



Comparison of perceived parental empathy between adolescents with leukemia and healthy adolescents: A comparative descriptive study

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ABSTRACT

Purpose: The purpose of this study was to investigate and compare perceived parental empathy between adolescents with and without leukemia.

Methods: This study used a cross-sectional, descriptive design. Thirty-eight adolescents with leukemia and 205 without, completed a self-reported questionnaire regarding their perceptions of parental empathy and general characteristics. For this comparative study, adolescents were selected through matched sampling, and 38 adolescents per group were used for analysis. Data were examined using independent t-tests.

Results: In terms of parental empathy, excessive emotional reactions and cold emotional reactions were perceived more frequently by adolescents with leukemia than healthy adolescents. Differences between the two groups were statistically significant.

Conclusion: Since parents caring for children with leukemia have an extra burden in caring for their children, these parents are continuously anxious about prognoses, and tend to feel guilty for their child's disease. Thus, healthcare providers need to develop a program for improving the ability of parents of cancer patients to demonstrate empathy, focusing on how to recognize and manage what may be perceived by their children as excessive or cold emotional reactions, and must take a role in communicating to parents how adolescents with leukemia perceive parental rearing behaviors and the impacts of these behaviors on their well-being.

1. Introduction

Leukemia is the most common cancer among children and adolescents under 15 years of age in Korea [1]. According to International Classification of Childhood Cancer (ICCC) standards, leukemia accounts for approximately 30 % of childhood cancers, and the incidence of leukemia in patients aged 0–14 years in Korea as of 2019 was approximately 49 per 1 million people [2]. In the early stages of diagnosis, many patients and parents feel hopeless and fearful about survival [3]. With the development of improved diagnosis and treatment techniques, however, the five-year survival rate of children with leukemia in Korea and Japan has reached 85 % and is as high as 90 % in the UK and United States [4]. Regardless of these increased survival rates in both Eastern and Western countries, however, side effects such as infection, coagulopathies, hepatotoxicity, and neuropathy may still occur during treatment. Moreover, fatigue and sleep disorders induced by these side effects can negatively impact quality of life [5]. Particularly, as children

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diagnosed with cancer in childhood become adolescents and adults, they face challenging tasks beyond those of their healthy counterparts [6].

1.1. Background

Through communication with others and experience of sudden changes in physical, mental, social, and emotional domains, adolescence is a period of important developmental tasks such as individual value formation and interpersonal relationship building [7]. The most important change in adolescence is the expansion of interpersonal relationships, with the formation of peer relationships being essential [5]. More specifically, adolescents develop their self-esteem within their peer groups [8]. Adolescents with leukemia, however, naturally have difficulties developing and retaining peer relationships, adjusting in school, and academic achievement areas that reflect the principal developmental tasks of adolescence [8]. Adolescents with leukemia returning to routine daily activities and re-entering school after completing their treatment experience complex physical and psychological development challenges while trying to adapt to the considerable changes in daily life caused by the disease [6].

The interpersonal relationships between parents and children affect the social development of children from infancy to adulthood [9]. When parents and children communicate openly, adolescents are more capable of forming positive relationships with their peers [10]. Also, positive parenting behaviors, such as appropriate interest and affection for their children, help adolescents form peer relationships and adjust to school [10]. In particular, the importance of parents' empathic attitudes in understanding children's thoughts and feelings has been continuously emphasized as critically important, as empathy allows parents to emotionally interact and form positive relationships with their children [11]. Parental empathy affects children's self-regulation, motivation, and self-efficacy, in addition to helping them to achieve scholastic success and adapt to school life [12,13]. When parents empathize with their children, adolescents' self-esteem increases and negative emotions such as depression decrease [14]. It is evident that parental empathic attitudes are an important factor for adolescents in various aspects of growth, including social development, peer relationships, school adjustment, academic achievement, and depressive symptoms.

