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Original Article

The Effect of self-care on the lives of children suffering from acute lymphocytic leukemia

*Mehri Golchin *, Najmeh Sharifi **,*
*Shohreh Ziaee *, Parvin Taheri **

Abstract

BACKGROUND: Acute lymphocytic leukemia is one of the common cancers of childhood and currently, 80 percent of these children survive more than 5 years by getting the right treatment. Since long-term treatment is painful and invasive, preventing the side effects and their influence on quality of life is an important issue which introduces consideration for self-care. Consequently, the present study was conducted in 2007-2008 about the effects of self-care on the lives of children suffering from acute lymphocytic leukemia**,** referring to treatment centers in Isfahan City.

METHODS: The present study was a two-staged, two-group clinical trial. 48 children aging 5-18 and suffering from acute lymphocytic leukemia were selected through convenient sampling method and the training program was administered before them and afterwards, they were divided randomly into two groups of experiment (n = 24) and control (n = 24). The General Scale and Cancer Scale Quality of Life Identification Questionnaires were used to define the quality of life of the children. The validity and reliability of the questionnaire were in turn defined by content validity method and Cronbach's alpha test. The experiment group received the self-care checklist after training and was controlled and examined for 3 months. The pre-and-post self care Quality of Life Questionnaire were both filled out in both groups and accordingly, the SPSS software, independent t test, chi-square and paired t tests were used to analyze the data.

RESULTS: The findings of the study showed that both groups were homogeneous by virtue of influential factors on quality of life, like age, gender, type, stage and duration of treatment ($p > 0.05$). There was no significant difference between the experiment and control groups' quality of life average scores before administering the self-care training program. The results of paired-t test in the experiment group after administering the self-care program showed a significant difference in General and Cancer Scale Questionnaires Quality of Life with that before administering the program, while no significant difference was observed in the control group. Also, the independent t-test showed a significant difference in the average of quality of life score shift after administering the self care between the experiment and control groups.

CONCLUSIONS: Quality of life improved after administering self-care training program in the experiment group while it did not improve in the control group and even the increase in average score of quality of life in Cancer Scale in this group was an indicator of an increase in problems related to disease, treatment and care. The results of this study showed the positive effects of administering self-care on the quality of life of children suffering from acute lymphocytic leukemia.

KEY WORDS: Acute lymphocytic leukemia, quality of life, self care, child.

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Leukemia is the commonest type of children cancer which has had a significant increase of occurrence rate among children under the age of 15 in the past 20 years.[1] Currently, the annual occurrence rate of leukemia is 3 to 4 cases in every one hundred thousand white-skinned children[2] so that the occurrence rate of acute lymphocyte leukemia in the USA is 2500 to 3000 new cases every year.[3]

Within the past 30 years, the treatment of malignancies has had a great progress.[4] Presently, 80 percent of children suffering from acute lymphocyte leukemia under new treatment me-

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* MSc, Department of Pediatric Nursing, School of Nursing and Midwifery, Isfahan University of Medical Sciences, Isfahan Iran
** MSc Student, Department of Pediatric Nursing, School of Nursing and Midwifery, Falavarjan Branch, Islamic Azad University, Isfahan Iran.
Correspondence to: Najmeh Sharifi, MSc.
E-mail: sharifi_n@iaufala.ac.ir
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thods survive more than 5 years. With regard to this point that 2500 to 3000 new cases of acute lymphocyte leukemia are diagnosed every year, it is expected to have 2000 patients getting rid of this disease every year.[5]

The treatment of leukemia is long, painful and invasive. Frequent hospitalizations, numerous physical side effects and limitations in daily activities following the treatment all affect significantly on the child's quality of life.[6] Consequently, treatment side effects and its impact on children's quality of life has gained great importance and quality of life issue will be paid more attention than survival duration.[7] Numerous studies indicate the resulted changes in the quality of life of children who suffer from acute lymphocytic leukemia. Thus, the issue of quality of life is very important in this group so that the Children's Cancer Group has set quality of life as one of its fundamental goals and it aims to focus their research on promoting the quality of life of children and young adults who suffer from cancer alongside their families.[8]

