

Effects of supportive-educative program on quality of life of adolescents living with a parent with cancer

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ABSTRACT

Background: Cancer has significant traumatic effects on the family members of the patients, particularly in Asia's tightly knitted families. Research evidence suggests a debilitating impact of cancer on the quality of life of the afflicted individuals, their spouses, and their families. Since a few studies have been carried out on the quality of life of adolescents living with parents diagnosed with cancer, especially in Iran, the research team decided to evaluate the quality of life of them and also investigate the effects of supportive-educative program on it.

Materials and Methods: The present quasi-experimental, one-group study had a pre-test–post-test design and was performed in Esfahan in 2014. The sample of this study consisted of 30 adolescents. The data gathering tool was the short form of quality of life questionnaire (SF-36). Data were analyzed by descriptive statistics and paired sample *t*-test. *P*-value of 0.05 was considered significant.

Results: The paired sample *t*-test showed that before and after presenting the program, there were significant statistical differences in some aspects of quality of life, such as physical functioning ($P = 0.01$), energy/fatigue ($P < 0.0001$), emotional well-being ($P < 0.0001$), social functioning ($P = 0.001$), pain ($P < 0.0001$), and general health ($P = 0.01$).

Conclusions: This research showed that supportive-educative program can enhance some aspects of quality of life. Therefore, nurses and other health professionals can use this scheme or similar programs for helping adolescents living with a parent with cancer.

Key words: Adolescent, neoplasm, parents, program, quality of life, supportive information

INTRODUCTION

Cancer has significant traumatic effects on the family members of the patients, particularly in Asia's tightly knitted families. Cancer is debilitating because, by itself, it threatens the health, structure, and dynamics of human beings.^[1] Despite current advances in cancer treatment, even the most potent cancer treatments often bring debilitating physical, psychosocial, and emotional side effects in the family members.^[2] It is normal for families facing cancer to be upset and worried about this crisis. Families with young children or adolescents are often concerned about how children will react to cancer in a family member.^[3,4] Adolescents may be more at risk than

younger children for becoming distressed, as they are old enough to be aware of and understand what the parent is going through and the existential issues that may arise. Between 20 and 32% of adolescent boys and girls were reported to have experienced clinically elevated levels of emotional and behavioral problems throughout the first year after a parent was diagnosed with cancer.^[5] Confrontation with parental cancer can be highly threatening for children and may result in the development of psychosocial problems such as anxiety, confusion, sadness, anger, and feelings of uncertainty with respect to the outcome of the illness. They may face many changes in daily family routine due to repeated hospital admissions, hospital visits, and care of the parent when at home.^[6] Adolescents whose parents are ill may manifest their distress through changes in school performance, physical complaints of pain and discomfort, as well as changes in social and interpersonal relations.^[7]

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Adolescents, in general, are under constant pressure, striving for independence and for a separate identity, and express feelings of conflict between the wish to break away from the family origin versus the reality that they need at home both emotionally and physically.^[2] Therefore, adolescents may experience many changes in their quality of life. According to research, cancer affects the quality of life of the family members of the patients in five major areas: emotional, social, physical, spiritual, and financial.^[8] Quality of life is a matter of importance for health care professionals and policy makers. Quality of life assessment can help to facilitate communication with clients and identification of their preferences, for example, to select a specific treatment or plan.^[9] Some researches have been conducted in the field of the effects of cancer, especially advanced cancer, on the psychological aspects of children living with them^[6,10-12] and a few studies in the field of quality of life of adolescents living with parents with cancer, but there has not been any study conducted in our country so far. Therefore, the researchers decided to assess this issue and they planned to evaluate the effects of their proposed program on the aspects of quality of life of these adolescents.

MATERIALS AND METHODS

The present study was a quasi-experimental, one-group study with a pre-test–post-test design, which was conducted in Esfahan, from March up to October 2014. Pre-test–post-test designs are widely used in behavioral research, primarily for the purpose of comparing groups and/or measuring changes resulting from experimental treatments.^[13] We used convenience sampling. The sample of this study consisted of 30 adolescents in the age group 11–20, without a history of any major disease, and who were living with a parent with cancer at the first year of diagnosis and the parent was at the stage of chemotherapy or radiation therapy, with no metastasis of this cancer. These adolescents were selected from two main special cancer centers, one cancer clinic, and one oncologist's clinic in Esfahan. The exclusion criterion was the unwillingness of subjects at any time of research. To attain this sample size, during 6 months, the researchers spoke to 113 patients with cancer who had referred to the centers of collecting samples, leaving their adolescent children at home; only 43 of them allowed their children to join the research and of these 43 adolescents, 30 adolescents completed both pre-test and post-test questionnaires (response rate 69.76%).

The medical ethics committee of Esfahan University approved the study. All the parents and adolescents were given verbal and written information about the purpose and importance of the study. Written, informed consent was obtained from the adult participants and from the parents

of adolescents before they completed the first questionnaire and they were free to withdraw from the study at any time.