Empathy is one of the most essential resources for parents of children with a chronic disease [15]. When parents are more attuned to their children's thoughts and feelings, adolescents with chronic diseases demonstrate greater self-care and fewer depressive symptoms [15]. Higher empathic disposition in parents has been shown to predict lower distress and higher cooperation in children during treatment procedures [16]. The existing literature demonstrates that parents' empathic disposition is an important factor for adolescents with chronic disease. Nevertheless, parents of child cancer survivors tend to overlook aspects of their health-related quality of life and limit outdoor activities or peer-group gatherings due to concerns about illness, even though many children with cancer can perform such activities [6,8]. These parental behaviors stem from a lack of understanding of their children's thoughts and feelings, causing children with chronic diseases to feel increased negative emotions such as anxiety and anger [6,17].

Family dynamics are an essential factor in determining how cancer survivors experience the various changes in their lifestyle, and it is the most important support system throughout treatment from childhood to adolescence [6]. In addition, pediatric oncology research on psychosocial factors deals largely with long-term family adjustment processes [18]. However, adolescence can involve decreased communication and/or increased conflict within the family, complicating parental duties. One factor in these changes is lack of parental empathy toward their children's opinions [11]. Accordingly, studies in parental rearing behaviors of adolescents with leukemia are being actively conducted. However, there is no study that explicitly investigates only empathy variables in parenting behaviors, and there is no study comparing parental empathy between adolescents with leukemia and healthy adolescents. Previous research emphasizes the need to assess discrete parenting behavior variables in order to identify illness-related risk factors that cause poor child adjustment in the context of chronic disease [18].

1.2. Purpose

The purpose of the current study is to investigate and compare parental empathy between adolescents with leukemia and healthy adolescents. The research hypothesis of the present study is that 'there is a difference in the perceived parental empathy between the adolescents with leukemia and healthy adolescents in Korea.'

2. Methods

2.1. Study design

This study is descriptive in order to investigate and compare parental empathy between adolescents with leukemia and healthy adolescents. It was described according to the STROBE cross-sectional reporting guideline.

2.2. Participants

Our target sample comprised two groups, adolescents with leukemia and healthy adolescents attending middle or high school and aged 13–18 years. The group of adolescents with leukemia received either maintenance therapy in an outpatient clinic or experienced ongoing follow-up visits for leukemia after completing hospitalized treatment. All subjects understood the purpose of the study and voluntarily consented to participate.

Forty adolescents with leukemia were initially enrolled in this study, with data collection subsequently impeded due to COVID-19.

After excluding two participants who failed to complete the questionnaire, data collected from 38 adolescents with leukemia were used for analysis. For comparative study between the two groups, healthy adolescents were selected through matched sampling to equalize conditions across the two groups as much as possible, retaining homogeneity and limiting effects of exogenous variables [19]. The exogenous variables of perceived parental empathy would be sex, educational level, having siblings, religious beliefs, parental marital status, parental educational levels, and perceived economic status from the literature review [20–23]. Therefore, 38 out of 205 healthy adolescents were selected while controlling these exogenous variables. Referring to previous studies using matched sampling, sample sizes ranged from 9 to 24 individuals per group [24,25]. The minimum sample size was 34 using the G*power 3.1.9.4 program for a significant level of 0.05, power of 80 %, and effect size of 0.5 with a matched pairs *t*-test [26]. Accordingly, 38 participants were assigned to each group in this study, which was deemed reasonable. A total of 211 healthy adolescents participated in this survey in which missing data were found in six questionnaires. Thus, to conduct matched sampling, data for 205 healthy adolescents were used. Finally, healthy adolescents were paired with adolescents with leukemia controlling the exogenous variables, resulting in the inclusion of 38 healthy adolescents for analysis.

2.3. Data collection

After obtaining approval from the Institutional Review Board of the Catholic University of Korea, St. Mary's Hospital and the Catholic University of Korea, Songeui Campus (KC19QNSI0432 and MC22QISI0020), data were collected from leukemic and healthy adolescents. Consecutive sampling method were used for both of groups. Data collection took place from December 2019 to May 2020 among adolescents with leukemia, who were recruited for participation in this study during regular visits to an outpatient pediatric clinic for check-ups or treatment. A research assistant explained this study and its purpose, together with the benefits and risks of the study, options for participants to withdraw during the study, and confidentiality. After acquiring consent forms both from participants and their parents, the research assistant explained the self-reported questionnaire. Questionnaires were given to adolescents with leukemia to fill out for approximately 10 min in the waiting room of the outpatient clinic. After completing the survey, participants received the gift card as an incentive.

