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Comparison of Coping Styles and Self-system in Adolescents with Leukemia, Hemophilia and Healthy Control

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Abstract

Background: Having a chronic illness and going through its challenging and lengthy treatment can lead to significant stress and psychological damage for children.

Objectives: The present study compared coping styles and self-systems (self-esteem, self-concept, and social self-efficacy) among teenagers with leukemia, hemophilia, and healthy control.

Methods: In this research, which was a causal-comparative method, the statistical sample included a total of 110 people from three groups of people in the age range of 12 to 15 years, including 30 teenagers with leukemia, 40 people with hemophilia, and 40 healthy teenagers during 2022-23 in Tehran, Iran, which were selected by convenience sampling method. Child and adolescent coping styles questionnaires (CCBQ), Rosenberg self-esteem (SES), Lipsite self-concept (SC), and Kenly adolescent social self-efficacy were used as work tools. A multivariate analysis of variance (ANOVA) was employed utilizing SPSS version 22 software.

Results: The results indicated that the mean scores for leukemia and hemophilia groups in the deviation from the problem and destructive coping categories were significantly higher (0.007 and 0.002) than the healthy group. Moreover, it was evident that the healthy group had a substantially higher average (P=0.001) compared to the leukemia and hemophilia groups, suggesting that the two patient groups exhibited lower levels of self-esteem in comparison to the healthy group.

Conclusion: The current research showed that coping styles like seeking social support, positive thinking, and spiritual beliefs are more common in patients, leading to higher social self-efficacy.

Keywords: Coping styles, Self-esteem, Self-concept, Self-efficacy, Leukemia, Hemophilia

1. Background

Recent research indicates that over 25% of individuals under the age of twenty-five, including both children and young adults, experience a chronic illness in both the Netherlands and the United States (1). Hemophilia is a chronic disease characterized by an inherited coagulation disorder associated with the X chromosome and affects approximately 1 in 10,000 individuals (2). Hemophilia, also known as classic hemophilia or hemophilia type A, is caused by a deficiency in coagulation factor

VIII, while coagulation factor IX causes hemophilia B. The levels of factor VIII can be measured in a laboratory, and hemophilia patients vary in terms of the severity of their deficiency (3). A normal individual typically has 100% factor VIII, whereas hemophilia patients usually have less than 30% of this factor. Those with a factor level between 5 and 30% are considered to have a mild form of the disease, while average patients have a factor value of 1 to 5%. Severe patients have only 1% factor in their blood (4). Hemophilia results from various genetic mutations in the factor VIII gene, including point mutations, gene deletions, and inversions (3). These mutations can affect the quantity and quality of factor VIII, disrupting its function. Even with normal levels of factor VIII, individuals with mutations may experience bleeding episodes (4). Children and adolescents with hemophilia suffer from many psychological problems in addition to physical problems. It seems that few studies have been done on the psychological issues of hemophilia patients, and most of the measures are in the field of self-care and provision of blood products (5).

The primary causes of stress for children include being away from their parents, being in an unfamiliar hospital environment, and undergoing unpleasant medical procedures (6). The separation from their parents, the unfamiliar hospital surroundings, and the uncomfortable treatment processes are the main factors contributing to stress among children (7). Cancer is another chronic disease that threatens the physical and mental health of children and adolescents (8). Empirical studies suggest that children express anxiety through regression in behaviors, aggression, lack of cooperation, withdrawal, and difficulty recovering from procedures (7). Literature shows that children involved in psychological programs were able to contain anxiety, showing lower levels of anxiety assessed before surgery and reporting less postoperative anxiety (9).

Moreover, hospitalization is uncomfortable for anyone, especially children (7). Children and adolescents diagnosed with cancer often experience various challenges, including a decline in self-esteem and self-perception, as well as an uptick in negative emotions (10). Furthermore, these difficulties can further exacerbate the initial struggles and impact the functioning and resilience of young cancer (11). On the other hand, people's reactions to psychological pressure and negative emotions and the coping strategies they choose to face them may also make people susceptible to diseases, including cancer (12).