The data gathering tool was the Iranian translation of the short form of quality of life questionnaire (SF-36). This questionnaire has been used many times in Iranian's researches and was found to have a good validity and reliability.^[14-17] This questionnaire contains 36 questions in eight categories. All the questions are scored on a scale from 0 to 100, with 100 representing the highest level of functioning possible.^[18] Besides this questionnaire, we used demographics questionnaire that contained questions about sex, age, types of parent's cancer, birthrate, and if there was any special disease in the adolescent participant. The questionnaire was completed at the hospitals, clinics, or adolescents' home before and 1 month after presenting supportive-educative program. All the subjects completed the pre-test questionnaire at the two major oncology hospitals, clinics, or adolescents' home separately. The supportive-educative program was presented individually at the home of adolescents or in a small group using lecturing methods at the hospitals depending upon adolescents' preference. According to the educational content of the program, this scheme was presented in at least two sessions up to four sessions, depending upon the adolescents' needs. Each session lasted about 45–90 min and the sessions were presented during 1 month. For the children who were taught at home, we used face to face instruction. The parents were not present in the in the first session of the education program, but if it was noticed that it was necessary to explain some items in their presence, they were asked to take part in the second or third session. Some of the adolescents had come to the hospital with their parents, so we decided to have a group discussion with them during their parent's treatment. Four adolescents had corporated in the group discussion. In the first session, after completing the pre-test questionnaire, we wanted them to explain their experiences to the group members; through this, they came to know that their feelings were the same as others. Then we explained to them how they could cope up with their problems. The second session was conducted following their parent's treatment and all the four adolescents were present in this session. In the second session, we explained the other aspects of living with a cancer parent to them. The sessions lasted about 120 min each time. After 1 month, the post-test questionnaire was completed at the adolescents' home or by calling one of them to complete the questionnaire. Thus, the pre-test and post-test interval was 2 months for all the subjects. Supportive-educative program was extracted from some references, similar programs, and by consulting the oncologist and onco-psychologist and oncology nurses.^[4,19-22] A booklet and compact disc of this program was given to the adolescents after the education, and also, a weblog (www.zendegi-ba-saratan.blogfa.com)

that was designed by the researchers was introduced to them where they could access further information. At this weblog, we presented a lot of information about cancer, types of cancer, treatment of cancer, prognosis and managing cancer, living with a cancer parent, coping with cancer, its complications, and also confronting with death. Descriptive statistics like frequency, mean, and standard deviation, and also paired sample *t*-test were used for analyzing data by SPSS (ver 16) software of International Business Machines Corporation (IBM) and the significance level of *P* value was 0.05.

RESULTS

The findings of this study showed the following: the subjects were in the age group 11–20, most of them were girls, school students, and the birthrate of them was from one to six [Table 1].

Paired sample *t*-test showed that before and after presenting the program, there were no statistical differences between role limitation due to physical health and role limitation due to emotional problems, but there were significant statistical differences between physical functioning, energy/fatigue, emotional well-being, social functioning, pain, general health, the subcategory of physical health, and the subcategory of psychological health [Table 2].

The findings also showed that before presenting the program, there were significant statistical differences in general health ($P = 0.024$) by knowledge and general health by birthrate ($P = 0.018$) and after presenting

the program, significant differences were found in social functioning ($P = 0.011$) and the subcategory of psychological health ($P = 0.035$) by sex, and energy/fatigue ($P = 0.016$), emotional well-being ($P = 0.006$), social functioning ($P = 0.001$), general health ($P = 0.014$), the subcategory of physical health ($P = 0.010$), and the subcategory of psychological health ($P = 0.001$) by knowledge.

Before presenting the program, the subcategory of psychological health ($P = 0.049$) and after presenting the program, the subcategories of physical health ($P = 0.002$) and psychological health ($P = 0.004$) had significant statistical differences by knowledge. All of these aspects showed an increase in scores.

DISCUSSION

The present study is the first project in Iran that directs attentions toward the effects of supportive-educative program on the quality of life in adolescents whose parents were diagnosed with cancer during the last year. The main goal of the study was to investigate the quality of life of adolescents before and after presenting the program. The results showed that before presenting the program, the quality of life scores of adolescents in many aspects like physical functioning, role limitation due to physical health, role limitation due to emotional problems, and pain were in good range and near 100. This finding that families with a parent with cancer may experience more positive family functioning than normal families had been noticed in some other researches also, thus supporting our research.^[23,24] In some aspects like energy/fatigue, the score of samples was about 56 and in emotional well-being, it was about 57, which were in the middle range. Huang and colleagues (2014) stated, “Many children described reduced energy, emotional vulnerability and negative behaviors of the ill parents,”^[25] which is in line with our findings, but contrast to the reports of Gazendam-Donofrio *et al.* and Ainuddin *et al.*, where they had not noticed a decrease in adolescents’ emotional functioning.^[23,26]

In Iran, the structure of families is very tightly knitted; therefore, when one of the members in a family confronts a disease, other members pay more attention to the patient and to each other as well. This might be the main reason why there is more positive functioning in many aspects, and perhaps for this special reason, we had not noticed apparent changes before presenting our program. On the other hand, because of this special care and uneasiness, their stress, fear about the disease, its treatments, complications, and its prognosis would increase and the adolescents would experience many problems, and consequently, this will have serious effects on some aspects of their quality of life such as like emotional well-being and energy/fatigue.

