted. Multi-collinearity was eliminated by removing causative variables one at a time. Regression analysis was then iterated, and after each successive calculation, the variable with the largest probability-of-*F* value was removed, until the probability-of-*F* value of all remaining variables was ≤ 0.1 .

As a complementary step, we conducted a sensitivity analysis for the selected variables (related to child's or parent's perception) to assess the difference between child- and parent-reported HRQOL scores. Descriptive statistics (mean and standard deviation [SD]) of the differences between and Pearson's correlation coefficient for child- and parent-reported HRQOL were calculated for mean score of the six subscales of PedsQL™ Brain Tumor Module. We also conducted a multiple linear regression to confirm that the selected variables were related to the difference between child- and parent-reported HRQOL.

Statistical analyses: differences between self- and interviewer-administered child-reports

In the third step of the analysis, we used path analysis [35] to estimate the points difference between self- and interviewer-administered PedsQL™ child-reported scores. While ideally both types of administrations would be compared via a randomized sequence of administration, we considered this an excessive burden on the children with brain tumors. However, a simple comparison of self- and interviewer-administered HRQOL scores is likely to be biased; in that, interviewer-administered scores tend to be lower than self-administered scores because parents ask for interviewer-administration when their child presents with difficulties, such as visual impairment, motor dysfunction, or cognitive deficit.

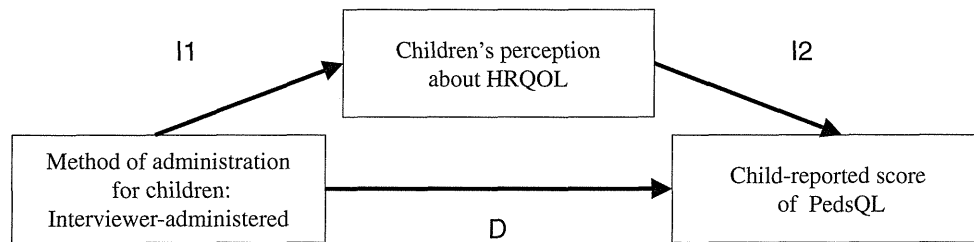


Fig. 4 Path analytic model to split the effect of the method of administration to child-reported HRQOL in two ways. Unique factors are not displayed. *D* direct effect; *I1*, *I2* subset of indirect effect

Bearing the above constraints in mind, we tested the direct and indirect effect of administration method on the children’s perception about their own HRQOL (Fig. 4). An “indirect effect” was defined as a change in a child-reported HRQOL score that occurs when interviewer-administration changes the child’s perception about HRQOL. A large indirect effect indicates a specific reporting bias by interviewer-administration that increases or decreases child-reported HRQOL. A “direct effect” was defined as a difference in child-reported HRQOL between self- and interviewer-administered scores, regardless of the perception. A larger direct effect indicates larger between-group differences in HRQOL condition, regardless of difference in perception.

For each PedsQL™ Brain Tumor Module subscale, we estimated three path coefficients and their standard error using path analysis [35]. The direct effect is the path from the method of administration to the child-reported scores of PedsQL™ (*D* in Fig. 4), and the indirect effect is the path from the method of administration to the children’s perception about HRQOL (*I1* in Fig. 4) times the path from the children’s perception about HRQOL to the child-reported scores of PedsQL™ (*I2* in Fig. 4). We also calculated 95% confidence intervals (CIs) for the direct and indirect effects [36].

All analyses were performed using SPSS software, version 12.0 J (SPSS, Inc., Chicago, Illinois, USA) and AMOS software, version 5.0 (SPSS, Inc., Chicago, Illinois, USA), and the level of significance was set at 0.05.

Results

Sample characteristics

The median age of the children was 11.0 years (Table 1). The sample was heterogeneous with respect to tumor pathology and treatment experience: the largest groups were embryonal tumors, germ cell tumors, and low-grade gliomas. Median time from diagnosis was 37 months, and 53 children (39.6%) were still under treatment. The other 81 children (61.8%) had completed treatment, and the

interval from completion of treatment to the survey was 0.1–13.3 years. Of the responses from 106 children aged 8–18 years, 89 (84.0%) surveys were self-administered, and 17 (16.0%) were interviewer-administered (two with difficulty understanding the questionnaire, one with difficulty sustaining attention, two with difficulty reading, seven with optical impairment, two with difficulty writing by hand, one with both optical impairment and difficulty writing by hand, and two experiencing fatigue). All 28 children aged 5–7 years received interviewer-administered surveys.

Most parents were mothers ($n = 126$, 94.0%), with a median age of 41.0 years; 51 (38.9%) were high school graduates, and 80 (61.1%) were college or university graduates, while 84 (63.6%) considered their economic status to be affluent.

Measurement of HRQOL

The MTMM model for the PedsQL™ Brain Tumor Module was tested by the chi-squared $P = 0.087$ ($\chi^2 = 36.43$, degrees of freedom = 27), NFI = 0.932, CFI = 0.978, SRMR = 0.053, and RMSEA = 0.054, showing that the model was valid and enabling calculation of latent scores of children’s and parent’s perception about HRQOL. The child and parent scores were determined based on each child’s or parent’s perception (2–45%) and rater-independent condition (7–98%) (Table 2). A significant correlation was noted between the calculated scores of the children’s perception about HRQOL and the child-reported—but not the parent-reported—global HRQOL ($r = 0.55$, $P < 0.001$ vs. $r = 0.07$, $P = 0.404$) (Table 3). Similarly, parents’ perception about HRQOL was correlated with the parent-reported—but not the child-reported—global HRQOL ($r = 0.49$, $P < 0.001$ vs. $r = 0.10$, $P = 0.251$).

Factors related to children’s and parent’s perception

The difference in children’s perception between self- and interviewer-administered reports was not significant ($P > 0.05$) (Table 4). In the multivariate analysis, the step-