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Anxiety and the Quality of Life of Children Living With Parental Cancer

KEY WORDS

Anxiety
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Dimensions
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KINDL
Multidimensional
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Psychological distress
RCMAS

Background: Previous research on children living with parental cancer has mainly focused on the psychosocial challenges, but few studies have explored their health-related quality of life (HRQOL). This is important to promote well-being and discover areas of distress, as well as positive aspects of the children's life.

Objective: The aim of this study was to study how children's HRQOL is influenced by anxiety and whether age and gender act as moderators for this relationship.

Methods: This study used a survey with a cross-sectional design, including 35 children between 8 and 18 years old (mean, 13.3 years old) living with parental cancer. Questionnaires of HRQOL (Kinder Lebensqualität) and anxiety (Revised Child Manifest Anxiety Scale) were used. **Results:** The children reported higher anxiety and lower HRQOL than the controls. The children's physiological ($P=.03$), emotional ($P=.04$), and school ($P=.00$) functions were significantly impaired, whereas they scored in line with the controls on self-esteem, family, friends, and overall HRQOL. A negative correlation ($r=-0.707$, $P<.01$) between anxiety and HRQOL was found. Neither age nor gender acted as a moderator between anxiety and HRQOL. **Conclusions:** A one-dimensional focus on anxiety may not capture these children's multidimensional challenges. In contrast, a focus on HRQOL may give important knowledge of the children's challenges, as well as areas where they function well. **Implications for Practice:** Healthcare professionals need to work collaboratively across disciplines and have a multidimensional focus in caring for patients with cancer who have children. They must provide both the parents and children with adequate information and tools to handle their family health situation to promote the children's HRQOL.

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Internationally, it is estimated that between 7% and 14% of patients with cancer have children younger than 18 years.^{1,2} In Norway, 3500 children annually experience a parent who is given a diagnosis of cancer, and nearly 700 children experience parental death.^{3,4} This means that many children live with parental cancer across the illness trajectory. Such children are at risk of psychosocial problems and distress such as anxiety and worry.⁵⁻⁹ In Norway, healthcare professionals have a legal responsibility to focus on children's well-being when living with parental illness.¹⁰ In both healthy¹¹ and sick¹² children, health-related quality of life (HRQOL) is increasingly used as an indicator for well-being to make informed choices about their situation, as well as to understand the children's own perception of their life situation.¹² Even if several studies document that children living with parental cancer experience multiple challenges, few studies have focused on their HRQOL.¹³⁻¹⁵ Because life for these children is more than coping with the parent's cancer, a focus on their HRQOL may provide parents and healthcare professionals with essential information about the impact of living with parental cancer across multiple domains of well-being.^{11,14,15} This may help to determine areas of distress, as well as the positive aspects of the children's life,¹⁴ thus serving as a framework for identifying and developing strategies to help these children.^{12,16,17} Therefore, the aims of this study were to examine the HRQOL of Norwegian children living with parental cancer, how anxiety influences their HRQOL, and whether age and gender are moderators of the relationship between anxiety and HRQOL.

■ Previous Research on Children Living With Parental Cancer

Parental cancer often involves intensive, multimodal, and long-lasting treatments with subsequent remissions, as well as possibilities for relapses and death, representing huge challenges for the entire family.^{1,18,19} Previous research on children living with parental cancer has mainly focused on the children's psychological problems and risk factors, with inconsistent findings reported. Overall, it seems that children's responses to parental cancer vary significantly with age and other factors such as the child's earlier experiences and maturity, the parent's disease severity, and parental coping.^{5,18,20} In addition, research also indicates that family function and openness regarding information and communication about the illness predict children's adjustment to parental cancer.^{15,21}

In general, minor children are more affected by the ill parent's hospitalization, changes in daily routines, and the ill parent's appearance and mood, than older children.^{6,22} Krattenmacher et al²⁰ found strong associations between impaired parental health and the children's psychosocial problems, and even very young children are aware of cancer as a life-threatening illness.²³ Although research has primarily focused on the children's psychological distress, some studies also document physical symptoms, such as headaches, stomach pains, sleep disturbances, and reduced energy levels, as well as problems with concentration and the follow-up of school tasks.^{5,24}

