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Original Article

Impact of Ego-resilience and Family Function on Quality of Life in Childhood Leukemia Survivors

Ok-Hee CHO [1], ****Yang-Sook YOO*** [2], ***Kyung-Hye HWANG*** [3]

1. *Dept. of Nursing, College of Nursing and Health, Kongju National University, Kongju, South Korea*
2. *College of Nursing, the Catholic University of Korea, Seoul, South Korea*
3. *Dept. of Nursing, Suwon Science College, Hwaseong, South Korea*

***Corresponding Author:** Email: ysyoo@catholic.ac.kr

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Abstract

Background: This study aimed to examine the impact of ego-resilience and family function on quality of life in childhood leukemia survivors.

Methods: This study targeted 100 pediatric leukemia survivors, who visited the Pediatric Hemato-Oncology Center in South Korea from Aug to Dec 2011. A structured questionnaire of ego-resilience, family function and quality of life used to collect data through direct interview with the pediatric patients and their parents. The correlation between the study variables analyzed using the Pearson's correlation coefficient, and the impact on quality of life analyzed using a stepwise multiple regression.

Results: Ego-resilience (r = 0.69, *P*<0.001) and family function (r =0.46, *P*< 0.001) had a positive correlation with quality of life and all the sub-categories of quality of life. Ego-resilience was a major factor affecting quality of life in childhood leukemia survivors, with an explanatory power of 48%. The explanatory power for quality of life increased to 53% when age and family function were included.

Conclusion: Ego-resilience, age, and family function affect quality of life in childhood leukemia survivors. Hence, strategies are required to construct age-matched programs to improve quality of life, in order to help restore the necessary ego-resilience and to strengthen family function in childhood leukemia survivors.

Keywords: Leukemia, Survivorship, Quality of life

Introduction

Pediatric patients diagnosed with cancer, including leukemia, suffer greatly in the process of receiving treatment such as chemotherapy, stem cell transplantation, and radiotherapy, depending on their disease. Even after complete remission, they experience physical side effects such as infection, pain, deterioration of physical function, endocrine disorders, visual impairment, and growth impairment, as well as psychological side effects such as anxiety, depression, and post-traumatic stress syndrome. They also have difficulty in social adjustment or coping due to memory impairment and lack of interpersonal skills (1-3). Such problems make it difficult for pediatric patients to return to social life after cancer treatment and bring about a negative impact on their quality of life (4). Long-term treatment also affects their school life and difficulties in readjustment to normal daily life experienced even after the completion of treatment (5).

Owing to the development of medical technologies, the 5-yr survival rate of Korean children with leukemia aged less than 15 yr reached 74.7% in 2011 (6). As a result, leukemia no longer is considered an incurable disease and instead viewed as a chronic disease requiring long-term

treatment. Consequently, it is important to help pediatric patients return to their daily lives, including school life, after the completion of treatment. Pediatric patients with leukemia experience the deterioration of physical functions and other diverse symptoms during treatment, which lowers health-related quality of life; long-term physical and psychological side effects as well as cognitive changes after completion of treatment continue through adulthood (7-9). In addition, because patients separated from school during the treatment period, they have difficulties with participation in education and learning, as well as social difficulties making close friends (10). Pediatric leukemia patients show worse social adjustment than their peers do, and this correlated with quality of life (9, 11). Therefore, it is necessary to explore the physical well-being of and emotional, social, and environmental quality of life perceived by childhood leukemia survivors after treatment completion, and related factors.

Ego-resilience, recently considered to relate to quality of life (12), is the ability for successfully adjust to changing situational demands and environments by responding flexibly based on self-control (13). Persons high in ego-resilience tend to handle stressful situations flexibly and dynamically, have a better ability to recover from negative emotional experiences, and have less perceived stress about such situations (13-14). Besides, it is meaningful to identify and strengthen the level of ego-resilience in survivors of childhood leukemia facing stressful situations.

Leukemia also changes home life as the patient's disease condition, activity level, and quality of relationships serve as stressors for the family and cause conflicts among family members (15-16). Further, such family relations and conflicts cause depression or anxiety in pediatric patients with leukemia (15). Adolescents with good relationships with their parents tend to be highly autonomous and have good psychological well-being due to mutual communication (17). Therefore, it is necessary to investigate the level of family function perceived by pediatric patients with leukemia and to identify factors affecting such functioning.