Data were collected from May 2, 2022, to May 27, 2022 among healthy adolescents. To recruit healthy adolescents, the researchers contacted teachers working at two schools located in the same city as the outpatient clinic. These teachers informed students of the recruitment opportunity and shared our mobile survey link in the group chatting room. Upon ensuring that adolescents understood and were sufficiently interested in this study, the survey was conducted voluntarily through the mobile survey link. Respondents could recommend the survey to other students for participation. Since the survey for healthy adolescents employed a mobile link and was conducted anonymously, researchers or teachers could not know who filled out the questionnaire. Additionally, all participants were informed that there would be no disadvantage if they did not fill out the questionnaire through the explanatory statement for consent. Therefore, all participants voluntarily decided whether or not to participate in the study by clicking a button. After completing the survey, participants received the mobile gift card as an incentive. Mobile phone numbers of participants were collected to provide the incentive for taking the online survey, and as a means of avoiding duplication and late bias in the process.

2.4. Instrument

Parental empathy, as perceived by adolescents with leukemia and by healthy adolescents was measured using an inventory developed and validated by Jo [11]. The parental empathy inventory consists of five factors that assess awareness of emotion, perspective taking, empathic emotional reaction, cold emotional reaction, and excessive emotional reaction in parents. The inventory is comprised of five questions related to each of these factors, with 25 items in total to be answered separately regarding participant perceptions of both mothers and fathers. This self-reported instrument uses a four-point Likert scale (with scores ranging from 1: strongly disagree to 4: strongly agree), although items 9 and 13 involving 'perspective taking' are reverse scored [11]. Possible scores for each of the factors range from 5 to 20.

Of the five factors, awareness of emotion, perspective taking, and empathic emotional reaction are associated with positive parental rearing behaviors such as monitoring, reasoning, and affection [11,27]. On the other hand, cold emotional reaction is associated with negative parental rearing behaviors such as inconsistency, over-expectation, intrusiveness, physical abuse, and neglect [11,27]. Last, excessive emotional reaction is associated with both negative (e.g., inconsistency, over-expectation, intrusiveness, and physical abuse) and positive (e.g., affection) parental rearing behaviors and is not associated with neglect [11,27]. When the instrument was first developed, the Cronbach's α value was 0.53–0.81 [11]. That in the present study was 0.62–0.87.

Adolescent sex, age, education level, sibling relationships, religion, and perceived economic status were collected as general characteristics. Regarding parents' characteristics, marital status and education level were additionally assessed.

2.5. Data analysis

Data were analyzed using IBM SPSS Statistics software Version 21.0. Descriptive statistics were used to identify participants' general characteristics and to investigate homogeneity between the two groups of adolescents with leukemia and healthy adolescents. Mean value and standard deviations were calculated to evaluate parental empathy levels, and independent *t*-tests were conducted to compare parental empathy between adolescents with leukemia and healthy adolescents. *P* value < 0.050 is considered as statistically significant.

3. Results

3.1. General characteristics of participants and homogeneity in the two groups

As shown in Table 1, general characteristics were not significantly different between adolescents with leukemia and healthy adolescents. Twenty-three (60.5 %) adolescents with leukemia and 20 (52.6 %) healthy adolescents were male, and both groups contained more males than females. In terms of education level, 14 (36.8 %) and 24 (63.2 %) participants in the group of adolescents with leukemia attended middle and high school, respectively. Twelve (31.6 %) and 26 (68.4 %) participants in the group of healthy adolescents attended middle and high school, respectively. Thirty-six (94.7 %) adolescents with leukemia and 33 (86.8 %) healthy adolescents had a sibling. Twenty-two (57.9 %) adolescents with leukemia and 24 (63.2 %) healthy adolescents reported having no religion. With regard to parental characteristics, most parents were married, with an education level of college or above, for both fathers and mothers in the two groups. Thirty (78.9 %) adolescents with leukemia and 30 (78.9 %) healthy adolescents perceived their economic status as average.

Regarding the disease-related characteristics of adolescents with leukemia, 22 (59.5 %) had acute lymphoblastic leukemia and 14 (36.8 %) received hematopoietic stem cell transplantation. Twelve (31.6 %) diagnosed at under 6 years old and 3 (8.8 %) were undergoing maintenance therapy.