Table 1: Demographic characteristics of the subjects

	Frequency	Valid percentage	Cumulative percentage
Age	Mean=15.80	SD=2.747	Variance=7.545
Sex			
Boy	13	43.3	43.3
Girl	17	56.7	100
Level of education			
School student	19	63.3	63.3
Diploma	3	10.0	73.3
University student	8	26.7	100
Birthrate			
1	8	26.7	26.7
2	8	26.7	53.3
3	9	30.0	83.3
4	2	6.7	90.0
5	2	6.7	96.7
6	1	3.3	100

SD: Standard deviation

Table 2: Paired t-test between aspects of quality of life before and after presenting the program

Dimensions of quality of life	Before presenting		After presenting		Paired t-test	Sig (2-tailed)
	Mean	SD	Mean	SD		
Physical functioning	93.66	9.55	98.33	6.47	-2.60	0.01
Role limitation due to physical health	92.50	22.88	99.16	4.56	-1.61	0.11
Role limitation due to psychosocial health	92.22	24.26	97.77	12.17	-1.40	0.16
Energy/fatigue	56.16	12.50	68.83	9.25	-6.32	0.0001
Emotional well-being	57.33	17.49	67.33	14.13	-4.16	0.0001
Social functioning	77.08	20.78	89.58	18.30	-3.57	0.001
Pain	89.08	13.52	97.75	6.20	-3.99	0.0001
General health	66.87	23.90	76.00	19.97	-2.57	0.01
Subcategory of physical health	85.53	12.51	92.81	6.97	-4.00	0.0001
Subcategory of psychological health	70.70	15.20	80.88	10.43	-5.18	0.0001

SD: Standard deviation

Our findings showed that there were no differences between age, sex, knowledge, birthrate, and the subcategories of physical health and psychological health before presenting the program. This is contrary to some other researches in which it was asserted that quality of life of female adolescents was more affected than that of male adolescents.^[6,26] Of course keeping in view the small sample of this research, this finding should be considered cautiously and supported by other studies with larger sample size.

The results showed that after presenting the program, all aspects of quality of life had an increase in scores, and in many aspects, this increase showed significant statistical differences. This finding showed that our program could enhance the aspects of quality of life. Visser *et al.*, in a review of literature, stated that intervention studies were aimed to help family members to communicate more openly with each other and to increase their coping strategies. All papers reported positive effects of the interventions, including less anxiety and more open communication.^[6] Since our supportive-educative program emphasized on open communication and coping strategies in families facing cancer, this might be the reason for the increase in scores of quality of life, although the elapse of time and increased coping of adolescents with their parents' cancer could be some other reasons.

The finding that the level of education of adolescents could be a factor accounting for the differences in the subcategories of physical and psychological health has not been mentioned in other researches.

The limitation of this study, which did not affect its main findings but had a bearing on how they are interpreted, that needs to be taken into account is that many parents were afraid of the emotional distress of their adolescents, or believed that the effects of cancer were small because minimal treatment was needed. Some others mentioned

that their adolescent children were not informed about the diagnosis and did not let them participate in this research. Therefore, the sample size was limited and the findings had minimum value for generalization to all adolescents living with a parent with cancer. Also, our small sample might have been one of the reasons affecting the results. On the other hand, the differences between samples in economic, social, and cultural aspects might have been the other limitations that could not be controlled by the research team.

CONCLUSIONS

The present results may heighten the awareness of health care providers that parental cancer may affect adolescents who live with them and the major problem of these adolescents is change in quality of life. Since references asserted that open communication between adolescents and their family and increasing coping strategies in adolescents can enhance the aspects of quality of life and our program had special emphasis on these issues, health care providers, especially nurses who are often well placed to initiate and facilitate the process of meeting these needs, should present these issues to the adolescents. The results of this study also showed that we need some special places in our hospitals for educating and supporting the adolescents who accompany their parents for their treatments, and also we need a planned program and special nurses for this in our cancer hospitals.

Adolescents who live with parents with cancer have many problems in their quality of life aspects; therefore, their parents must know about this and they should be educated about the ways that they can encounter this problem and help their children.

Of course, more studies are needed to investigate the effects of different programs for these adolescents, and this study

can be used as a basic research for nurses or other health professionals for further researches.

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