Original Article

Family functioning, parental cancer-related emotions, and quality of life in childhood cancer patients

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Abstract

Background Childhood cancer and its treatment affects not only children's health, but also children's and families' psychosocial function, relationship, emotion, and quality of life. Several studies in developed countries have been conducted to address this issue using the *Family Adaptation and Cohesion Scales III* (FACES III) and the *Situation-Specific Emotional Reaction Questionnaire* (SSERQ). Screening psychosocial problems is crucial as part of cancer comprehensive care.

Objective To investigate the dynamics of family functioning, parental cancer-related emotions, and to evaluate possible associations with the child's quality of life.

Methods This cross-sectional study was done in child with cancer aged 0-18 years. Parents completed the validated Indonesian versions of three sets of questionnaires regarding subjects' quality of life (PedsQL), family function (FACES III), and family cancer-related emotions (SSERQ). Validity and reliability tests were done to assess the Indonesian versions of the questionnaires.

Results A total of 269 subjects were recruited. Parental proxy of PedsQL evaluations revealed that the 8 to 12-year-old age group had significantly lower score than the other groups (P=0.014). Solid tumor subjects had significantly lower PedsQL score compared to subjects with hematological malignancy (P=0.001). The FACES III questionnaire results showed that connected families tended to have better PedsQL score based on children's evaluation compared to disengaged families (P=0.049). No significant difference was found between adaptability of family function and PedsQL score. The SSERQ revealed significant associations between negative emotions and lower PedsQL scores in the children (all P=0.000).

Conclusions Parental proxy of PedsQL scores were significantly lower in older children (8-12 years). Children with connected families have significantly higher PedsQL scores than disengaged families, for the PedsQL children's evaluation. Parents' emotions (loneliness, helplessness, and uncertainty) experienced by a family member of a child with cancer are also correlated with lower PedsQL scores by both evaluations. [Paediatr Indones. 2024;64:250-7; DOI: 10.14238/pi64.3.2024.250-7].

Keywords: family function; cancer-related emotion; quality of life; children; cancer

Around 300,000 children worldwide are diagnosed with cancer every year.[1] The global burden of pediatric cancer remains high, with more than 80% of childhood cancers occurring in developing countries.[2] According to the *Riset Kesehatan Dasar 2013* (*RISKESDAS 2013/2013 Indonesian Basic Health Research Survey*), the prevalence of cancer in children aged <1, 1-4, and 5-14 years in Indonesia were 0.3%, 0.1%, and 0.1% respectively.[3] Even though in 2018 there was a decrease in prevalence for those aged <1 and 1-4 years to 0.03% and 0.08%, respectively, the prevalence increased among 5 to 14-year-olds, reaching 0.31%.[4] The 5-year survival rate for children with cancer has risen significantly, exceeding 80% in developed countries, but is still less than 30% in developing countries. In low-resource settings, inadequate supportive care and suboptimal treatment quality result in a higher burden of care and lower survival rates.[5] To address these inequalities, the *World Health Organization Global Initiative for Childhood Cancer*

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developed a strategy to improve access and quality of care for children with cancer.[6]

Cancer therapy can lead to decreased quality of life (QoL) and social burdens in children and their families. Children diagnosed with cancer and their parents often experience increased stress, thus, marital and parent-child relationships can be greatly impacted.[7-9] Therefore, the evaluation of psychosocial problems in cancer patients and their families is imperative and should be included in comprehensive cancer care management. Compliance to appropriate treatment protocols can positively influence QoL.[1]

Previous studies revealed that children diagnosed with cancer and their parents differ in family adaptability and cohesion, especially during the first month of the cancer diagnosis.[8] Childhood cancer can cause an immense emotional trauma for parents and family members. Emotions can appear in the form of anxiety, anger, sadness, or feelings of guilt.[6] Parents and family members may face interference in conducting their daily routine, including changes in parent or partner roles, potential threats to work, financial or economic hardships, and emotional challenges.[9,10] In families facing childhood cancer, we aimed to assess family functioning, parental cancer-related emotions, as well as analyze associations with the child's QoL.

Methods

This cross-sectional study was performed from October 2020 to May 2021. Children aged 0-18 years diagnosed with solid tumors or blood cancer were included in this study by consecutive sampling. Informed consent and/or informed assent were obtained from all legal guardians and children. This study was approved by the Ethics Committee of the Faculty of Medicine, University of Indonesia/Dr. Cipto Mangunkusumo Hospital.

