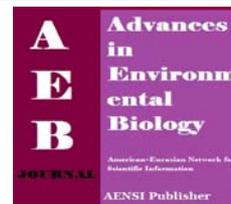




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Effect of Education on Quality of Life of Parents with Leukemic Children Referred to Oncology Clinic of Kerman's Afzali-Poor Hospital, 2012

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ARTICLE INFO

Article history:

Received 22 October 2013

Received in revised form 14

January 2014

Accepted 20 January 2014

Available online 25 February 2014

Key words:

Quality of life, Education, Leukemia. parents.

ABSTRACT

Background: Factors reducing quality of life of parents of children with leukemia are fear and anxiety after diagnosing leukemia, and absence and/or lack of knowledge of familial watchers -especially parents- about the illness and how they care diseased child. This research aims to investigate impact of education on quality of parents' life with leukemia children referring to oncology clinic of Kerman's Afzali-Poor hospital. Methodology: In this interventional study, 80 parents of children with leukemia, that had included in the research, are chosen using convenience sampling method, and categorized randomly into two groups of interventional and Control (each forty people). Research tools are: (i) data collecting tools include reliable and validated Quality of Life (QOL) questionnaires (a specific form for first-degree relative caregivers of patients with leukemia) contains demographic information, and questions related to quality of life in four dimensions of physical, mental, social, and spiritual, and has 37 questions totally. Maximum rating for Quality of life is 370 and the least one is zero in this questionnaire; the more score the better quality of life. Questionnaires were accomplished through interviewing with parents before intervention and 3 months after intervention for both groups. Intervention was done for 4 sessions of forty five- to sixty-minute educating classes, hold as lecture, question and answer (Q & A) sessions, educational booklets, and posters in groups with 4-6 members. Results: Based on findings of the research, mean scores of quality of life in interventional and control groups were 224.9 and 225.7, which, after training, changed to 338.2 and 226.77 respectively. T-test verified these increases ($P < 0.05$) in quality of life in the interventional group. Conclusion: According to effectiveness of education on the quality of parents' life, it is recommended to implement consulting and educational programs for parents, especially parents of children with leukemia, to promote caring, reduce anxiety, and consequently, enhance quality of their life.

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To Cite This Article: Fariba Ghodsbin, Navid Asadi, Sorur Javanmardi fard., Effect of education on quality of life of parents with leukemic children referred to Oncology Clinic of Kerman's Afzali-Poor hospital, 2012. *Adv. Environ. Biol.*, 7(14), 4655-4659, 2013

INTRODUCTION

Childhood cancer is an increasing and prevalent type of chronic illness worldwide [1]. Leukemia is one of the most common cancers in children under 15 and represents 25% of all cancers in children [2]. Such as other chronic diseases, it causes many physical and mental problems for the caregivers, who are mainly parents [3-6], and makes parents show various levels of anxiety, shock, depression, disappointment, and denial in initial stages of diagnosing kid illness [4, 7, and 8]. These issues can remain within them years after illness controlled, and they may transfer to patient kid and other healthy child in the family [4, 7, 9]. At the time of child's diagnosis of leukemia family is confronted with challenges, such as conflict and role ambiguity and sense of helplessness [9, 10], losing job, disruption, disorder in interpersonal relationships, inability in doing individual, familial, and social and other activities. Finally, decrease quality of life of child and the family members of children diagnosed with leukemia. [11]. A study has been carried out with 739 members of cancerous patients' families by Behavioral Research Center of American Cancer Society. Results reported the high levels of mental stresses associated with disorder in dimensions of physical, mental, and social performance [12]. In a study, Yamazaki compared quality of mothers' life with and without leukemic children; he found that dimensions of quality of mothers' life with

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leukemia child were low in five areas, particularly in physical and mental dimensions [13]. Although role of parents is paid attention in recent years, but quality of their life is not assessed overall, and there was a little focus on carrying out proper educational interventions in order to promote quality of familial careers' life- especially parents of leukemic children. Since, one of the ways to improve quality of life is implementing educational interventions for parents to face the effects and consequences of kid's illness and to restrain them for a life with better quality [14]. Results of implementing the interventions are parents' empowerment, which should be targeted on cooperation of nurse with family, emphasizing on reduction of hazardous factors and improvement of QOL. Nurse should mostly rely on positive capacities of family [15]. Therefore, this study aims to determine the effect of education on quality of life of parents with leukemic children's.