Regarding adolescents, the research shows conflicting results. Some studies report that adolescents experience higher levels of

anxiety and depressive symptoms, posttraumatic stress symptoms, and reduced self-esteem than their peers,^{2,7-9,25-27} wherein adolescent girls seem more vulnerable than boys.²⁸ Other studies have found that adolescents generally adjust well to parental cancer.^{27,29,30} However, previous research indicate that adolescents often internalize their problems by not sharing their feelings openly with either parents or friends.^{5,23,31} In addition, in general, parents seem to overestimate their children's quality of life, especially for nonobservable dimensions, for example, emotional or social HRQOL,^{12,17,32} and underestimate their children's distress when living with parental cancer.^{5,31}

Although previous research documents that children living with parental cancer can experience multidimensional challenges, few studies have focused on these children's HRQOL.^{9,20} In a qualitative study of children living with parental cancer, Helseth and Ulfsaet³³ concluded that the children's quality of life was fragile and especially vulnerable at the time of their parent's diagnosis and when the illness situation changed. In contrast, Bultmann et al³⁴ found that the HRQOL of such children was better compared with that of a general child population. Therefore, more studies of these children's HRQOL are needed, especially how anxiety influences their HRQOL and whether age and gender moderate the relationship between anxiety and HRQOL. A multidimensional focus on the children's HRQOL may provide both parents and healthcare personnel with a more comprehensive knowledge of the children's situation, thereby making them better able to specify their support to promote the children's well-being.^{11,12}

■ Theoretical Framework

Health-related quality of life is a term that is widely used to describe an individual's assessment of his/her own general well-being and often used as a main indicator of perceived health.^{11,12,16} However, there is no 1 consensus model or definition, and childhood HRQOL is defined in different ways.^{11,12,16,32} Commonly, HRQOL is viewed as an individual, subjective, multidimensional, and dynamic concept consisting of physiological, psychological, and social aspects of well-being.^{12,16,17,35} More specifically, the important aspects of children's HRQOL are related to self-esteem and activities, as well as to their relationship to family, friends, and school.^{12,17,32} In line with this, in this study, HRQOL is defined as "The subjective reported well-being in regard to the child's physical and mental health, self-esteem and perception of own activities (playing/having hobbies, perceived relationship to friends and family, as well as to school)."^{17(p11)} Attributes and strengths, difficulties, and deficiencies within each area contribute to the children's overall HRQOL.^{11,36} This implies that distress from living with parental cancer may influence different dimensions of life and the overall HRQOL.

■ Aims and Hypotheses

The aims of this study were to investigate the HRQOL of children living with parental cancer and the relationship between anxiety and HRQOL.

On the basis of previous research and the study's theoretical framework, and compared with 2 general child populations,^{17,37} we hypothesized the following:

1. The children living with parental cancer would report significantly higher levels of anxiety than the children in a control group.
2. The children living with parental cancer would report significantly lower levels of HRQOL than the children in a control group.
3. The children's anxiety would correlate negatively with their HRQOL.
4. The children's age and gender would moderate the relationship between anxiety and HRQOL.

■ Methods

Study Design

This study is a part of the Cancer-PEPSONE study, which has an overall purpose to gain knowledge regarding how to help children living with parental cancer.³⁸ We conducted a survey with a cross-sectional design to collect information to describe a group of children at the same time, based on self-administered questionnaires.³⁹

Eligibility Criteria, Recruitment, and Participants

The eligibility criteria were the eldest child in the family between 8 and 18 years old, living in a 2-parent household, where one of the parents was given a diagnosis of cancer within the last 5 years. The participants were recruited via their parents through hospital and primary healthcare nationally, through brochures and different Web sites.³⁸


Of the 47 families assessed for eligibility, nine did not return the questionnaires, and three withdrew from participation, leaving 35 children included in the study. The sample included 21 girls and 14 boys, with a mean age of 13 years (range, 8–18 years). Most of the children had a mother with metastatic cancer who had gone through a long-term and multimodal treatment. The children's demographic variables and the parents' illness variables are presented in Table 1.