3.2. Comparison of parental empathy between adolescents with leukemia and healthy adolescents

Table 2 shows the correlations of perceived parental empathy in groups of adolescents with leukemia and healthy adolescents. Regarding awareness of emotion, perspective taking, and empathic emotional reaction, differences in scores between the two groups were not statistically significant. The mean score of fathers' cold emotional reaction perceived by adolescents with leukemia was 10.29, while that of healthy adolescents was 9.13. The mean score of mothers' cold emotional reaction was 10.39 in adolescents with leukemia and 8.76 in healthy adolescents. Therefore, perceived cold emotional reactions in both fathers and mothers were higher in adolescents with leukemia than in healthy adolescents. Differences between the two groups were statistically significant in both fathers ($t = 2.033$, $p = 0.046$) and mothers ($t = 2.299$, $p = 0.024$), which indicates strong evidence against the null hypothesis. In addition, the mean score of fathers' excessive emotional reaction perceived by adolescents with leukemia was 14.47, compared with 10.47 for healthy adolescents. The mean score of mothers' excessive emotional reaction perceived by adolescents with leukemia was 15.29, and the mean score of mothers' excessive emotional reaction perceived by healthy adolescents was 12.24. Thus, perceived excessive emotional reactions in both fathers and mothers by adolescents with leukemia were higher than those in healthy adolescents. Differences between the two groups were statistically significant in both fathers ($t = 7.159$, $p = 0.000$) and mothers ($t = 4.252$, $p = 0.000$).

Table 1
General characteristics of participants and homogeneity in the two groups.

Variables	Adolescents with leukemia (n = 38)		Healthy adolescents (n = 38)		χ^2	p
	N (%)	Mean \pm SD	N (%)	Mean \pm SD		
Age, y		15.79 \pm 1.62		15.74 \pm 1.74	4.224	0.518
Sex	Male	23 (60.5)	20 (52.6)		0.482	0.488
	Female	15 (39.5)	18 (47.4)			
Education level	Middle school	14 (36.8)	12 (31.6)		0.234	0.629
	High school	24 (63.2)	26 (68.4)			
Siblings	Yes	36 (94.7)	33 (86.8)		1.416	0.234
	No	2 (5.3)	5 (13.2)			
Religion	Yes	16 (42.1)	14 (36.8)		0.220	0.639
	No	22 (57.9)	24 (63.2)			
Parental marital status	Married	36 (94.7)	36 (94.7)		0.000	1.000
	Divorce	2 (5.3)	2 (5.3)			
Father's education level	High school	8 (21.1)	6 (15.8)		0.350	0.554
	College or beyond	30 (78.9)	32 (84.2)			
Mother's education level	High school	11 (28.9)	7 (18.4)		1.165	0.280
	College or beyond	27 (71.1)	31 (81.6)			
Perceived economic status	Good	3 (7.9)	3 (7.9)		0.000	1.000
	Average	30 (78.9)	30 (78.9)			
	Bad	5 (13.2)	5 (13.2)			
Diagnosis	ALL	22 (59.5)				
	AML	15 (40.5)				
Age at diagnosis	<6 years old	12 (31.6)				
	\geq 6 years old	26 (68.4)				
Treatment status	Maintenance	3 (8.8)				
	Follow up	31 (91.2)				
HSCT	Yes	14 (36.8)				
	No	24 (63.2)				

AML: Acute Myeloid Leukemia, ALL: Acute Lymphoblastic Leukemia, HSCT: Hematopoietic Stem Cell Transplantation.

Table 2
Comparison of parental empathy in adolescents with leukemia and healthy adolescents.