MATERIALS AND METHODS

The current interventional research was performed in Afzali-Poor Hospital of Kerman in 2012, where is a main center of providing services for leukemic children in Iran southern. In addition, research sample consist of 80 parents with leukemia kids, who are randomly categorized into two groups of test and control (40 persons in each group). Included criteria of the study was parents, who had leukemic child and child's age was in the range of 7-10, have the minimum literacy, have no record in using previous consulting systems, filling in a specific form for conscious consent by samples, and excluded criteria were lack of cooperation of parents with researcher. Data collecting tool includes two parts. The first one contains demographic information, and the second one is a reliable and validated questionnaire of quality of life (a specific form for house, first-degree relevant careers of leukemia patients) regulated by Ferrell and Grant including 37 questions. In this tool, questions about dimensions of quality of life is set in four dimensions of physical, mental, social, and spiritual. This scale ranges from zero to 10 scores. In 16 questions, zero rating represents the worst situation and 10 stands for the best condition for that person. In the rest 21 questions, zero score is the best mode. Hence, there is a direct relation between measurement scale in the first 16 questions and overall score of quality of life, and a reverse relation in other 21 questions. Questions, which their scores have reverse relation with quality of life, are marked by (*) in the questionnaire. The overall score is calculated by adding scores of questions. To rank the scores, 0-123 scores are considered as unfavorable quality, 124-246 as partly favorable, and 247-370 as favorable quality.

After preparing questionnaire, translating to Persian, retranslating to its original language, and again translating to Persian, and acquiring approval of scientific referee, questionnaire is examined for validity by 10 medical and nursing professors, which their comments is applied in the tool. Questionnaire's validity is also studied using test-retest method among 10 people of attendees. Cronbach's Alpha is calculated $r=0.87$. Samples were picked out using convenience and available sampling based on entry conditions. Then, a research assistant, who learnt how to fill in questionnaire, accomplished quality of life questionnaires through interviewing with parents of both interventional and control groups. Next, test and control groups were specified by random allocation, as the first member was randomly put on in one of test or control group and rest of participants were divided between both groups alternatively in a way that each group contained 40 members. To heed ethical issues in research as well as prevent possible errors, completed questionnaires were codified. After that, the intervention was applied on test group. Intervention was in the form of education and educational booklets. Education, implemented by researcher, included 3 sessions of educational class took 45-60 minutes holding as lecture or Q & A sessions in 4-6 members groups. The following matters were presented to parents in these sessions: appropriate and required information about leukemia and its remedy, effects of illness on family and ways to cope with them (session 1); ways to communicate with child, impacts of illness on various dimensions of kid's life, how to mitigate them, and promote quality of kid's life (session 2); and how they take care of sick child in hospital and home (session 3). According to parents' academic education and their understanding level, other teaching aids such as posters were employed, enough time spent to ensure full realization of the attendee. Regarding to severe need of these parents to gain information about the illness and caring their children, they endeavored too much to learn all of educational matters in these three planned sessions. In addition, after each session of instruction, parents of test group received instructional booklets contain necessary information, as a teaching aids to review their possible questions in the booklet. Again, two months after accomplishment of intervention, the questionnaire of QOL was completed by researcher via interviewing with parents in both groups of test and control. Collected data were analyzed by SPSS v.11 and using analytic and descriptive statistics. P-value equal to 0.05 was set as level of significance. Current study noticed ethical considerations too.

Results:

Based on findings of this study, average ages are 34.1 and 34.83 years for mothers, 46.8 and 44.6 years for fathers, and 9.54 and 9.31 years for children in test and control groups respectively. Sixty-five percent of samples' children in test group and 72% of samples' children in control group was boy. Among fathers, 60% in test group and 50.6% in control group were self-employed, and most of the mothers were homemaker (95.6%).