Control Groups

For comparison regarding HRQOL, we used a Norwegian norm population of 1966 children (990 girls and 1006 boys) aged 8 to 16 years studied by Jozefiak et al.¹⁷ Because no Norwegian norm population regarding children's anxiety exists, we used a Dutch norm population,³⁷ consisting of 521 children (240 boys and 281 girls) between 12 and 18 years, because Norway and Netherland are seen as culturally comparable.

Data Collection

The Revised Child Manifest Anxiety Scale (RCMAS)⁴⁰ was used to measure the degree and quality of anxiety experienced

 **Table 1 • The Children's Sociodemographic Variables (N=35) and the Parents' Illness Variables (N=34)**

Variables	n (%)	Mean (SD)
Children's sociodemographic variables		
Gender	21 (60) girls 14 (40) boys	
Age, y		12.6 (2.8)
Age by gender, y	Girls Boys	
8–10	6 (29) 2 (14)	
11–13	7 (33) 7 (50)	
14–18	8 (38) 5 (36)	
Siblings		2.1 (1.2)
School	19 (54) primary school 12 (34) secondary school 4 (12) college	
Parents' illness variables		
Gender of ill parents	21 (60) mothers 14 (40) fathers	
Age of ill parents, y		46.4 (8.0)
Type of cancer	11 (31) breast 4 (12) gynecological 4 (12) lymphomas 4 (12) gastro/intestinal 3 (9) testis/prostate 9 (24) Other	
Months since diagnosis		27.9 (37.9)
Type of treatment	24 (69) multimodal treatment 11 (31) single treatment	
Months of treatment		16.9 (26.3)
Cancer severity	22 (63) metastases 12 (34) no metastases 1 (3) missing	
Present treatment status	25 (71) active treatment 8 (23) finished primary treatment (close follow-up) 1 (3) palliative 1 (3) missing	

by the children. The RCMAS is a self-reported questionnaire that is suitable for children aged 6 to 19 years, showing sound psychometric properties.^{40,41} Anxiety is operationalized through 37 questions answered with "yes" (1) or "no" (0). A total anxiety score (sum of all the 28 anxiety items) and 3 subscales representing different aspects of anxiety are calculated. Physiological anxiety consists of 10 items about somatic manifestations of anxiety such as sleep difficulties, nausea, and fatigue. Worry consists of 11 items measuring concerns about a variety of topics including fears about being hurt or emotionally isolated. Concentration consists of 7 items measuring distracting thoughts and fears that have a social or interpersonal nature. An overall cutoff point of 19 of 28 is recommended to identify children

experiencing clinically significant levels of anxiety.⁴¹ The Cronbach's α for RCMAS in this study was .86.

Kinder Lebensqualität (KINDL) was used to assess the children's self-reported quality of life.⁴² This is widely used internationally and nationally (<http://www.kindl.org>) and reckoned as a psychometrically sound and flexible instrument.^{17,35} Here, HRQOL is operationalized through 30 items, each answered from "never" (1) to "always" (5). The raw scores are recalculated into a 0 to 100 scale. A sum score is calculated for the overall HRQOL, and 7 subdomain scores representing children's everyday life are also computed: physical well-being, emotional well-being, self-esteem, family, friends, school, and the impact of the disease. Higher values mean higher levels of well-being for the overall HRQOL and for the subdimensions.⁴² A cutoff value less than 70 is recommended, implying that children scoring lower than this level probably have mental or psychosocial health problem.⁴³ The Cronbach's α for KINDL in this study was .87.

Statistical Analyses

Statistical analyses were performed using SPSS Statistics v.22. Descriptive statistics (mean, standard deviations [SDs], or percentages) were used to describe the data. *Z* tests were performed to explore the differences between the sample mean and means reported in other studies.⁴⁴ Cohen's *d* was used to examine the effect size of difference between the groups [$d = (\text{Mean}_1 - \text{Mean}_2) / \text{SD}_i$, where SD_i is the pooled within-group SD] and judged against the following criteria: small ($d \geq 0.2$), medium ($d \geq 0.5$), large ($d \geq 0.8$), or very large (≥ 1.3).⁴⁴