	Variables	Adolescents with leukemia	Healthy adolescents	t	p-value
		Mean \pm SD	Mean \pm SD		
Father	Awareness of emotion	14.66 \pm 2.43	14.34 \pm 3.36	0.470	0.640
	Perspective taking	17.39 \pm 1.70	17.00 \pm 2.62	0.779	0.439
	Empathic emotional reaction	16.82 \pm 2.12	17.29 \pm 2.90	-0.813	0.419
	Cold emotional reaction	10.29 \pm 2.39	9.13 \pm 2.57	2.033	0.046
	Excessive emotional reaction	14.47 \pm 1.93	10.47 \pm 2.85	7.159	0.000
Mother	Awareness of emotion	16.08 \pm 2.28	15.97 \pm 3.36	0.160	0.873
	Perspective taking	16.79 \pm 2.49	16.76 \pm 2.71	0.044	0.965
	Empathic emotional reaction	17.11 \pm 2.40	17.97 \pm 2.50	-1.544	0.127
	Cold emotional reaction	10.39 \pm 3.39	8.76 \pm 2.76	2.299	0.024
	Excessive emotional reaction	15.29 \pm 2.40	12.24 \pm 3.72	4.252	0.000

4. Discussion

As a factor of parental empathy for both fathers and mothers, our findings show that mean scores of excessive emotional reactions in parents perceived by adolescents with leukemia were higher than those of healthy adolescents. Excessive emotional reactions include parental rearing behaviors that are both positive (e.g., affection) and negative (e.g., inconsistency, over-expectation, and intrusiveness) [11,27]. Consistently, findings from Kim et al. [5] of parental rearing behaviors in adolescents with leukemia indicate that mean scores in parental emotional warmth perceived by adolescents were higher than perceived rejection and control for both mothers and fathers. The authors of that research point out, however, that some parents caring for children with chronic disease could choose overprotection, which is defined as a pattern of parental behaviors intended to promote the safety and security of the child [18]. In particular, mothers of children with leukemia have been shown to have anxious and fearful feelings about disease-related treatment, survival, relapse, death, and the future. These feelings lead mothers to overprotect their children and to react sensitively to behaviors that are normal in adolescence [3]. As evidenced in the results of this study and previous research, parents caring for children with chronic illness tend to promote the safety of their children and take on more indulgent, protective, intrusive caregiving roles [18].

We also found that mean scores in perceived cold emotional reactions in parents of adolescents with leukemia were higher than those of healthy adolescents for both fathers and mothers. Cold emotional reactions are similar to excessive emotional reactions in that they are associated with negative parental rearing behaviors such as inconsistency, over-expectation, and intrusiveness [11,27]. Parental intrusiveness is over-involvement and interference in a child's daily life, requiring the child to comply with rules without regard to the independence or interests of the child, together with anxiety about the child's behavior [27]. At the same time, cold emotional reaction differs from excessive emotional reaction in that coldness is not related to any positive parental rearing behaviors, such as affection [11,27]. Adolescent leukemia survivors report striving to engage in social or physical activities, with their efforts and desires often frustrated by excessive parental worries [8]. Adolescent leukemia survivors report anger at their parents treating them differently in daily life due to their cancer [8]. Interestingly, parental empathy for adolescents' negative emotions such as anger was also important [15]. Main A. et al. [15] found that parents' ability to empathize with their adolescents' negative emotions was associated with fewer depressive symptoms, better clinical test values, and greater self-care in chronic disease. On the other hand, parents have been shown to overestimate the health-related quality of life in adolescent leukemia survivors [6]. This phenomenon can lead parents to overlook delayed effects (e.g., educational disadvantages and infertility) or the anxiety of adolescent leukemia survivors [6]. Accordingly, clinical research is needed to develop an empathy improvement program for parents of adolescents with chronic disease, emphasizing why and how to attune to their thoughts and feelings.

Parents caring for children with leukemia have an enormous responsibility to protect their children and provide additional support because of the physical difficulties related to their illness [28]. Naturally, parents of children with blood cancer are continuously anxious about treatment outcomes and prognosis [3], coupled with feelings of guilt and distress while taking care of their children struggling with cancer [28]. Considering that empathy is difficult to retain when problematic situations occur in parent-child relationships [29], it is understandable that the unique burdens and anxieties of parents of adolescents with leukemia may lead the parents to present apathetic and/or excessive emotional reactions. Particularly in Korean society, parent-child relationships are based on close connection [30] and most parents recognize that their role is to provide attention and support to their children [7]. Indeed, total devotion by parents to their children is seen in Korean culture as affection and concern, with little discourse on any potential drawbacks of overprotection [30]. Even though adolescence is a time for children to prepare for independence from their parents and develop self-esteem [31], well-intentioned parents occasionally deprive their children of opportunities to have certain needs met, such as the desire to ask for assistance when they feel they require it, and to be listened to Ref. [7].