Quality of life has a close relationship with nursing cares since the nurses not only are in touch with lowering deaths and increasing survival also they are in touch with the totality of human and they help the patient in taking care of the patients who suffer from cancer to control the side effects of the disease and adjust to the changes in the mental image, functioning and the appearance of the individual and can finally, live with an acute disease.[9]

Because the main goal in treating all diseases is increasing the level of functioning and promoting quality of life and helping the patients to get a satisfactory quality of life, this goal is materialized only by providing self-care programs and seeking proper solutions for helping the patients. By changing the pattern of diseases from acute to benign, self-care has become a logical necessity and an appropriate strategy.[10] According to Urom, self care consists of activities which start by the individual and are done in order to preserve his/her survival and well-being.[11] Self care involves the "self-care factor" and "dependent care factor"; regarding the children, their parents are the dependent care factor and they do most self-care activities of children.[12] In spite of such dependence in children from the age of 5, they are able to take care of themselves; children are also independent and reliable and they can be counted on for taking care of themselves.[13]

The conducted studies about evaluating the quality of life of children, especially those suffering from acute lymphocytic leukemia, are very limited; in addition, none of the studies has examined the effect of self-care on children's quality of life while studies about the quality of life and self-care appropriately have shown the positive effects of self-care on the quality of life. Accordingly, the researcher decided to conduct a study aiming at defining the effect of self care on the quality of life of children suffering from acute lymphocytic leukemia who referred to training centers of Isfahan University of Medical Sciences. The aims of this study included the comparison of quality of life average scores before and after administering self care in two groups of experiment and control, the comparison of quality of life average scores in both groups before administering self care and definition of the average of quality of life score shifts before and after administering self care in both groups of experiment and control.

Methods

This study was a clinical trial. The context of the study was the Chemotherapy Clinic at Seiedo Shohada Hospital and the Chemotherapy Section of Al Zahra Hospital in Isfahan City which are both known centers for treating children suffering from cancer. The research population included all children suffering from acute lymphocytic leukemia who referred to these centers. The samples of the study were 48 sick children who qualified to enter into the study.

The defined criteria for the units of study included children aging 5 to 10 years, with certain diagnosis of acute lymphocytic leukemia who had passed the first stage of chemotherapy and are not at the final stages of the disease without having any known cognitive and mental problems, children who live with their real families, and children or parents who have the ability to read and write and speak Persian and no stressful event had occurred to them for the last month. Sampling was conducted by the easy, continuous method in a manner that the children who were qualified to enter the study were selected. The training program was administered for all of them, and then, the patients were randomly assigned to two groups of experiment and control. In order to collect the data, a questionnaire and a checklist were used which included the questionnaire of demographic features, the training, needs analysis questionnaire, the self-care checklist and the questionnaire of children's quality of life.