The academic educational level for most of fathers (74.2% in both groups), and most of mothers (73.5% in test and 77.6% in control group) was elementary. Generally, independent T and Chi-square tests showed that there were no difference in demographic attributes of both groups statistically, and both groups were similar regarding to these features. Results demonstrated that overall score of quality of life was 224.9 ± 24.11 for test group and 225.7 ± 7.86 for control group. However, after two months of training, this score reached to 338.2 ± 7.86 in test group and 226.77 ± 23.8 in control group. Independent T-test confirmed that there was not a significant difference between both groups respecting to scores of quadruplet dimensions of quality of life as well as total score of QOL statistically ($p < 0.05$), while after educating this difference became significant (Table 1). QOL scores and the scores differences in both considered groups, before and after intervention, are compared in table 2. So as, in test group, average scores increase for all dimensions of QOL after training. The most increase occurs in mental dimension with average difference of 49.9 ± 7.25 and the least one takes place in physical dimension with average difference of 15.73 ± 5.9 . These findings also show that social dimension remains almost same in control group after training (average difference of 0.00 ± 0.45), mental and spiritual dimensions increase slightly (average score differences 0.97 ± 4.2 and 1 ± 8.6 for mental and spiritual dimensions respectively), while physical dimension mitigates (average difference of -1 ± 6.3). Total score difference of QOL is 56.65 ± 29.26 before and two months after training in the test group, while this number is 0.97 ± 18.14 for control group. Paired T-test demonstrates that increases in QOL's dimensions scores in test group are significant ($P < 0.05$), while it does not validate changes in QOL's scores of control group. Furthermore, independent T-test shows that there is a statistical significant difference between test and control groups after two months of education versus difference of QOL's dimensions scores as well as overall score of QOL ($p < 0.05$) (Table 2).

Discussion:

According to results, overall score average of QOL of parents with leukemia children is partly desirable (224.9 ± 24.11 in test group and 225.7 ± 24.33 in control group). Our results are consistent with those of work of Fatookian *et al* in which more than four-fifth of samples have a partly desirable or undesirable physical situation and only 15.7% of samples have a desirable physical situation, which could be stemmed from lack of social support [15]. To resolve it, caring roles and tasks should be divided between parents [16].

According to findings of current study, QOL scores of under-study parents with respect to physical conditions, for test and control groups before intervention, was 26.33 ± 6.7 and 25.8 ± 7.11 respectively. They reached to 42.06 ± 3.8 and 24.8 ± 7.11 two months after intervention in test and control group respectively. Results of assessment, done before intervention, show that there is a lack of information in many dimensions. In comparison, average of QOL's overall score raised up to 338.2 ± 7.86 for test group and 226.77 ± 23.8 for control group after two months of training. Independent T-test shows no significant statistic difference between two groups before training in terms of QOL overall score and its quadruplet dimensions ($p < 0.05$), but after training, this statistic difference become significant. So as, average scores elevated for all dimensions in the test group. Many studies have discussed undesirable effect of a sick child in the family on QOL, physical and mental health of parents, and influence of education on QOL of familial-watchers for chronic illnesses, such as Fatookian [15], Khanjaani [17], Arfa *et al* [2], Yaari [13], and Hicks [18], which their results demonstrates positive impacts of education on patient child's carers. Among them, we can point out Klassen *et al* [19]. The research's results, which studied 513 parents aiming to appraise effect of caring cancerous children on health-related QOL, show that parents of leukemia child have a poor QOL just like the current research. The authors suggest educational intervention for parents as a part of remedial programs of leukemia kids. In a comparative study, Yamazaki also compared QOL of Mothers with cancerous children and mothers with non-cancerous diseased children in Japan; average scores of QOL were poor in five of eight areas, and the maximum weaknesses were in mental, physical, and social performances [12].

Based on our results, the QOL's overall scores of all samples were partly favorable before intervention. In contrast, the scores enhanced obviously in all areas after two months of training especially in mental health, which the average difference reached to 49.9 ± 7.25 in test group and 4.2 ± 0.97 in control group. These results are consistent with those of Khanjaani *et al*, who studied effects of educating how parents should take care of children with cerebral palsy on QOL of 25 familial carers. In this research, QOL scores were higher three months after accomplishing training than scores before getting education in three areas. So as, this change in physical and emotional roles were outstanding ($p < 0.001$), that were 50.66 ± 78.24 and 31 ± 26.30 respectively [17]. It is noteworthy that chronic diseases have their unique attributes and effects on family. So as, taking care of mentally-retarded and disabled children causes less decreases in scores of physical and mental health dimensions, while, in cases of cancerous kids, it leads to more fear, anxiety, and mental problems in carers.

Reviewing other studies, it was revealed that educated mothers caring mentally retarded children leads to attitude improvements and better adaptation comparing with before training [20]. Sanjari *et al* argue that diagnosing and curing cancer require diseased child and its parents understand truly how they should deal with stressful aspects of the illness [21]. Since parents often take on preparing daily needs of child, they can use coping procedures to get over the issues [22]. It is also suggested that nurses and responsible persons can

contribute in promoting QOL of diseased children and their families by providing them with consulting services and developing and executing documented educational programs to help them learn proper methods of coping [21]. Results of another study in Kerman reveal that 94.1% of research centers employ reliance and belief in God as a coping method [22]. In a study aimed to investigate compatibility methods and experiences of fathers with leukemia children, researchers found that, for most of fathers, compatibility approaches included gaining knowledge, receiving others' aid, problem-resolving method, and using religious beliefs [23].