Pearson's *r* was used for the correlation between variables, and squared correlation (r^2) was used to describe the explained variance. The Kruskal-Wallis test was used to compare the variables on a nominal level, based on the small sample size.⁴⁴ For KINDL, no items were missing, and for RCMAS, 8 random items were missing. According to the RCMAS manual, these missing items were calculated through the mean because at least half of the items from the scale were answered.⁴⁰

Multiple regression analyses were performed to test the study's moderating (buffering) model. It was reported with the regression coefficient (*B*) and the associated confidence intervals (CIs), *P* values, and explained variance (r^2). For all analyses, a 2-tailed $P < .05$ was set as the significance level.⁴⁴

Ethics

The Regional Committee of Research and Ethics in Western Norway and the Norwegian Social Science Data Services approved the study. Study participation was based on written and oral information, as well as written consent. For children younger than 12 years, the parents gave consent, whereas for the 12- to 18-year-old children, both the child and the parent gave consent. Study participation did not include any expenses for the families; they did not get any payment to participate. No specific risks were anticipated from study participation. The participants were informed that, if they were disturbed by the

experience, the team should refer them to appropriate support, but no such events occurred.

Results

In the following, the results for each hypothesis are presented separately.

The Children's Level of Anxiety

The first hypothesis, stating that children living with parental cancer experience significantly higher levels of anxiety than the controls, was mainly supported. The children scored significantly higher on total anxiety and physiological anxiety but not on worry and concentration compared with the Dutch norm population.³⁷ The differences (effect size) were small for total anxiety and moderate for physiological anxiety (Table 2).

Only 2 children (5.8%) reported clinically significant levels of total anxiety, reporting total scores higher than the cutoff value of 19. The Kruskal-Wallis test showed no significant differences between any of the anxiety scales related to ill parents' gender, severity of illness (no metastases/metastasis), or any differences related to the type of treatment (single/multimodal). Neither time since diagnoses nor length of treatment was correlated to any of the anxiety scales. However, the children's age was positively correlated to total anxiety ($r = 0.414$), worry ($r = 0.418$), and concentration ($r = 0.368$), all significant on the 0.05 level. This means that the older the child, the more total anxiety, worry, and concentration problems they reported.

The Children's Self-Reported HRQOL

The second hypothesis, stating that children living with parental cancer score significantly lower on HRQOL than the controls, was partly supported. The children scored significantly lower on physical and emotional well-being and the school dimension but not significantly different on overall HRQOL, self-esteem, family, and friends compared with the Norwegian norm population.¹⁷ The differences were large for the school dimension but small for physical and emotional well-being.

Most of the children reported lower than the recommended cutoff value of 70 on the overall HRQOL, physical well-being, self-esteem, and school. Nearly half of the children scored lower than the cutoff value on the impact of disease, indicating that their parent's cancer impacted them (Table 3). Even if no significant differences were found between genders on any of the HRQOL dimensions, more girls than boys scored lower than the cutoff on all of the dimensions, except for friends, where nearly 60% of the boys scored lower than the cutoff. Family was the dimension with the fewest individuals of both genders scoring lower than the cutoff value.

Pearson's correlation showed no significant correlations between most of the HRQOL dimensions and the children's age, except for a negative correlation between age and physical well-being ($r = -0.385$, $P = .022$) and self-esteem ($r = -0.350$, $P = .039$). This means that the older the children, the lower their reported

Table 2 • RCMAS Mean Scores (N=35), Mean Scores Differences, and Effect Sizes

	Scale Range	This Study, Mean (SD)	Dutch Child Norm, ^a Mean (SD)	Mean Score Difference, Z Score (P)	Effect Size, ^{b d}
Total anxiety	0–28	9.6 (6.8)	7.0 (6.0)	2.21 (.03)	0.43
Physiological	0–10	3.4 (2.2)	2.2 (2.1)	3.14 (.00)	0.57
Worry	0–11	3.9 (3.4)	3.1 (2.9)	1.36 (.17)	0.28
Concentration	0–7	2.3 (2.0)	1.7 (1.8)	1.73 (.08)	0.33

Abbreviation: RCMAS, Revised Child Manifest Anxiety Scale.

^aDutch norm population (Muris et al, 2002; N = 521).