Subjects and their legal guardians completed the 3 questionnaires, written in the Indonesian language. Those subjects who did not complete the questionnaire or did not speak Bahasa Indonesia were excluded. The three questionnaires assessed (1) subjects' quality of life (PedsQL), (2) family function (FACES III), and (3) family cancer-related emotions (SSERQ). In this study, family is defined as the parents

of the child with cancer, not including their siblings or extended family. By dividing the subjects based on PedsQL cut-off of <70 and >70, we compared their quality of life with their families' function and cancer-related emotions by using FACES and SSERQ questionnaires, respectively.

The PedsQL 4.0 was originally developed in English.[11] The Indonesian version of PedsQL was used in this study.[12] *The PedsQL 4.0* evaluates four domains of functioning: (1) physical (8 items), (2) emotional (5 items), (3) social (5 items), and (4) school (5 items), utilizing a five-point Likert scale from 0 (never) to 4 (almost always).[13] Items are scored and converted to a 0-100 scale through a linear transformation: 0=0, 1=25, 2=50, 3=75, and 4=100.14 The total score is calculated by taking a sum-total average of the individual item scores within each subdomain. This assessment tool is reported on a 0-100 scale, with higher scores indicating better health-related quality of life (HRQoL).[13] There are four versions of the scale based on age-group: 2-4 years (toddlers), 5-7 years (young children), 8-12 years (children), and 13-18 years (teenagers). There is also an additional format intended for parents or caregivers of children aged 5-18 years (proxy report). Numerous studies have established cut-off scores for PedsQL, with the most frequent range within 70-79.[13,15] The cut-off scores for our study were chosen based on two previous studies which concluded that a PedsQL cut-off score of 70 effectively distinguished between favorable and impaired QoL.[13,16]

The Family Adaptation and Cohesion Scales III (FACES III) was developed to investigate family dynamics, focusing on two major dimensions: family adaptability and cohesion.[17,18] There are four levels of family adaptability: rigid, structured, flexible, and chaotic. Additionally, there are four levels of family cohesion: disengaged, separated, connected, and enmeshed. The two central levels (structured and flexible for adaptability, and separated and connected for cohesion) are considered to be balanced levels of family dynamics. According to the curvilinear hypothesis, balanced levels of cohesion and adaptability reflect more healthy family functioning, while unbalanced levels tend to reflect more problematic family functioning. The FACES III comprises 10 items each for cohesion and adaptability. Parents use a *Likert Scale* from 1 (almost never) to 5

(almost always) to indicate the frequency of described behaviors in their family. The total scores of cohesion and adaptability domains ranged from 10 to 50 points, with balanced (mid-range) scores reflecting healthy family functioning.[17,19] Following the classification method of Olson *et al.*,[17] family adaptability and cohesion are categorized into four levels based on their respective scores. Family adaptability is categorized as follows: rigid (10.00-25.39), structured (25.40-31.59), flexible (31.60-37.79), and chaotic (37.80-50.00). Family cohesion is categorized as follows: disengaged (10.00-26.81), separated (26.82-33.00), connected (33.01-39.19), and enmeshed (39.20-50.00).

The Situation-Specific Emotional Reaction Questionnaire (SSERQ) was originally developed by Grootenhuis *et al.*,[20] and was adapted for children by Houtzager *et al.*[21] to assess family emotional responses. This questionnaire consisted of 30 items, divided into four subscales: (1) loneliness (11 items), (2) helplessness (7 items), (3) uncertainty (6 items), and (4) positive feelings (6 items). These items capture feelings that can be considered situation-specific for parents of children with cancer. Parents were asked to express their emotional experiences on a 4-point Likert scale from 0 (almost never) to 3 (almost always). Higher scores indicated more emotional reactions, encompassing both negative (loneliness, uncertainty and helplessness) and positive (positive feelings).[22]

Validity tests with Pearson's correlation and reliability tests with Cronbach's alpha were used to assess the Indonesian versions of FACES III and SSERQ. A value of P<0.05 for Pearson's correlation and >0.6 for Cronbach's alpha were considered to be valid and reliable.

Subjects' family function and PedsQL results were analyzed with ANOVA or Kruskal-Wallis test. Subjects' family cancer-related emotions and PedsQL results were analyzed by Mann-Whitney test, after assessing data normality with Kolmogorov-Smirnov test.