This study aimed to examine the impact of ego-resilience and family function on quality of life in childhood leukemia survivors.

Methods

Study Design

This study employed a descriptive survey research design to examine the impact of ego-resilience and family function on quality of life in childhood leukemia survivors.

Participants and Data Collection

Participants recruited on childhood leukemia survivors aged between 7 and 15 yr, diagnosed with leukemia in the Pediatric Hemato-Oncology Center of C University Hospital located in Seoul, South Korea and achieved complete remission after completing chemotherapy treatment. Convenience sampling used to recruit a sample of 100 participants considering an attrition rate.

After obtaining approval from the Institutional Review Board (IRB) of C University regarding the study objectives, methods, and procedures, data collected from Aug to Dec 2011. The researcher received written consent for participation through direct interview with pediatric patients and parents, after explaining the study objectives and questionnaire content. After receiving instructions from one trained research assistant, the pediatric patients filled out the questionnaire without interruption from their parents.

Instruments

The ego-resilience of pediatric patients with leukemia measured using the self-report ego-resilience tool for early adolescents modified by Cho and Lee (18) from the parent-report ego-resilience tool (19). This instrument has 24 questions measured on a 4-point scale (1–4 points). It comprises the following areas: peer group relations and optimism, sympathy and self-acceptance, concentration and confidence about tasks, understanding, and leadership. The score ranges from 24 to 96 points, where higher scores are indicative of higher ego-resilience. The Cron-

bach's α value indicating the internal consistency reliability was 0.83 in the study (16) and was 0.87 (.55–.87) in the present study.

Family function measured using a tool (20) from the Family APGAR scores (21). This tool has five questions measured on a 3-point scale (0–2 points). It evaluates the adaptability, cooperation, development, affection, and resolution of family members. The total score ranges from 0-10 points. Total scores in the range of 0–3 categorized in the severely dysfunctional group, 4–6 points denoted the moderately dysfunctional group, and 7–10 points denoted the highly functional group. The Cronbach's α value for internal consistency reliability was 0.80 in the study in it developed, and 0.72 in the present study.

Quality of life was measured using a standardized tool to suit the Korean context (2), based on the KIDSCREEN 52-HRQOL (22). This tool has 52 questions measured on a 5-point scale (1–5 points), across the following areas: physical well-being, psychological well-being, mood and emotions, social support and peers, parent relations and home life, autonomy, self-perception, school environment, social acceptance (bullying), and financial resources. In the present study, the quality of life score was calculated as the T conversion score with a mean of 50 and standard deviation of 10, to ensure that the scores comparable to those of previous studies. The Cronbach's α value for internal consistency reliability was 0.77–0.95 in the Korean version of KIDSCREEN 52-HRQOL (2) and 0.94 (0.75–0.94) in the present study.

Statistical Analysis

The data analyzed using SAS Version 9.2. General characteristics of participants, ego-resilience, family functioning, and quality of life were examined using frequency, percentage, mean, and standard deviation. Differences in quality of life-based on participants' general characteristics confirmed using *t*-test, ANOVA, and Scheffé's test. Correlations among ego-resilience, family function, and quality of life examined using Pearson's correlation coefficients. Finally, factors affecting quality of life identified using a stepwise multiple regression.

Results

General Characteristics of Participants

The mean age of the participants was 10.9 yr (7–15 yr) and those aged 7–12 yr accounted for 74% of the sample. Boys accounted for 59%, and elementary school students, middle school students, and students on leave of absence accounted for 50%, 40%, and 10% of the sample, respectively. Those with a religion accounted for 59%, and those whose fathers and mothers had jobs accounted for 94% and 43%, respectively. Further, 52% had siblings. Acute lymphoblastic leukemia (ALL) accounted for 81% of the sample (Table 1).