^bCohen's *d*, effect size of difference between groups [$d = (\text{Mean}_1 - \text{Mean}_2) / \text{SD}_i$, where SD_i is the pooled within-group SD].

physical well-being and self-esteem. No significant correlations between the time since diagnosis or the length of treatment for the sick parent and any of the children's HRQOL dimensions were found. The Kruskal-Wallis test showed no significant differences between any of the HRQOL dimensions and the ill parents' gender, illness severity, or type of treatment.

The Connection Between the Children's Anxiety and HRQOL

In the third hypothesis, we assumed a significant negative correlation between the children's self-reported anxiety and HRQOL. The result supported this assumption, showing that the negative correlations between total anxiety and total HRQOL ($r = -0.707$) explained 50% of the variance ($r^2 = 0.50$). Negative correlations also appeared between all of the HRQOL subscales and the subscales of anxiety, except for the family dimension and between the school dimension and physical anxiety (Table 4).

Age and Gender as Moderators Between Psychological Distress and HRQOL

On the basis of previous research, we assumed that the children's age and gender moderated the relationship between psychological distress and HRQOL. Gender or age was not significantly correlated to the overall HRQOL, but age was positively correlated to anxiety ($r = 0.414$, $P = .013$), explaining 17% of the variance in total anxiety ($r^2 = 0.17$).

Testing the moderation model for age and gender separately, we found that neither age nor gender moderated the effect of anxiety on HRQOL (Table 5).

Discussion

The findings partly supported the hypotheses in this study, showing that children living with parental cancer reported higher anxiety and lower HRQOL on physical well-being, emotional well-being, and the school dimensions than the control groups. The result also showed a high negative correlation between anxiety and HRQOL. We could not establish age or gender as a moderator between psychological distress and HRQOL. To our knowledge, this is the first study that focuses on anxiety and HRQOL and the relationship between these variables in children living with parental cancer.

Few Children Reported High Levels of Anxiety

The children in this study scored higher on total anxiety compared with the controls. This is in line with previous research documenting increased anxiety and psychological distress in children living with parental cancer.^{8,24,25} In our study, the physical signs of anxiety were pronounced, showing the highest difference from the controls. This indicates that the children experienced problems related to breathing, sleeping, stomach aches, hand sweats, and tiredness.⁴⁰ These results are in line

Table 3 • HRQOL Mean Scores From This Study (N=35) Compared With the Norwegian Norm

KINDL Dimensions	This Study, Mean (SD)	Norwegian Norm, ^a Mean (SD)	Mean Score Difference, Z Score (P)	Effect Size, ^{b d}	Low Scoring (<70), ^c % (n)
Overall HRQOL	67.95 (11.89)	70.57 (12.42)	-1.29 (.20)	-0.21	57.1 (20)
Physical well-being	62.68 (21.99)	70.86 (17.76)	-2.19 (.03)	-0.46	65.7 (23)
Emotional well-being	71.79 (13.16)	76.34 (15.01)	-2.02 (.04)	-0.30	22.9 (8)
Self-esteem	61.43 (19.68)	55.90 (19.75)	1.65 (.10)	0.28	71.4 (25)
Family	79.64 (14.25)	77.11 (17.80)	1.04 (.30)	0.14	28.6 (10)
Friends	75.54 (17.51)	76.08 (16.33)	-0.18 (.86)	-0.03	45.7 (16)
School	56.61 (11.13)	67.13 (18.62)	-5.45 (.00)	-0.57	88.6 (31)
Impact of disease	70.24 (18.14)				45.7 (16)

Abbreviations: HRQOL, health-related quality of life; KINDL, Kinder Lebensqualität.

^aNorwegian norm studied by Jozefiak et al (2008) and personal correspondence (N = 1966; age, 8–16 years).

^bCohen's *d*, effect size of difference between groups [$d = (\text{Mean}_1 - \text{Mean}_2) / \text{SD}_i$, where SD_i is the pooled within-group SD].

^cPercentage (n) lower than the cutoff value recommended by Serra-Sutton et al (2009).