Results

A total of 299 children and their legal guardians were recruited. Validity and reliability of the 3 questionnaires was assessed in 30 subjects. Therefore, 269 subjects were included in the final study analysis. The Indonesian version of the FACES III questionnaire had good validity, with all questions having Pearson's correlation P values <0.05. FACES III also had good reliability, with Cronbach's alpha of 0.87. The Indonesian version of SSERQ also had good validity (all questions had P values<0.05). The reliability test of the SSERQ showed excellent agreement reliability, with Cronbach's alpha of 0.96. Therefore, the FACES III and SSERQ questionnaires were valid and reliable for evaluating family function and cancer-related emotions.

Of our 269 subjects, 59.85% had a ≥1 year duration of cancer and 40.15% had <1 year duration of cancer. Hematological malignancy (75.10%) was more commonly found than solid tumors (24.91%). Throughout our consecutive sampling method, we did not found subjects <2 years old. Most subjects' parents were married (89.96%), while the others had divorced or widowed parents. Most subjects also lived with their nuclear family (52.41%), while the others lived with their second degree relatives. Around half of subjects (50.19%) had only their parents as their caregivers.. The characteristics of subjects are presented in **Table 1**.

Analysis of PedsQL scores and subjects' characteristics is shown in **Table 2**. There were no significant associations between PedsQL score based on parental proxy and children's evaluations and sex, parents marital status, number of relatives in the same household, caregiver, other family members with chronic illness or special needs, and duration of cancer. However, a low PedsQL score (<70) was noted in the divorced parents group, based on children's evaluation (median score of 62.5; P=0.489). The 8-12 years age group had a significantly lower median PedsQL score based on parental proxy evaluation compared to the other age categories, while the highest median score was in 2-4-year age group (P=0.014). According to the children's evaluations, 13-18-year age group had the lowest median score (69.69), while the 5-7 year age group had the highest (72.97), although not statistically significant (P=0.489). Subjects with solid tumors had lower PedsQL scores for both parental proxy and children's evaluations compared to scores of hematological malignancy subjects (P=0.001 and P<0.001, respectively).

Subjects' family function consisted of two categories, cohesion and adaptability. Family cohesion

Table 1. Characteristics of subjects

Characteristics	(N=269)
Sex, n (%)	
Male	173 (64.31)
Female	96 (35.69)
Mean age (SD), years	8.64 (4.5)
Age group, n (%)	
0-<2 years	0 (0)
2-4 years	96 (35.69)
5-7 years	72 (26.77)
8-12 years	55 (20.45)
13-18 years	46 (17.10)
Parents' marital status, n (%)	
Married	242 (89.96)
Widowed	14 (5.21)
Divorced	13 (4.8)
Number of families living in the same house, n (%)	
Nuclear family	141 (52.41)
Second degree relatives*	67 (24.91)
Extended family**	61 (22.68)
Caregiver, n (%)	
Only parents	135 (50.19)
Nursemaid	8 (2.97)
Extended family members	126 (46.84)
Siblings, n (%)	
None	46 (17.10)
<3	170 (63.19)
>3	53 (19.71)
Other family members with chronic illness or special needs, n (%)	
Yes	10 (3.7)
No	259 (96.28)

*Exclusively living with grandparents; **extends beyond living with the grandparents

was classified as disengaged, separated, connected, or enmeshed. Family adaptability was categorized as rigid, structured, flexible or chaotic. Analysis of subjects' family function and QoL based on both parental proxy and children's evaluation is shown in **Table 3**. For cohesion family function, there was a significantly higher percentage of connected families in the higher PedsQL group (score >70) than in the lower PedsQL group, as well as higher percentage of disengaged families in the lower vs. higher score PedsQL groups, as reported by the children's evaluation results (P=0.049). No such significant differences were reported in the parental proxy evaluations.

We also evaluated family cancer-related emotions: loneliness, helplessness, and uncertainty, as shown in **Table 4**. Analysis of PedsQL and SSERQ scores showed that low PedsQL scores (both parental proxy and children's evaluations) were significantly associated with loneliness, helplessness, and uncertainty (all P<0.001).