People respond to stressful situations such as illness in various ways, and these responses have different outcomes. Therefore, identifying the coping styles of individuals with chronic diseases is crucial as it can determine how a person adapts to the challenges brought about by their illness (13). Authors define coping as involving practical and intra-psychological actions to manage internal and external demands and conflicts. In a favorable scenario, individuals direct their efforts toward finding solutions to their problems (7). However, they may avoid or escape from dangerous situations when attempting to handle conflicts between their circumstances and capabilities. They may also passively accept unreasonable circumstances (13). Alternatively, the self-system can influence coping mechanisms and how individuals adjust to physical ailments, encompassing self-esteem, self-concept, and social self-efficacy (14). Those dealing with long-term illnesses often grapple with body image issues, particularly

when the condition or its treatment leads to noticeable changes in their physical appearance (15). These factors can impact the overall well-being of these individuals (12-14).

One vital component of this system is self-esteem, which pertains to an individual's perception of themselves and is shaped by their behaviors, appearance, intellect, social achievements, and feedback from others. Self-esteem is closely tied to an individual's self-perception and adjustment ability (16). Having a positive body image creates a sense of worth, while any changes to this image can affect one's self-worth (17). Illnesses, their treatments, and related complications can alter one's self-image and self-esteem, particularly in chronic diseases with long and unpredictable courses (18).

2. Objectives

Hemophilia and cancer are two examples of chronic diseases that, despite advancements in treatment, still bring pain, limitations, deformities, and potential death. Those with chronic illnesses often experience psychological challenges such as anxiety, negative self-perception, and feelings of social isolation (14-18). Moreover, Self-concept is compromised in youth with a chronic illness (19). In adolescents, it is crucial since it indicates an adequate physical, cognitive, behavioral, affective, and social integration of the individual20. In analyzing 60 studies, it was found that youth with a chronic illness generally had a weakened self-concept. Research using normative data showed higher levels of self-concept in youth with a chronic illness, while studies that included healthy controls found lower self-concept in these individuals (19). Chronic illnesses can also affect social self-efficacy, which measures an individual's confidence in completing tasks. Self-efficacy depends on a person's thoughts and actions, usually in certain areas or situations (20). This means someone may strongly believe in their skills in various domains or specific circumstances. Chronic illnesses can lead to notable changes in performance, which may impact self-efficacy (21). Chronic diseases like hemophilia and cancer can create limitations for children and teens, leading them to view these conditions as disabilities affecting their social lives. Psychological factors such as coping styles, self-esteem, self-concept, and social self-efficacy may be essential to explore in these patients (19-21). Thus, this study aims to compare coping styles and the self-system in individuals with blood cancer, hemophilia and healthy individuals.

3. Methods

The current study utilized a causal-comparative research design for the post-event type. The research involves a statistical population of 167 male adolescents aged 12 to 15 years with hemophilia from Tehran Comprehensive Hemophilia Clinic sixty male adolescent patients aged 12 to 15 years with leukemia from Mahak Hospital during 2022-23. Due to the nature of causal-comparative research, a minimum of 30 individuals are selected for each group. The sample size for adolescents with leukemia is 30 from Mahak Hospital, 40 adolescents with hemophilia from Comprehensive Hemophilia Clinic, and 40 healthy adolescents from Shahid Asadi School and Moalem School in Shahyar, selected through convenience sampling method. The sample size was adequate using G-Power software, considering α = 0.05, effect size = 0.07, power test = 0.80, and number of groups = 3 (35). Based on this formula, the sample size was equal to 90 people, but due to the possibility of the sample size falling during the research process, the researcher considered the number of 110 people (Figure 1).