The training, needs-analysis questionnaire included a list of 32 problems related to cancer and treatment which had been prepared by the researcher by using scientific resources and papers, about which the units of study and their families were asked to answer with "yes", "no" or "to some extent". By having the answers, the training needs were defined and the training content and the mentioned factors in self-care checklists were compiled. The self-care checklist was designed according to the collected data from training, needs-analysis questionnaire and with regard to children's common problems which included 7 checklists related to infection, diet, nausea and vomit, mouth injuries, pain, constipation, and irritable bladder. Each checklist had been scheduled for one month and included a series of self care activities related to that problem. The checklists were given to the patients in the experiment group and the manner of checklist completion was accordingly explained to them and they were asked to examine the checklist daily and in case of doing any self-care activates, put a sing in front of that activity. The quality of life questionnaire consisted of two Examining Children Quality of Life Standard Questionnaire, the General Scale (ECLQSQGS version 4), and Examining Children Quality of Life Standard Questionnaire, Cancer Scale (version 3). The ECLQSQGS evaluates children's quality of life in 4 dimensions (physical functioning, excitement functioning, social functioning, and educational functioning) and included 23 questions which are classified into 0 to 4 points; and the highest score after the completion of the questionnaire would be 92 and the lowest would be 0. The means of examining the quality of life of children suffering from cancer is a questionnaire which has been designed on the basis of common cancer-related problems which includes 8 dimensions (pain or damage, nausea, procedures anxiety, treatment anxiety, concern, cognitive problem, physical appearance, relationships) and 27 questions; the highest score after completion would be 108 and the lowest would be 0 and totally, the highest score that the research units could get after completing the questionnaires would be 200 and the lowest would be 0. With regard to the nature of answering to the questions, the lower the scores, the higher the quality of life would be. Thus, the zero score indicates a high quality of life and the score 200 indicates a low quality of life. The reliability and validity of the quality of life examination questionnaires were defined in turn by using content validity method and Cronbach’s alpha test, through which the alpha coefficient of children's questionnaire aging 5 to 7 years was 0.8 and the alpha coefficient of children's questionnaire, aging 8 to 18 was 0.98.

The method of the research was that initially the aims and research methodology were explained to children and their family and their conscious written consent was taken. Since one of the main components of self-care is training the patient, thus there was a need to conduct the program in the experiment group but the researcher conducted these sessions for all patients and in two groups for considering ethical norms. As a result, all samples filled out the training need-analysis questionnaire after completing the demographic data questionnaire at the first stage. With regard to the attained information from the training need-analysis questionnaire, the content of training sessions and self-care checklists were set up. The content of training was designed for 4 sessions which included data regarding the nature of disease, disease-related problems, treatment side effects and related cares, ways of dealing with anxiety and stress and nutrition-related issues.

All the samples were divided into two groups by virtue of their age category (5-7 years) and (8-18 years) and the training sessions were held within 4 weeks, twice in each session. All the children alongside their main care taker, which was mainly their mothers, participated in the sessions. Due to discussing about the nature of disease, and treatment and its related issues in the first session and in order to prevent the unpleasant psychological effects on the child, the parents were asked to take part in it without their child's presence. The training sessions were conducted by the researcher but for training the methods of dealing with anxiety and stress following the disease and its related psychological issues, a psychologist in the field of child and family joined and regarding the nutrition-related issues, a nutritionist helped the main researcher. The sessions were held on a question/answer basis, group discussion by using colored caricatures, showing films, and power point software for children; at the end of each session, the samples' questions were answered and a set of pamphlets were prepared about the presented materials and given to them. At the beginning of the nest session, some questions were asked about the already presented materials and they were restated in case of having any problem. In addition, in order to encourage and engage the children more throughout training, a series of awards were given to them. In the last session, some instructional manuals were prepared which contained all presented materials and were given to all samples. At this stage, the samples were randomly divided into two groups of experiment and control and their homogeneity, regarding different variables (age, gender, treatment type) was assured by doing statistical analysis.

After the last training session, the quality of life questionnaire was given to samples in each group to fill out and then the self-care checklists that had been provided according to the needs-analysis questionnaire were given to the experiment group and they were asked to do self-care activities daily on the basis of the self-care activities checklist and in case of doing each of the activities, put a sign in front of it. The checklists were set monthly. During the study, the researcher called the samples every week. Also, every two weeks, he contacted them in person and examined their training problems and at the same time, encouraged the children to do the self-care activities by giving some gifts to them and also gave them every necessary recommendation for filling out the checklists after doing each activity. At the end of the month, the previous checklist was taken and a new checklist related to that month was given to them. The new checklist did not have any difference with the previous checklist and all items were the same. Since the purpose was to examine the quality of life of the patients, quality of life had to be examined in different time intervals and for examining the effectiveness of the intervention, it was necessary for the samples to have enough time for practicing the self care in their own personal lives. The duration of following and repeated assessment of quality of life in this study was 3 months. After 3 months, the checklists were gathered from the experiment group and for the second stage, the life-quality questionnaire was given to all research samples in control and experiment groups to be filled out. The data in this research were of quantitative type and for analyzing them, the independent t-test, chi-square and the SPSS software were used and a 0.05 error was considered for all the tests.