Discussion

The QoL of children with cancer is an important indicator of optimal healthcare provision. We assessed children's QoL by PedsQL parental proxy evaluations and found that children aged 8-12 years had significantly lower median PedsQL score than other age groups, followed by 13 to 18-year-olds (P=0.014). A previous study showed that older children had the worst total PedsQL score.[23] A systematic review of 22 studies evaluated HRQL of acute lymphoblastic leukemia patients and showed that older children had worse HRQL scores. The review suggested that school-aged children (>5 years) had greater reductions in HRQL compared to preschool-aged children.[24] It may be that children and young adolescents possess a greater understanding of their internal experiences, whereas parents often depend on observable behaviors and information provided by their children.[25] Additionally, research

Table 2. Analysis of subjects' characteristics and PedsQL scores based on parental proxy and children's evaluations

Characteristics	PedsQL parents' evaluation		PedsQL children's evaluation	
	Mean (range)	P value	Median (range)	P value
Sex				
Boys	74.69 (0-100.00)	0.346[a]	72.29 (1.84)[#]	0.133[b]
Girls	68.86 (11.67-100.00)		66.25 (0-100)	
Age groups				
2-4 years	75.29 (36.67-95.83)	0.014[c]		0.392[c]
5-7 years	73.28 (25.78-100.00)		72.97 (40.63-100.00)	
8-12 years	71.72 (0-100)		71.72 (0-100.00)	
13-18 years	72.10 (37.50-100.00)		69.69 (30.78-100.00)	
Parents' marital status				
Married	71.80 (0-100)	0.306[c]	71.80 (0-100)	0.489[c]
Widowed	74.06 (51.89-100.00)		70.00 (49.53-100.00)	
Divorced	75.00 (31.78-90.99)		62.50 (31.25-90.94)	
Number of relatives living in the same household				
Nuclear family	72.88 (1.83)[#]	0.828[d]	71.96 (1.87)[#]	0.551[d]
First degree relatives	71.25 (3.37)[#]		68.31 (3.98)[#]	
More than second degree relatives	69.99 (3.90)[#]		68.61 (3.76)[#]	
Caregiver				
Parents only	71.72 (2.04)[#]	0.644[d]	70.53 (2.10)[#]	0.999[d]
Nursemaid	68.61 (10.17)[#]		70.86 (8.44)[#]	
Other family members	72.38 (2.31)[#]		70.44 (2.49)[#]	
Other family member with chronic illness or special needs				
Yes	85.94 (48.28-100.00)	0.517[b]	80.63 (30.78-100.00)	0.630[a]
No	71.80 (0-100)		70.16 (0-100.00)	
Duration of cancer				
<1 year	71.97 (2.54)[#]	0.341[a]	70.97 (2.59)[#]	0.825[a]
>1 year	71.93 (1.88)[#]		70.24 (2.00)[#]	
Cancer type				
Hematological malignancy	75.65 (11.67-100.00)	0.001[a]	74.53 (0-100.00)	0.000[a]
Solid tumors	57.81 (0-100.00)		55.16 (15.94-100.00)	

[a]analysis of two means by Mann-Whitney U Test as an alternative to student's T-test (non-parametric); [b]comparison of two means by student's T-test; [c]Kruskal-Wallis independent test as an alternative to ANOVA (non-parametric); [d]ANOVA test with Tukey post-hoc analysis. Equality of variances calculated by Levene's test; [#]mean (SD); normality test was done using Kolmogorov-Smirnoff test

Table 3. Analysis of PedsQL and subjects' family function (FACES III)

Family function	PedsQL parental proxy evaluation			PedsQL children's evaluation		
	<70 (n=166)	≥70 (n=103)	P value	<70 (n=88)	≥70 (n=85)	P value
Cohesion, n (%)						
Disengaged	49 (29.52)	25 (24.27)	0.069	31 (35.23)	17 (20.00)	0.049
Separated	35 (21.08)	16 (15.54)		18 (20.45)	17 (20.00)	
Connected	34 (20.48)	36 (34.95)		16 (18.18)	29 (34.12)	
Enmeshed	48 (28.92)	26 (25.24)		23 (26.14)	22 (25.88)	
Adaptability, n (%)						
Rigid	113 (68.07)	70 (67.96)	0.99	65 (73.86)	51 (60.00)	0.22
Structured	33 (19.88)	21 (20.39)		14 (15.91)	22 (25.88)	
Flexible	8 (4.82)	5 (4.85)		3 (3.41)	6 (7.06)	
Chaotic	12 (7.23)	7 (6.80)		6 (6.82)	6 (7.06)	

Chi-square test

suggests that children aged 12 and older tend to distance themselves from their parents, potentially spending more time with peers and obtaining support from them.[26]

The FACES-III was used to assess family functioning, consisting of two subscales: cohesion and