Ego-resilience, Family Function, and Quality of Life

The mean ego-resilience score of the participants was 67.65 points out of the total 96 points possible. With reference to the sub-categories, peer group relations and optimism had the lowest mean scores, while leadership had the highest. The mean family function score was 6.52 points out of a total possible 10 points. The severely dysfunctional group, moderate dysfunctional group, and highly functional group accounted for 12%, 35%, and 53% of the sample, respectively. The mean total quality of life score was 49.85, physical well-being and autonomy had the lowest scores, and parent relations, home life, and financial resources had the highest scores (Table 2).

Differences in Quality of Life Based on Participants' General Characteristics

The mean quality of life score in pediatric patients aged 13–15 yr was 48.19 points, which was lower than the mean of 50.43 points for those aged 7–12 yr (P=0.050). Middle school students had a mean score of 48.26 points, which was lower than the mean of 51.14 points for those in elementary school (P= 0.024). Those diagnosed with ALL had a mean score of 49.29 points, which was lower than the mean score of 52.23 for those with AML (P = 0.020) (Table 1).

Table 1: Quality of life according to general characteristics of participants (n=100)

Variables		Quality of Life	
	% or Mean±SD (range)	Mean ± SD	t/F (p)
Age (yr)	10.9 ± 2.1 (7~15)		
7 ~ 12	74.0	50.43 ± 5.15	1.98 (.050)
13 ~ 15	26.0	48.19 ± 4.26	
Gender			
Male	59.0	49.25 ± 5.04	1.45 (.151)
Female	41.0	50.71 ± 4.90	
Education			
Absence	10.0	49.74 ± 3.95	3.89 (.024)
Elementary	50.0	51.14 ± 4.94[a]	a>b
Middle school	40.0	48.26 ± 4.97[b]	
Religion			
Yes	59.0	49.86 ± 5.14	0.02 (.981)
No	41.0	49.83 ± 4.87	
Father's job			
Yes	94.0	49.79 ± 4.98	0.45 (.653)
No	6.0	50.74 ± 5.88	
Mother's job			
Yes	43.0	50.29 ± 4.94	0.77 (.443)
No	57.0	49.51 ± 5.08	
Sibling			
Yes	52.0	50.06 ± 4.51	0.43 (.665)
No	48.0	49.62 ± 5.53	
Diagnosis			
ALL	81.0	49.29 ± 5.08	2.36 (.020)
AML	19.0	52.23 ± 3.99	

ALL= Acute lymphoblastic leukemia; AML= Acute myeloblastic leukemia; [a,b]: Scheffé test

Table 2: Level of ego-resilience, family function and quality of life (n=100)

Variables (range of possible scores)	% or Mean±SD
Ego-resilience (24-96)	67.65 ± 9.23
Peer relation and optimism (1-4)	2.76 ± 0.58
Sympathy and proprioception (1-4)	2.78 ± 0.42
Concentration on task and confidence (1-4)	2.79 ± 0.54
Understanding (1-4)	2.89 ± 0.54
Leadership (1-4)	3.06 ± 0.80
Family function (0-10)	6.52 ± 2.37
Severely dysfunctional	12.0
Moderately dysfunctional	35.0
Highly functional	53.0
Quality of life (T-score)	49.85 ± 5.01
Physical well-being	49.80 ± 8.27
Autonomy	49.80 ± 7.14
Psychological well-being	49.83 ± 7.97
Moods & emotions	49.81 ± 7.59
Social acceptance (bullying)	49.83 ± 8.66
Self-perception	49.90 ± 7.26
Social support & peers	49.92 ± 8.77
School environment	49.92 ± 7.90
Parent relations and home life	50.00 ± 7.92
Financial resources	50.00 ± 8.62

Correlations among Ego-resilience, Family Function, and Quality of Life

Ego-resilience had a positive correlation with quality of life (r = .69, *P* <.001) and all the sub-categories of quality of life. Family function had a positive correlation with quality of life (r= 0.46, *P*<0.001) as well as mood and emotions, parent relations and home life, self-perception, autonomy, school environment, and financial resources among the sub-categories of quality of life (Table 3).