Adolescents are in a transitional period toward adulthood, and they expect appropriate support and concern from their parents [30]. Nevertheless, this study found that apathetic and/or irritable emotional reactions in parents of adolescents with leukemia were higher than those of parents of healthy adolescents. Negative parental rearing behaviors create more protective and repressive environments for the children, preventing them from growing independently and developing abilities such as physical prowess, academic performance, and problem-solving [32]. Also, excessive concern and protection by parents may cause adolescents to feel guilty, or frustrated [8]. Thus, parents' cold and excessive emotional reactions in the form of overprotection, interference, and constraint tend to be associated with irritability, egocentrism, and lack of self-confidence in children. Parents of children with leukemia report higher

parenting stress than parents of healthy children, with this stress arising from their belief that physically vulnerable children need to be overprotected and due to the excessive burden of rearing a child struggling with chronic illness [28].

When adolescents' needs are not met or when they are deprived of opportunities to engage in activities, they experience conflict in parent-child relationships and miss out on chances for growth and development [7]. Previous studies related to adolescents with leukemia have emphasized the importance of family intervention, with parents identified as crucial targets [5,6,28,32]. Interestingly, Kim et al. [5] reported that paternal and maternal rearing behaviors were correlated for adolescents with chronic disease—and the finding is particularly prominent in terms of negative parenting behaviors. Accordingly, healthcare providers should communicate to parents how adolescents with leukemia perceive parental rearing behaviors and the impact of parental empathy on children's well-being.

4.1. Limitations

This study has several limitations. First, adolescents with leukemia were recruited from a single university-affiliated tertiary medical center in Korea and healthy adolescents were recruited from online link using group chatting room, limiting the generalizability of findings. Future studies targeting children with other chronic diseases are needed, and these studies should recruit participants from more than one hospital. Second, the data collection period between the two sample groups was very wide. However, in this study, the sample of healthy adolescents was selected to maximize similarity. Finally, the present study is cross-sectional in design. Further longitudinal studies are needed to provide a more advanced investigation of variables. Despite these limitations, by analyzing perceptions of empathy in detail, our study is meaningful in identifying which factors of empathy are in need of improvement in order to increase quality of life for adolescents with leukemia.

5. Conclusion

This study compares perceived parental empathy between adolescents with leukemia and healthy adolescents. We found that mean scores in excessive and cold emotional reactions of parents by adolescents with leukemia were higher than those of healthy adolescents for both fathers and mothers. Since parents caring for children with leukemia have an extra burden in caring for their children, parents are continuously anxious about prognoses, and tend to feel guilt for their child's disease. Thus, healthcare providers need to develop an empathy improvement program for parents of cancer patients, focusing on decreasing the excessive and cold emotional reactions, and must take a role in communicating to parents how adolescents with leukemia perceive parental rearing behaviors and the impacts of these behaviors on their well-being. In addition, future research is needed to explore parental empathy directly to parents for healthy adolescents as well as adolescents with leukemia.

IRB approval no

KC19QNSI0432 (the Catholic University of Korea, St. Mary's Hospital) and MC22QISI0020 (the Catholic University of Korea, Songeui Campus).

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Data availability statement

Data will be made available on request.

Ethics statement

Institutional Review Board (IRB)s of the Catholic University of Korea, St. Mary's Hospital and the Catholic University of Korea, Songeui Campus (KC19QNSI0432 and MC22QISI0020) approved the present study, which adhered to the guidelines and principles outlines in the Declaration of Helsinki. All participants informed about the study using the explanatory statement for consent.

CRedit authorship contribution statement

Youngji Moon: Data curation, Formal analysis, Investigation, Methodology, Software, Writing – original draft. **Sunhee Lee:** Conceptualization, Funding acquisition, Project administration, Supervision, Validation, Writing – review & editing.

Declaration of competing interest

The authors declare the following financial interests/personal relationships which may be considered as potential competing interests: Sunhee Lee reports financial support was provided by the National Research Foundation of Korea (NRF).

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Appendix A. Supplementary data

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