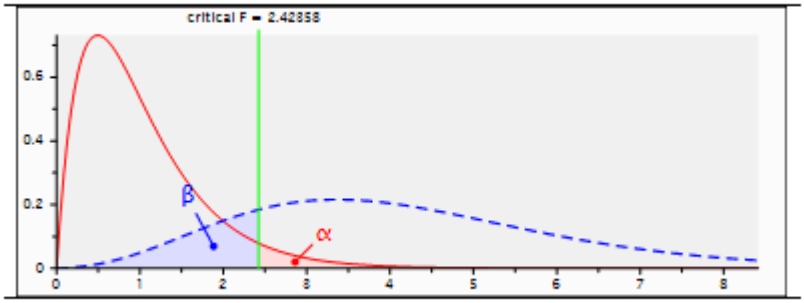

Figure 1. Sample size calculation with G*Power software

The study's eligibility requirements are to be a male with leukemia and hemophilia aged between 12 and 15 and to provide consent to participate. Exclusion criteria involve excluding incomplete or confusing questionnaires and individuals who do not consent to participate in the study.

The method of implementation involved obtaining necessary permits and consent from the subjects before distributing questionnaires to individuals with hemophilia at a comprehensive clinic in Tehran, as well as individuals with leukemia at Mahak Hospital in Tehran, along with healthy individuals. The questionnaire-filling process was explained to the participants, who were then asked to complete them. Patients with leukemia undergoing treatment were assisted in completing the questionnaire by having the questions read aloud to them and their responses recorded by the researcher. The current study utilized Descriptive and inferential statistics for data analysis. Initially, descriptive methods were used to study demographic variables from the questionnaire data, followed by inferential statistics to test the research; the normal distribution of the data was verified through the Kolmogorov-Smirnov test. As a result, a multivariate analysis of variance (ANOVA) was employed using SPSS version 22 software.

Research tools

Children's Coping Behavior Questionnaire (CCBQ):

The scale developed by Hernandez (2008) contains 57 statements and three scales, including diversion of problem, coping with the problem to solve it, and destructive coping, which is scored on a four-point Likert type (1 = never, 2 = sometimes, 3 = often, 4 = almost always) (23). Hernandez (2008) obtained Cronbach's alpha for all three scales (0.94). Since the validity and reliability of the questionnaires are not evident in Dubai and these questionnaires in Dubai have conducted no study, the author examined the reliability and validity of the questionnaire (23). In this study, Cronbach's alpha was used to determine the reliability. This method calculates the internal consistency of material, which measures various properties. In CCBQ, the highest Cronbach's alpha belongs to the diversion of the problem (0.90), and the lowest alpha is related to coping with the problem (0.78). In the Iranian study, Cronbach's alpha and test-retest for the total scale were between 0.74 and 0.91 (24). In this study, the alpha was 0.82 for all subscales.

Rosenberg Self-esteem Scale (RSES):

The scale measures overall self-esteem and personal value, including ten general items that measure life satisfaction and a good sense of self (25). The RSES is one of the most common scales for measuring self-esteem. In this questionnaire, the subject is asked to answer the questions accurately on a 4-point Likert scale from strongly agree to disagree strongly. The scores on this scale ranged from 10 to 40, with higher scores indicating higher self-esteem. This scale

includes five positive items (numbers 1 - 5) and five negative items (numbers 6 - 10). Recent discussions have focused on using the RSES as a single or two-factor structure. Bohlel and Rajabi (26) reported Cronbach's alpha coefficients of 0.66 and 0.79 for positive and negative self-esteem, respectively. This study calculated internal consistency using Cronbach's alpha coefficient for positive self-esteem (0.75) and negative self-esteem (0.80).