Results

The findings showed that the average age of participating children in this study was 9.8±3.2 in the experiment group and 9.3±3.6 in the control group. The majority of the samples were male in the experiment group (79.2 percent) and in the control group (66.7 percent). The educational level of most samples in both groups was pre-school (37.5 percent) and elementary school (33.3 percent). The life place of research samples at the experiment group (62.5 percent) and at the control group

Table1. Comparison of quality of life scores' average before and after conducting the self-care training program in the experiment group

Group	Quality of Life Scores Of Questionnaires	before Conducting Self Care		after Conducting Self Care		Number	Statistical Results	
		mean	standard Deviation	mean	standard Deviation		Paired t-test	P value
Experiment	General Scale	27.30	12.40	26.26	13.14	24	-.087	0.15
	Cancer Scale	30.44	16.07	27.36	12.00	24	-1.67	0.046
	General Questionnaire	28.39	12.88	26.31	11.08	24	-1.61	0.05
Control	General Scale	28.30	15.67	28.03	17.38	24	-0.18	0.43
	Cancer Scale	28.80	15.25	30.76	19.34	24	1.005	0.15
	General Questionnaire	28.00	14.27	28.89	17.63	24	-0.629	0.26

(54.2 percent) was the towns and counties at the suburbs of Isfahan. Regarding the treatment program, the experiment group (50 percent) and the control group (66.7 percent) were under standard treatment. In addition, with regard to the type of treatment at the standard group, the majority of samples at the experiment group (41.7 percent) were at the third stage of treatment and at the control group, 41.7 percent were at the fourth stage of standard treatment. Samples that were under highly risky treatment (25 percent), samples in the experiment group at the third stage of treatment (20.8 percent) and samples in both experiment and control groups were at the fifth stage of treatment. By virtue of the return of the disease or having its record, 58.3 percent in experiment group and 66.7 percent in control group did not have the record of affliction to the disease. The affliction duration in the experiment group was 29.95 ± 34.2 months and this amount was 29.75 ± 21.13 months in the control group. The frequency of getting hospitalized at hospital was 5.8 ± 4.7 times and for the control group, it was 5.4 ± 3.1 times. The educational level of most samples' fathers was 37.5 percent diploma in both groups and this rate for their mothers was 33.3 percent elementary education and diploma for the experiment group and 45.8 percent elementary education in control group. The fathers of samples in the experiment group were 70.8 percent self-employed and this amount was 62.5 percent in the control group. Mothers of most samples were 91.7 percent housewives in the experiment group and 95.8 percent in control group. The average number of family members was 3.9 ± 0.9 in the experiment group and 4.4 ± 1.2 in the control group. With regard to the record of suffering from cancer, 54.2 percent in the experiment group and 58.3 percent in the control group had the positive record of suffering from different kinds of cancer in their families.

The comparison of quality of life scores before and after conducting self care in the experiment group showed that the average of quality of life scores had decreased after conducting self care compared with prior conduction time, meaning that children's quality of life improved but only within the cancer scale. In the general questionnaire, the results of paired t-test ($p \leq 0.05$) showed such a significant decrease in scores as well. Although there was an increase in scores in the control group, the results of paired t-test ($p > 005$) did not show a significant difference in general scale, cancer scale and the general questionnaire (Table 1). Besides, the independent t-test did not show any significant difference ($p > 0.05$) when comparing the average scores of quality of life before conducting self-care between the two groups of experiment and control while the results of this test showed a significant difference between the average scores of quality of life score shift in the experiment and control groups before and after conducting

Table2. Comparison of quality of life score shift average before and after the self care in both experiment and control groups

Group quality of life scores of questionnaires	Experiment Mean	Experiment Standard Deviation	Experiment Number	Control Mean	Control Standard Deviation	Control Number	Statistical Results Student t-test	Statistical Results P value
General Scale	-1.04	5.83	24	-0.27	7.38	24	-0.401	0.34
Cancer Scale	-3.08	9.01	24	1.96	9.09	24	-1.93	0.03
Total/General Questionnaire	-2.08	6.32	24	0.89	6.97	24	-1.55	0.05

self care within the cancer scale and the general questionnaire (Table 2).