Table 4 • Significant Pearson's Correlations (*r*) between the Different HRQOL Dimensions (KINDL) and the Anxiety Dimensions (RCMAS)

KINDL RCMAS	HRQOL	Physical Well-Being	Emotional Well-Being	Self-Esteem	Family	Friends	School	Disease
Total anxiety	-0.707 ^a	-0.652 ^a	-0.608 ^a	-0.670 ^a	-0.393 ^b	-0.412 ^b	-0.702 ^a	
Physiological anxiety	-0.651 ^a	-0.621 ^a	-0.588 ^a	-0.665 ^a	-0.337 ^b		-0.714 ^a	
Worry	-0.647 ^a	-0.608 ^a	-0.585 ^a	-0.591 ^a	-0.356 ^b	-0.429 ^b	-0.621 ^a	
Concentration	-0.623 ^a	-0.533 ^a	-0.457 ^a	-0.575 ^a	-0.379 ^b	-0.425 ^b	-0.581 ^a	

Abbreviations: KINDL, Kinder Lebensqualität; RCMAS, Revised Child Manifest Anxiety Scale.

^aCorrelation is significant at the 0.01 level (2 tailed).

^bCorrelation is significant at the 0.05 level (2 tailed).

with newer research, indicating that up to 50% of children living with parental cancer or who have lost their parents because of cancer may have physical symptoms.⁵ We may speculate that somatic symptoms could be of special importance in families with a serious illness, even to the extent that physical symptoms can become a way of communicating distress and achieving adult attention.

The children did not score significantly higher on worry and concentration than the controls. This may reflect, as previous research has indicated,²³ that older children tend to internalize their problems by not sharing them openly. In line with this, a Danish study⁵ exploring children living with parental cancer or having lost their parents to cancer found that more than 30% of the children internalized their problems. The results from our study also mirror those of Dyregrov and Dyregrov,⁶ with a comparable sample of children, finding similar levels of anxiety. In line with Krattenmacher et al,²⁰ we found no association between any of the anxiety scales and the ill parents' gender, time since diagnosis, severity of cancer, type of treatment, or length of treatment. However, we did find that the children's age was positively correlated to total anxiety, worry, and concentration, supporting findings from earlier studies showing increased stress for adolescents.^{8,25,26} We found no significant gender differences within any of the anxiety scales, as other

researchers have.²⁸ However, these negative findings may also be explained by the low sample size.

Although the children in our study scored higher on total anxiety than the controls, overall, the children did not evidence high clinical levels of anxiety because very few scored higher than the recommended cutoff level.⁴¹ Therefore, limiting the studies of children living with parental cancer to detecting various scores higher than the cutoff levels for anxiety may not adequately reflect their life world. For example, Jeppesen et al²⁹ measured psychological problems by dichotomizing 6 selected variables (somatic stress, feeling lonely, eating problems, low self-esteem, anxiety/depression, school problems, and psychosocial problems) to either having a high degree of a problem (often/very often) or scoring higher than the cutoff values. This means that the results only reflect high levels of distress. Similarly, Jantzer et al³⁰ based their results on scorings higher than the cutoff on various problems (conduct problems, hyperactivity, peer problems, eating disorders, substance abuse, and suicide behavior), concluding that adolescents generally adjusted quite well to parental cancer. We wonder whether this analytic approach may undermine the children's distress and the complexity of their situation and thereby their need for support.

Most Children Reported Impaired Quality of Life

In contrast to a one-dimensional pathological perspective, a broader HRQOL approach is advocated for children living with parental cancer. This perspective takes into account that various spheres of the children's life can be affected. An HRQOL approach may help both healthcare professionals and parents to detect areas of concern and to identify issues that demand support before serious problems occur.³²

In line with this perspective, the children in this study reported impaired HRQOL within several dimensions. They scored lower on physical well-being than the controls, which is in line with newer research.⁵ The anxiety findings support this, indicating that the children experienced physical symptoms such as feeling ill, headaches, tummy aches, or tiredness.⁴² Taken together, this should remind us that both parents and healthcare professionals need to be aware of such symptoms and to handle them adequately.