Adolescent Self-Efficacy Questionnaire:

Developed by Connolly (1989), the Adolescent Self-Efficacy Questionnaire aims to assess the self-efficacy levels of teenagers (27). Comprising 25 statements, this questionnaire evaluates various aspects such as social assertiveness, performance in social settings, involvement in social groups, friendship, intimacy, and giving or receiving assistance. Responses are rated on a 7-point Likert scale, and the scores are totaled to determine an individual's self-efficacy level. Scores range from 25 to 175, with a lower score indicating low social self-efficacy, an average score falling between 50 and 100, and a high score exceeding 100. To calculate scores for each dimension, the points from the related questions are added, and to obtain the total score, all questions are combined. Higher scores signify higher self-efficacy and vice versa. The reliability of the questionnaire was assessed using Cronbach's alpha coefficient, yielding values of 0.90, 0.92, and 0.95 in different groups and a retest reliability of 0.94 over two weeks. Gender-specific reliability coefficients were reported at 0.81 for males and 0.86 for females. A study by Rezaei et al. (28) confirmed the reliability of the questionnaire with a Cronbach's alpha value of 0.82, and in the current research, the internal consistency was found to be 0.79 using the same method.

4.Results

Based on the descriptive results, 27.3% (30 individuals) of the sample studied were teenagers diagnosed with leukemia, 36.4% (40 individuals) were teenagers with hemophilia, and another 36.4% (40 individuals) were healthy teenagers. The age group of 14-year-olds had the highest average sample size at 30 individuals, whereas the 12-year-old age group had the smallest average sample size at 16.4 individuals. The eighth grade had the largest sample size at 29.1 individuals, while the ninth grade had the smallest sample size at 20.9 (Table 1).

Table 1. Frequency distribution of the studied sample by group.

Group		F	%
Patient group	leukemia	30	27.3
	hemophilia	40	36.4
healthy group	healthy	40	36.4
Age	12	18	16.4
	13	32	29.1
	14	33	30
	15	27	24.5
Degree	sixth grade	24	21.8
	seventh grade	31	28.2
	eighth grade	32	29.1
	ninth grade	23	20.9
Father's education	illiterate	9	8.2
	under diploma	35	31.8
	diploma	40	36.4
	Master's degree and bachelor's degree	21	19.1

	Master's degree and above	5	4.5
Mother's education	illiterate	6	5.5
	under diploma	33	30
	diploma	46	41.8
	Master's degree and bachelor's degree	21	19.1
	Master's degree and above	4	3.6

Based on the information provided in Table 2, it shows that the healthy group has the lowest average in the subscale of deviation from the problem and destructive coping (77.25 and 25.65), while they have the highest mean in the subscale of coping with the issue to improve it (37.60). For the self-esteem variable, the healthy group achieved the highest mean (23.77) compared to the leukemia group, which had the lowest mean (20.10). In the self-concept variable, the healthy group obtained the highest mean (89.70), while the hemophilia group had the lowest mean (86.35). Furthermore, in the self-efficacy variable, the blood cancer group had the highest mean (118.93), and the healthy group had the lowest (111.92).

Table 2. Descriptive findings of research subscales by groups

Statistical index	Leukemia	Hemophilia	Healthy
Scale	**Mean± SD**	**Mean± SD**	**Mean± SD**
Deviation from the problem	84.13±9.47	83.58±8.98	77.25±6.45
Coping with the problem	30.60±5.19	31.47±8.64	37.60±3.57
Devastating Coping	31.63±6.13	32.35±6.99	25.65±4.64
Coping styles	145.36±19.39	146.87±23.36	134.50±14.92
self -esteem	20.10±4.67	20.55±4.95	23.77±3.37
self-concept	88.60±7.81	86.35±11.78	89.70±8.64
Social assertiveness	26.36±4.99	23.52±5.15	23.45±5.60
Performance in social situations	21.26±4.11	22.25±4.87	21.95±6.10
Participation in social groups	25.66±4.93	26.03±6.34	21.82±5.50
Aspects of friendship and intimacy	31.26±6.55	28.47±7.37	32.29±8.82
Helping and getting help	14.36±3.73	15.10±3.29	15.37±6.65
self-efficacy	118.93±18.42	115.07±21.36	111.92±24.28