Discussion

Social, environmental, political, and economical factors and health condition all affect the individual's quality of life. Health condition is defined as physical, psychological and social health not a mere absence of diseases or maladies.[14] Health-related evaluation of quality of life examines the effects of diseases on the condition of health. Cancer has significant effects on physical and psychological dimensions and social health. Correct information about health quality related to general health has an important role in promoting the quality of life of children who are afflicted with cancer.[15] Despite the importance of this issue, little amount of studies has been done on the effect of cancer and its treatment on the quality of life of children who are afflicted with cancer.

According to our findings, this was the first study that examined the effects of conducting self-care on the quality of life of children who suffer from acute lymphocytic leukemia. The results of Table 1 showed that conducting self care in the experiment group had led to a decrease in the average score of quality of life among the children who suffer from acute lymphocytic leukemia at cancer scale and total questionnaire which indicated an improvement in the condition of children who suffer from cancer regarding the problems related to their disease; and its treatment accordingly promoted the quality of life of children in these dimensions. In this regard, Zandi (2003) concluded in their study after conducting self-care for 3 months on patients suffering from Sirus that the patients' quality of life was promoted after doing self-care measures[16] which is in line with the present study.

Besides, with regard to promoting health quality by using self-care programs, Wattana, et al (2007) examined the effect of self care of diabetics, type 2, on the quality of life of patients, whose findings showed a significant increase in the quality of life of the group under the study.[17] By virtue of conducting self care for patients suffering from cancer, Davoodi's study on patients suffering from esophagus cancer following the esophagectomy operation showed that conducting self care for one month after the operation led to preservation of patients' quality of life while the quality of life of the patients in control group decreased.[18] Conducting the self care not only increased the quality of life of patients under the study, it also led to its preservation and prevention from a higher decrease in quality of life. The patients were followed up for one month in Davoodi's study[18] but in the present study, the patients were followed up for 3 months with regard to following self-care measures which finally resulted in promoting their quality of life.

Svavarsdottir and Orlygsdottir mentioned that the children who suffer from acute lymphocytic leukemia following the affliction to the disease experience lots of problems while getting treatment that affect their quality of life.[19] The results of the present study in control group indicated that children's quality of life decreased by passing the time and the problems of these patients at cancer scale decreased which indicated the less problems related to the disease and its treatment.

Apajasalo et al concluded in their study that the children who suffered from acute lymphocytic leukemia had a lower psychological and cognitive score compared with the healthy population.[20] Also, the results of Billson and Walker study showed that 67 percent of children suffering from leukemia had defections in one or several aspects of quality of life[21] and in Yaris study, 96.7 percent of children had defections in one or several quality of life aspects and more that 96 percent of them reported to have psychological problems.[22]

Considering the results in Table 2, it seems that conducting self care and continuous follow up of patients had positive behavioral effects on the experiment group and led to a larger difference in the quality of life score shift of these patients compared with the control group and compared with the condition before conducting of self care. The quality of life of patients who are afflicted with the acute version of the disease can be improved if they are trained the self care measures and followed up on conducting the self care. Therefore, it can be stated that conducting the self care measures in the present study to some extent has met the requirements of children suffering from acute lymphocytic leukemia and had positive effects on their quality of life. Despite the great willingness of patients and their families to receive training programs and supporting follow ups, unfortunately there is no systematic program for these patients at the moment. Thus, it is suggested that training and self care programs and continuous follow up of these patients be compiled and conducted like the present study.

The authors declare no conflict of interest in this study.

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