Supporting previous research,^{6,8,25,26} the children scored lower on emotional well-being than the controls. In KINDL, emotional well-being is related to being afraid, feeling alone,

Table 5 • Results of the Moderation Models, HRQOL on Total Anxiety, and Age/Gender

Explanatory Variable on HRQOL		B (CI)	P
Age	Age	-0.09 (-1.21 to 1.02)	.866
	Total anxiety	-1.34 (-1.84 to -0.83)	.000
	Interaction effect (total anxiety × age)	-0.05 (-0.19 to 0.09)	.460
Gender	Gender	-0.91 (-7.13 to 5.31)	.767
	Total anxiety	-1.42 (-1.94 to -0.91)	.000
	Interaction effect (total anxiety × gender)	-0.61 (-1.69 to 0.47)	.261

Abbreviations: B, regression coefficient; CI, confidence interval; HRQOL, health-related quality of life.

being bored, and less time having fun.⁴² Furthermore, nearly half of the children scored lower than the cutoff, indicating clinical levels of emotional distress.⁴³ This may reflect that most of the parents had gone through multimodal treatments and lived with a serious disease. Several studies have shown a strong association between the children's psychological problems and impaired parental health.^{20,24} Therefore, emotional support for children living with parents having a serious disease may be especially important.

A finding of great concern is the children's low score on the school dimension, which indicates high concerns related to school satisfaction, homework, and worries related to marks.⁴² Here, anxiety, worry, and difficulties in concentration may be an explanation because the older children scored higher on these dimensions and these dimensions were negatively correlated to school well-being. Supporting these results, Mandag Morgen⁵ found that close to 40% of the children expressed that they could not talk to their teachers about their situation during their parents' illness or after their death. The findings of Dyregrov and Dyregrov,⁶ indicating that the children experienced limited help and support from their schools, also corroborate this. As Dyregrov and Dyregrov⁶ found, this study concurred that the older children experienced more difficulties related to school than younger children did. In contrast, Jeppesen et al²⁹ found no significant school problems for these children compared with the controls related to attention, conduct, and dissatisfaction. However, this study gives no information about the parent's illness severity and anxiety levels. Children and adolescents spend most of their awaken week-time hours at school. Our results may highlight the importance of open and good communication between the parents, students, and school. It seems important that the teachers have sufficient knowledge and skills to support these children and be aware of their situation and able to communicate with them at their premises.

Nearly half of the children reported less than the recommended cutoff on the impact of the disease. This means that they experienced sadness because of the illness, fears that the illness may get worse, or missing out on something because of it.⁴² In line with previous research,²⁸ this may indicate that the children were conscious of and concerned about their parents' disease and that they experienced restrictions in their life because of the cancer. An explanation may be the changes in family roles,^{8,19} wherein the children may have to take on more domestic tasks because of the parental cancer.²³ As such, previous research⁵ stress the importance in allowing such children an "illness-free" zone from the cancer. Healthcare professionals can inform the parents and help them to facilitate this.

Even if the children in this study scored lower on some dimensions in HRQOL, they scored in line with the controls on self-esteem, family, and friends, indicating areas of good function. In contrast to other researchers,^{5,25} we found no significant impairment in the children's self-esteem and being with friends and families. This may be because the parents in this study managed to uphold their children's self-esteem and, despite their illness situation, managed to uphold a family function in line with the controls. An alternative explanation that is in line with previous research⁴⁵ may be that the children appreciated

their family more than before the diagnosis. The self-esteem level can also be seen in connection with the friend dimension, indicating that the children had created their own space, an "illness-free" zone, when being with friends.^{5,6} It may also be that children hide their emotions to protect their parents from an extra burden. These results show that healthcare personnel and parents must be cognizant of the need to support the children's self-esteem and that family and friends are crucial factors for their HRQOL.

Theory states that each HRQOL dimension, in turn, contributes to the children's overall HRQOL.^{11,16,17} Even if the children scored lower than the controls on some dimensions, they did not differ significantly from the controls on the overall HRQOL. However, the dimensions with low scores may still represent a threat to their everyday life.⁴² In contrast to the anxiety results, most of the children scored lower than the cutoff on most dimensions, implying that they probably experienced clinical levels of impairment.⁴³ These results then indicate that HRQOL may be a more suitable way to explore these children's situations than a one-dimensional measure, especially if only a diagnosable status is given attention. In line with our results, Helseth and Ulfsaet³³ found that the quality of life of children living with parental cancer was fragile because the children experienced difficulties that affected their entire life such as school life, sports and leisure activities, family life, and relationships with friends. In contrast, Bultmann et al³⁴ found that children living with parental cancer scored better than the controls. According to the theory of HRQOL,^{11,16} threats to impaired HRQOL can be reduced with more attention given to the low-function areas and initiating help before severe problems develop, to reduce the children's distress and improve their HRQOL.