The results in Table 3 indicate that the coping styles of individuals in the three groups - leukemia, hemophilia, and healthy individuals - differ. Specifically, the average scores for leukemia and hemophilia groups in the categories of deviation from the problem and destructive coping were significantly higher (0.007 and 0.002) than the healthy group. These two groups tend to use more aggressive coping strategies, while the healthy group scored higher in problem-focused coping to address and improve the situation. This suggests that coping styles vary based on physical health status, with individuals adapting their coping strategies when faced with illness. Moreover, the outcomes presented in Table 3 indicated a noteworthy disparity among the three groups regarding self-esteem. It was evident that the healthy group had a substantially higher average (P=0.001) compared to the leukemia and hemophilia groups, suggesting that the two patient groups exhibited lower levels of self-esteem in comparison to the healthy group. However, there was no significant variation in the self-concept variable among the three groups (P=0.297). Furthermore, a marked distinction was observed between the social groups, with the leukemia group displaying a higher average than the healthy group, indicating that the leukemia group possessed greater social

assertiveness than the other two groups (P=0.019). Additionally, participation in social activities revealed that the leukemia and hemophilia group had a higher average than the healthy group (P=0.019). Conversely, no significant differences were noted in the remaining aspects of self-efficacy.

Table 3. The results of univariate analysis of variance on the mean of coping styles and self-system in people with leukemia, hemophilia, and healthy people

Variables	SS	MS	F	P
Deviation from the problem	611/845	306/428	5.412	0.007
Coping with the problem	254/672	127/472	6.145	0.003
Devastating Coping	432/006	216/003	6.383	0.002
Coping styles	3241/457	1624/143	7.896	0.001
self -esteem	300/825	150/412	7.922	0.001
self-concept	231/664	115/832	1/227	0.297
Social assertiveness	230/613	115/306	4/128	0.019
Performance in social situations	16/952	8/476	0.316	0.730
Participation in social groups	267/183	133/592	4/133	0.019
Aspects of friendship and intimacy	136/656	68/328	1/142	0.323
Helping and getting help	18/058	9/029	0.378	0.686
self-efficacy	842/547	421/273	0.890	0.414

5. Discussion

The research focused on comparing coping styles and self-systems between individuals with leukemia and hemophilia and healthy teenagers. Results indicated that coping styles vary based on physical health, with individuals who are sick using more emotional coping styles. The study found differences in coping styles among the three groups, with those with leukemia and hemophilia using deviation from the problem and destructive coping styles more than the healthy group. Additionally, healthy individuals tended to use coping with the problem style more frequently. The findings of the study were consistent with previous research by Delvecchio et al. (۷), Man et al. (11), Ding et al. (12), and Calhoun (15). A study compared the stress and coping mechanisms of both healthy individuals and cancer patients. Jitendra et al. (29) and Maghsoodi et al. (30) revealed that there are variations in stress and coping styles between the two groups, such as seeking social support, positive reappraisal, confrontational coping, distancing, restraint, escape, and avoidance. The findings indicated a significant connection between social support and coping mechanisms for managing the disease.

Additionally, problem-solving coping was found to have the strongest and most direct correlation with social support. The regression analysis revealed that emotional support (such as kindness and sharing positive experiences), practical assistance, and financial aid could predict coping strategies for dealing with the disease (29,30). The study found that destructive coping styles and avoidance of problems are linked to low self-esteem. Adolescents with low self-esteem tend to use emotion-based coping strategies, while those with high self-esteem use methods focused on solving problems. Teenagers with chronic illnesses may face challenges related to self-esteem and coping styles, impacting their ability to adapt (7-12).