Table 4. Analysis of PedsQL scores and family cancer related emotions (SSERQ scores)

SSERQ scores	PedsQL parents' evaluation			PedsQL children's evaluation		
	<70	≥70	P value	<70	≥70	P value
Loneliness	5 (0-3)	1 (0-7)	0.000	5 (0-33)	1 (0-7)	0.000
Helplessness	7 (0-1)	2 (0-2)	0.000	6 (021)	3 (0-5)	0.000
Uncertainty	6 (0-8)	3 (0-4)	0.000	6 (0-18)	4 (0-4)	0.000

Data is presented as median (range) score of family-cancer related emotion; Normality test was done using Kolmogorov-Smirnoff test; Mann-Whitney U Test was used as an alternative to student's T-test (non-parametric)

adaptability.[27] Families tend to become resilient after being exposed to significant risk (diagnosis of pediatric cancer), whereas extreme levels of adaptation and cohesion were related to less adaptive functioning. Cohesion reflects the emotional connection among family members.[28,29] We found that a majority of families were classified as disengaged (74; 27.51%) or enmeshed (74; 27.51%), using the parental proxy questionnaires. A systematic review reported significantly higher levels of family cohesion during and after treatment. Parents also commonly reported that the illness strengthened family cohesion, sometimes leaning towards enmeshment. The adaptability category refers to the degree of flexibility in the leadership, role dynamics, and relationship rules within a family.[28] In our study, most families were categorized as rigid (183; 68.03%), according to parental questionnaires. Some studies found that survivors' parents were overly protective and less flexible than parents of healthy children. Other studies reported that the quality of family cohesion and adaptability was positively related to survivors' psychosocial outcomes.[30,31] We could make no such determination, as we did not compare our findings to those of healthy children or to our subjects prior to their cancer diagnoses.

We used a PedsQL cut-off score of 70 to compare two PedsQL subgroups (<70 and ≥70) and family function.[32] PedsQL children's evaluations showed that disengaged families tended to children with lower QoL score, while connected families tended to have children with higher PedsQL scores (P=0.049). A previous study compared family function and QoL in pediatric cancer subjects, using the *Family Environmental Scale* (FES), PedsQL 4.0, and the general life satisfaction subscale of the *Maudsley Marital Questionnaire* (MMQ). Their results were in agreement with that of our study analysis, based

on parent's evaluations. They found a significant association between balanced level of family cohesion and higher children's QoL.[22] Quantitative studies in parents also reported that the more cohesion or emotional closeness within family, the better the child's QoL.[33,34]

Based on parental proxy evaluations, we noted that that flexible family adaptability tended to have better QoL. However, children's evaluations revealed that chaotic adaptability tended to have better QoL. Even though we found no significant differences between family adaptability and QoL, for either the parental proxy or children's evaluation. A previous study described that poor adaptation in families with cancer was associated with greater psychosocial family risk. Analytic study between psychosocial family risk and HRQoL revealed that psychosocial family risk was negatively associated with both parents' and children's HRQoL reports.[26]

Our study showed that parent emotion (feelings of loneliness, helplessness, and uncertainty) were significantly associated with lower PedsQL score (P<0.005 for all). A qualitative study showed that parents of children with cancer struggled with physical, psychological, social, and even existential aspects of life. They reacted to a frightening and uncontrollable situation with sleeplessness, eating difficulties, exhaustion, feelings of unfairness, and uncontrollable anger.[35] Another study also showed that parents of children with cancer had post-traumatic stress symptoms, psychological distress, and lower quality of life compared to population norms.[36]

A meta-analysis reported that children's QoL was significantly related to parent psychosocial adjustment which led to their family adaptation.[37] Additionally, a study also confirmed that parents with psychosocial distress reduced child QoL.[37] However, in our study, we cannot conclude whether psychosocial distress

can reduce QoL.

In conclusion, PedsQL parental evaluations revealed that children age 8-12 years had significantly lower scores than children of younger and older age groups. Children whose families are connected have better PedsQL score compared to that of disengaged families. Parental cancer-related emotions are significantly correlated with children's lower PedsQL scores. The incorporation of early palliative care for children diagnosed with cancer and their families is crucial right from the onset of diagnosis. This type of care can offer comprehensive support encompassing treatment, as well as psychosocial and spiritual facets, aiming to enhance the quality of life of children battling cancer.

Conflicts of interest

None declared.

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