The Children's Anxiety Influenced Their HRQOL

The results revealed a strong connection between the children's level of anxiety and their HRQOL, except for the family dimension. Even if the children did not report a clinical level of anxiety, their anxiety level still influenced their HRQOL negatively. This means that we have to see the children's psychological distress living with parental cancer in connection to their overall HRQOL, with a special attention to the different life domains. Consequently, it also seems important to intervene to decrease anxiety and worry, for example, through information, communication, and openness,^{20,24} as well as to strengthen the different dimensions of HRQOL.

The Role of the Children's Age and Gender

In previous research, both age and gender seem to be important predictors for psychological distress and well-being.^{7,25,28} Our result shows that neither age nor gender moderated the relationship between anxiety and HRQOL. However, more girls scored lower than the boys did in all of the HRQOL dimensions, except from the friend dimension, even if these differences were not statistically significant. This finding may reflect those of previous research, showing that especially adolescent girls are vulnerable

to parental cancer.²⁸ However, this result may also reflect the low sample size, and further investigation is warranted.

Clinical Implications

The study's results show that living with parental cancer can be challenging in multiple ways and that a one-dimensional focus on distress may not capture these challenges. In contrast, healthcare professionals need to have an HRQOL focus in caring for patients with cancer who have children. Furthermore, they ought to work in an interdisciplinary fashion and provide both the parents and children with adequate information and tools to handle their situation to promote HRQOL and well-being. Having an HRQOL perspective gives a variety of possibilities for health-promoting interventions. Such interventions may be related to practical coping, physical activity, and information and communication, as well as social network support and facilitating school and learning activities.^{5,6} The results also indicate that healthcare professionals and researchers should have a family-oriented focus and develop interventions that are targeted toward the entire family and contextual factors such as the children's school and friends.

Study Limitations and Recommendations for Future Research

The main limitation of this study is the sample size, which may explain some of the nonsignificant findings related to age, gender, and the parental illness variables.³⁹ We used an extended and intensive recruitment procedure to reach families nationally, but this is a small population to reach.^{3,4} Challenging recruitment may also be related to healthcare professionals and parents' tendency to underestimate the children's challenges living with parental cancer, as well as a lack of a family perspective in healthcare professionals caring for patients with cancer.^{5,32}

Another limitation may be that the sample had an overrepresentation of girls. Furthermore, the children filled out the questionnaires at home, and we do not know to what degree their parents were present and may have influenced the results. Thus, the findings cannot be generalized to the broader population of children living with parental cancer.

Because this is one of the first studies focusing on HRQOL of children living with parental cancer, more research within this field is needed with larger populations. The relationship between parents' illness variables and the children's gender and age on their HRQOL should be further investigated. Because the family function is important for how children cope with their challenges, further research should also connect the parents' HRQOL with their children's HRQOL to see how these interact to develop helpful interventions. A mixed method approach that combines HRQOL data with in-depth interviews from both the children and the parents would also take this field an important step further.

Conclusions

The children in this study reported higher anxiety and lower HRQOL than the controls. The children's physiological, emo-

tional, and school well-being were significantly impaired, whereas they scored in line with the controls on self-esteem, relations to family and friends, and overall HRQOL. The children's anxiety influenced their HRQOL negatively, but neither age nor gender seems to act as a moderator for this connection. The findings of this study are particularly relevant for nurses caring for patients with cancer who have children. The results indicate that focusing on the children's HRQOL may give a better indication of their challenges, as well as resources, instead of a 1-dimensional focus on psychosocial distress. An HRQOL perspective may give both parents and healthcare professionals an indication of the areas of special importance. On the basis of this, adequate and tailored interventions to promote HRQOL and health can be developed.

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