Moreover, the results revealed differences in self-esteem among teenagers with leukemia and hemophilia and healthy individuals. Teenagers with leukemia and hemophilia had lower self-esteem compared to those who were healthy. The study conducted by Aydin Köker et al. involved 32

hemophilia patients with an average age of 16.2 years and 35 healthy male individuals with an average age of 16.02 years. The hemophilia patients scored lower on the Offer Self-Image Questionnaire (OSIQ) than their healthy peers. Patients who received secondary prophylaxis showed no difference in total OSIQ scores compared to those who did not. The median total OSIQ score of patients with abnormal Hemophilia Joint Health Score (HJHS) was lower than those with normal HJHS (31). Patients with hemophilia must face the typical challenges of adolescence alongside challenges specific to hemophilia. They are at high risk of developing hemophilia-related complications due to issues associated with low adherence, the psychosocial impact of the disease, and the burning desire to fit in with their peers (32). In a different research, it was discovered that young adult men with bleeding disorders had slightly lower self-esteem compared to their peers.

On the other hand, young adult women with bleeding disorders did not show any differences in comparison to their peers in terms of outcomes (32). In a study that described and analyzed the data, 372 adolescents aged 11-21 with hemophilia participated. The adolescents' resilience in hemophilia was influenced significantly by factors such as social support, spiritual beliefs, and coping strategies (33).

Moreover, there is no significant difference in self-concept among the three groups. Individuals with chronic illnesses frequently experience apprehensions regarding their physical appearance and sense of self. This is particularly true when the illness or its management results in noticeable changes to the body. These aspects can have an impact on individuals' well-being (٢٠). The groups differ in social assertiveness and participation in social groups. The group with leukemia showed higher social assertiveness than the other two groups, while the leukemia and hemophilia groups had higher participation in social groups than the healthy group. The study suggested that encouraging social participation may benefit boys with hemophilia by increasing self-perception and strengthening their social support network (34). Sick individuals have higher self-efficacy in social assertiveness and participation in social groups than healthy individuals. There are significant differences in other dimensions of self-efficacy among the three groups. Thus, these findings align with previous research (21,22,27,28).

Research has indicated that children with chronic illnesses demonstrate social behaviors that are similar to those of their peers in various ways. Children undergoing chemotherapy for cancer have similar emotional health to their peers without cancer and demonstrate better social functioning (21,22). Individuals with leukemia and hemophilia show higher social assertiveness than healthy individuals, indicating that social support, disease prognosis, and family dynamics influence their social self-efficacy. Studies have shown a positive correlation between social support, self-efficacy, self-esteem, and life satisfaction. Family communication patterns can also shape an individual's self-efficacy beliefs (27,28).

Adolescents and young adults with bleeding disorders, who are a vulnerable patient group, face unique challenges compared to healthy individuals as they transition into adulthood. This transition phase involves accepting the limitations of their disorder, taking on self-care responsibilities, moving from pediatric to adult treatment facilities, seeking employment with adequate medical insurance, and potentially starting a family. Typically, adolescents with bleeding disorders begin to learn self-infusion around age eleven, a process that requires advanced self-management skills. While managing their care at home can be advantageous in terms

of fewer hospital visits and increased independence, the significant responsibility associated with managing the disorder can be overwhelming for individuals with hemophilia (31).

Due to limitations in research on differences between leukemia, hemophilia patients, and healthy individuals, plus small sample size and lack of control over intervening variables. Limited history of research on specific patients like hemophilia and blood cancer, especially teenagers, lack of cooperation from other hospitals, and limited access to statistical samples. Weakness, fatigue, and boredom from illness or treatment caused interruptions in questionnaire collection. Generalization of results is limited because of the small sample size and lack of access to more samples.

6. Conclusion

The current research findings suggest that patients cope with problems by seeking social support, developing positive habits, thinking positively, and focusing on spiritual matters. This coping style may contribute to their higher social self-efficacy, specifically in terms of participation in social groups. Utilizing a confrontational approach to dealing with problems could enhance patients' ability to engage with social support networks.

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Consent for publication: The Publisher receives the signed Consent to Publish from the Authors in order to obtain permission to publish their Work.

Ethical approval and consent to participate: The research involving human subjects followed the ethical guidelines established by the Karaj Branch of Islamic Azad University under the code IR.IAU.K.REC.1402.098. The authors thank the participants for their help and valuable contributions to the study's success.

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