Table 3: Correlation among ego-resilience, family function and quality of life (n=100)

Variables	Ego-resilience	Family function
	r (*P*)	
Quality of life (total)	0.69 (<.001)	0.46 (<.001)
Social acceptance (bullying)	0.30 (.003)	0.15 (.130)
Financial resources	0.32 (.002)	0.31 (.002)
Social support & peers	0.38 (<.001)	-0.03 (.774)
Autonomy	0.40 (<.001)	0.28 (.006)
Self-perception	0.42 (<.001)	0.32 (.001)
Parent relations and home life	0.47 (<.001)	0.60 (<.001)
Physical well-being	0.49 (<.001)	0.12 (.242)
School environment	0.53 (<.001)	0.25 (.012)
Psychological well-being	0.48 (<.001)	0.40 (<.001)
Moods & emotions	0.45 (<.001)	0.46 (<.001)

Factors Affecting Quality of Life

To examine the factors affecting quality of life of pediatric patients with leukemia, a stepwise regression analysis was conducted using the following independent variables: age and educational level (dummy variables) among the general characteristics, because they showed a difference for quality of life; and ego-resilience and family functioning, correlated with quality of life. A major factor affecting the quality of life of pediatric leukemia patients was ego-resilience, with an explanatory power of 48%, which increased to 53% when age and family function were included (Table 4).

Table 4: Stepwise multiple regression analysis for quality of life

Predictors	Partial R^2	Standardized β	SE	*t*	*P*
Ego-resilience	0.48	0.60	1.02	7.70	<.001
Age (years)	0.03	-0.17	0.17	-2.41	.018
Family function	0.02	0.16	0.17	1.99	.049
R^2=0.53, Adjusted R^2=0.52, F (*P*)=36.74(<.001)					

SE : standard error

Discussion

In the present study, the mean quality of life score of the participants was 49.85 points, which was similar to the 49.12 points scored by children aged 6–17 yr in the 4th month after being diagnosed with pediatric cancer in a Swiss pediatric hospital (23). Survivors of childhood leukemia showed similar quality of life scores as compared to pediatric patients with pediatric cancer in the process of treatment, probably because they still had delayed symptoms after treatment, were receiving follow-up care even though treatment has been completed, and were in the process of recovery. Hence, it is necessary to monitor pedia-

tric leukemia survivors and provide them continuous care in physical, psychological, and social domains.

In the present study, physical well-being and autonomy had the lowest average scores among the sub-categories of the quality of life, while parent relations and home life, and financial resources had the highest scores. This result was similar to that of pediatric patient's aged 12–17 yr old receiving treatment for bone tumors, as their average score for the physical well-being category was low, while those for financial resources, and parent relations and home life were the highest (24). Survivors of childhood leukemia who participated in the present study were recovering after the completion of treatment, while the pediatric patients with bone tumors were within 3 months of adjuvant treatment. Therefore, the side effects of active treatment were assumed to have a negative effect on their physical well-being. However, healthy school-aged children (25) showed different results, as their scores on the financial resource, free time categories were the lowest, and those on social acceptance, and mood, and emotions were the highest. This is probably because childhood leukemia survivors cannot lead an autonomous life due to their physical health issues, whereas healthy school-aged children are able to enjoy friendships, but have limited time due to school life and studies after school.

In the present study, the quality of life of patients aged 13–15 yr was lower than that of those aged 7–12 yr. This was similar to a result in which the quality of life perceived by 13–18 yr old adolescent cancer patients was lower than that of 8–12-yr-old pediatric cancer patients (26). Quality of life presumably deteriorated due to physical discomfort and emotional distress after treatment in addition to the sudden physical and emotional changes that happen during adolescence.

In the present study, the quality of life of patients who were middle school students was lower than that of patients who were elementary school students. This is presumably because adolescent's survived leukemia has low social adaptability. In addition, their quality of life in schoolwork likely deteriorates because they experience physical discomfort and emotional distress after treatment along with adolescence, which is a period when sudden physical and physiological changes occur and social relations expand according to the characteristics of this developmental stage (26). Therefore, more attention and active support needed for early adolescent patients.