In current research, social state remains unchanged even after training in both groups. In other researches, 3.5% of participants have a desirable social state, and 3.4% have an undesirable spiritual and mental condition [15]. Researches' results demonstrate that social supports are among the less used sources in families, stemmed from this fact that people do not accept direct helps due to cultural circumstances. Therefore, this duplicates importance of institutions' reinforcement and supporting patients and their families to adapt effectively to problems. Thus, sufficient social support can improve their adaptive skills; and have a direct effect on improvement of QOL [24]. hence, it is suggested that required facilities are provided for them through social-supportive and welfare services, and nurses should be familiar with the services and introduce them to watchers.

Conclusion:

Since parents of children suffering from leukemia need more attention than other illnesses, it is necessary that supportive programs for parents be included in child's remedial program immediately after diagnosing the illness. Research's results show that educating is affecting on quality of parents' life, particularly in mental dimension. According to parents' role in taking care of kids, it is recommended to present programs in order to promote mental health's level of families with leukemia kids besides remedial cares. In addition, nurses can provide families with information about supporting systems and consulting services available in society, and considering their accessible sources, facilitate utilizing these services for them and help to improve quality of their life.

According to our findings, participants need physically, mentally, and –particularly- social supports. Thus, it is suggested that Ministry of Healthcare contributes in affording costly medicines demanded by cancerous patients and taking care of these patients at home for the watchers by providing them with social, supportive, and welfare services such as improving health insurances.

Table 1: A comparison between QOL's score for parents with leukemic children referring to Kerman's Afzali-Poor Hospital before training and two months after training in both case and control groups.

Time	Before intervention Mean (\pm standard deviation)		P-Value	After intervention Mean (\pm standard deviation)		P-Value
	Test	Control		Test	Control	
QOL dimensions						
Physical	26.3 \pm 6.7	25.8 \pm 7.11	0.76	42.06 \pm 3.8	7.11 \pm 24.8	0.00
Mental	96.43 \pm 7.92	97.3 \pm 3.2	0.9	146.33 \pm 5.17	3.6 \pm 98	0.00
Social	55.3 \pm 10.73	55.9 \pm 11.8	0.83	86.63 \pm 2.35	55.9 \pm 11.8	0.00
Spiritual	46.83 \pm 9.93	46.96 \pm 9.93	0.95	63.16 \pm 2.47	47.96 \pm 9.8	0.00
Overall QOL score	224.9 \pm 24.11	225.7 \pm 24.33	0.89	338.2 \pm 7.86	226.77 \pm 23.8	0.00

Table 1: A comparison between QOL's scores change before and after intervention in both case and control groups for parents with leukemic children referring to Kerman's Afzali-Poor Hospital.

Group	case Mean (\pm standard deviation)		p- Value	Control Mean (\pm standard deviation)		p- Value	Difference before and after intervention for Test group	Difference before and after intervention for Control group	P-Value
	Before intervention	After intervention		Before intervention	After intervention				
QOL dimensions									
Physical	26.33 \pm 6.7	42.06 \pm 3.8	0.00	25.8 \pm 7.11	7.11 \pm 24.8	0.8	15.73 \pm 5.9	-1 \pm 6.3	0.00
Mental	96.43 \pm 7.92	146.33 \pm 5.17	0.00	97.03 \pm 3.2	3.6 \pm 98	0.09	49.9 \pm 7.25	0.97 \pm 4.2	0.00
Social	55.3 \pm 10.73	86.63 \pm 2.35	0.00	55.9 \pm 11.8	55.9 \pm 11.8	0.44	31.33 \pm 10.9	0.00 \pm 0.45	0.00
Spiritual	46.83 \pm 9.93	63.16 \pm 2.47	0.00	46.96 \pm 9.93	47.96 \pm 9.8	0.57	16.33 \pm 10.57	8.6 \pm 1	0.00
Overall QOL score	224.9 \pm 24.11	338.2 \pm 7.86	0.00	225.7 \pm 24.33	226.77 \pm 23.8	0.83	56.65 \pm 29.7	0.97 \pm 18.14	0.00

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