We found that the quality of life of ALL patients was lower than that of AML patients, which was different from a study that reported that quality of life did not differ depending on the type of pediatric cancer (26). AML patients accounted for 19% of our sample, while ALL patients accounted for 81%. In addition, previous studies (7, 27) revealed that the quality of life of pediatric cancer survivors varied depending on the type of cancer, specific diagnosis, and lapse of time after treatment completion, and related to performance level and the number of side effects. Therefore, future replication studies of variables related to quality of life need to include a larger sample.

According to our findings, the higher the ego-resilience score, the higher was the quality of life. This was similar to the result found (28) targeting pediatric cancer patients. In previous studies, adolescents with high ego-resilience and social support showed high adaptability to school life (29) and the better they adapted to social life, the more the quality of life improved among adolescent survivors of leukemia (9). Ego-resilience is an internal element that helps the individual to respond and adapt to external stress. For childhood leukemia survivors, increased resilience toward internal and external stress leads to strengthened social adaptability, believed to have a positive effect on their physical, emotional, and social quality of life. Ego-resilience, related to an individual's internal characteristics (30), can serve as a parameter affecting quality of life along with other characteristics such as physical health and self-esteem (12). Therefore, future studies must identify factors affecting ego-resilience and quality of life.

In the present study, higher family function perceived by leukemia patients corresponded to higher quality of life in the categories of mood

and emotions, parent relations and home life, self-perception, autonomy, school environment, and financial resources. This was similar to a study in which higher family function and social support perceived by 13–18-yr-old adolescents corresponded to higher quality of life (31). This was also similar to another study in which higher maternal support corresponded to higher quality of life of adolescent survivors of pediatric cancer, and higher scores for physical, emotional, social, and the schoolwork related quality of life corresponded to higher general quality of life (27). Direct comparison of these findings is impossible, as no other studies have examined the relations between quality of life sub-categories and family function. However, it presumed that if family support, family cohesion, and family function perceived by pediatric patients are high, it brings about a positive effect on ego-resilience and quality of life. Therefore, it is important to examine if family support and ego-resilience serve as parameters affecting quality of life.

A major factor affecting the quality of life of pediatric patients with leukemia was ego-resilience, with an explanatory power of 48%, which rose to 53% upon inclusion of age and family function. It is hard to compare these findings with other studies because no previous study analyzed factors influencing quality of life. However, these findings are similar to studies (28, 31) that revealed that ego-resilience and family function of pediatric cancer patients had a positive correlation with quality of life. In previous studies, quality of life was low in school-age children from higher grades (25) and resilience was high in adolescent pediatric cancer patients who had good communication among family members for problem-solving (30). Considering these findings, positive communication among family members presumed to affect ego-resilience and improve quality of life. A study (32) supported this result as the author claimed that the resilience of adolescents increased if family atmosphere and protective function were high and the stronger the resilience, the higher was their quality of life. Therefore, improving ego-resilience of cancer patients is an important element in the psychological and social care of pediatric patients (33). These findings show that ego-resilience, age, and family function affect quality of life in childhood leukemia survivors. Besides, it is necessary to strengthen ego-resilience in the development phase, as well as family function, to improve quality of life in childhood leukemia survivors.

Study Limitations

The small sample of survivors of childhood leukemia survivors limits the possibility of drawing firm conclusions regarding robustness. We have not found a correlation between clinical and psychosocial data.

Conclusion

The ego-resilience and family function had a positive correlation with quality of life. A major factor affecting quality of life was ego-resilience, with an explanatory power of 48%, which rose to 53% on including age and family function. Considering these findings, interventions to improve quality of life in childhood leukemia survivors configured to provide information required for physical symptom management; to increase ego-resilience by evaluating the characteristics of pediatric patients, ego-resilience, and family function; and to strengthen the support of parents and family. In the future, a multi-faceted study should investigate the psychological variables and parameters affecting quality of life in childhood leukemia survivors. A longitudinal study is also required to track changes in ego-resilience, family function, and quality of life according to the growth of pediatric patients. Another study also needed to develop and apply clinical nursing practice interventions to improve quality of life in childhood leukemia survivors and evaluate their effectiveness.

Ethical considerations

Ethical issues (Including plagiarism, consent, misconduct, data fabrication and/or falsify- caution, double publication and/or submission, redundancy, etc.) have been completely by the authors.

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