



## When your parents have cancer: adolescents' psychosocial aspects

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### ABSTRACT

Adolescents, whose parents have cancer, may manifest their distress through changes in school performance, physical complaints of pain and discomfort, as well as changes in social and interpersonal relations. In Asian's tightly-knitted families this matter would be very severe. There has been very little research about the effects of cancer on adolescents in Iran, so the purpose of this study was to explore the Iranian adolescents' experiences about living a parent with cancer. The present study is a quantitative part of a mixed method research with one group, pretest-posttest design. The sample of this study was 30 adolescents. A supportive-educative program was presented to them and one month later the effect of this program was examined by DASS-21 questionnaire. T-test showed that the mean of depression, stress and anxiety had significant statistical differences before and after the program's presentation ( $p=0.0001$ ). Also, before and after presenting program, there were significant statistical differences in some aspects of quality of life like physical functioning ( $p=.014$ ), energy/fatigue ( $p=.000$ ), emotional well-being ( $p=.0001$ ), social functioning ( $p=.001$ ), pain ( $p=.0001$ ), general health ( $p=.016$ ), subcategory of physical health ( $p=.0001$ ) and subcategory of psychological health ( $p=.0001$ ). Our research asserted that, in Iran because of families' structure, the adolescents who live with parents having cancer, have many psychological problems like stress, anxiety, depression and changes in quality of life due to lack of information about cancer and support from others, therefore presenting a supportive-educative program for them could reduce these factors.

**Keywords:** Adolescent; Neoplasm; Parents; Psychosocial aspects

### INTRODUCTION

The impact of cancer on an individual is invariably a profound and life-changing experience, with the consequences frequently continuing long beyond the initial period of treatment. The impact of this disease on the family and friends of someone with cancer may be equally disturbing, but perhaps harder to recognize or know how to support[1]. The diagnosis of cancer in a parent triggers psychological and social pressure in children. Children and adolescents are severely impacted by a parent's cancer diagnosis in all domains of child functioning, in particular emotional well being[2]. Adolescents may be more at risk than younger children for becoming distressed as they are old enough to be aware of the situation and understand what the parent is going through and outcoming issues that may arise. Between 20-32% 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[3].

Adolescents are considered to be the group most susceptible to negative psychosocial outcomes when faced with a parent's illness[4]. 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[5]. Adolescents may experience stress when confronted with the symptoms of the illness, the consequences and side effects of the treatments, and the threat of a parent's death. Alteration in daily family routines due to hospital visits and admissions can also be stressful for adolescents who may manifest such stress in increased levels of emotional and behavioral problems[6]. Adolescents, in general, are under constant pressures, 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 were needed at home both emotionally and physically[7]. limited attention has been paid to the effects on adolescents when a parent is diagnosed with cancer[2], furthermore adolescents with different cultural backgrounds may react differently. Earlier studies found that children in an American norm group had significantly more emotional and behavioral problems than children in a Dutch norm group[8]. May be, in some cultures like Iranian's culture in which family relationships are very strong, there will be differences at this issue. Iranian adolescents are reliant on their parents more than other countries such as western countries. There has been very little research about the effects of cancer on adolescents in this country and the current knowledge on this topic is mainly based on American and British researches. Therefore researchers decided to evaluate this issue and after that, they plan to evaluate the effects of their proposed program on aspects of quality of life of these adolescents.

### ***Aims***

The purposes of this study were to investigate the psychosocial aspects of Iranian's adolescents who have a parent with cancer and also offering a supportive-educative program based on socio-cultural aspects and after that comparing the effects of this program on reducing the psychosocial problems of these adolescents.

## **MATERIALS AND METHODS**

This is a report of quantitative part from a mixed method research. At this phase of research we used quasi-experimental, one group, pretest-posttest design. Pretest-posttest designs are widely used in behavioral research, primarily for the purpose of comparing groups and/or measuring change resulting from experimental treatments [9]. We used convenience sampling. The samples of this study were 30 adolescents at the age of 11-20, without history of depression, stress or anxiety before their parent's cancer and now living with a parent who had cancer at the first year of diagnosis and he/she was at the stage of chemotherapy or radiation therapy, with no metastasis of this cancer. The exclusion criterion was the unwillingness of samples at any time of research. To attain this sample we spoke to 113 patients who had cancer and adolescents at home, only 43 of them let their children join the research and from this 43 adolescents, 30 adolescents completed both pretest and posttest questionnaires (response rate 69.76%).

The medical ethics committee of the 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 parent of adolescents who were not in adult's range before completing the first questionnaire and they were free to withdraw from the study at any time.

The gathering data tools were the Iranian translation of a short form of depression, anxiety and stress scale (DASS-21) questionnaire and the Iranian translation of a short form of quality of life (SF-36 questionnaire). DASS-21 questionnaire had a good validity and reliability (Cronbach's alpha 0/78 for depression, 0/74 for anxiety and 0/80 for stress). This questionnaire contained 21 questions and each part of depression, stress and anxiety 14 questions that could get 0 to 42 score. The scores 5-6 for depression, 8-9 for stress and 4-5 for anxiety showed the mild level, scores 7-10 for depression, 10-12 for stress and 6-7 for anxiety showed moderate level, the scores 11-13 for depression, 13-16 for stress and 8-9 for anxiety showed severe and the scores +14 for depression, +17 for stress and +10 for anxiety showed the extremely severe range [10]. Also, SF-36 questionnaire had been used many times in Iranian's researches and had a good validity and reliability[11]. This questionnaire contained 36 questions, 10 in physical functioning, 4 in role limitation due to physical health, 3 in role limitation due to emotional problems, 4 in energy/fatigue, 5 in emotional well being, 2 in social functioning, 2 in pain, 5 in general health. One question was not considered in any aspect. All of the questions were scored on a scale from 0 to 100 with 100 representing the highest level of functioning possible[12]

The questionnaires were completed at the hospitals or adolescents' home before and one month after presenting supportive-educative program. All the samples completed the pretest questionnaire at the two major oncology

hospitals or adolescents' home separately. The supportive-educative program was presented individually at the home of adolescents at least in 2 sessions up to four sessions depending on adolescent's needs. Each session lasted about 45 to 90 minutes. A team organized by a psycho-oncologist, an oncology nurse, a psychiatrist and one of the researchers incorporated for presenting the program. We used face to face instruction for each adolescent. The parents were not present in the education program in the first session, but if we noticed that it was necessary to explain some items at their presence, we asked them take part in the second or third sessions. After one month the posttest questionnaire was completed at the adolescents' home or by calling one of them to complete the questionnaire. If the scores of posttest questionnaire had shown the high level of depression, anxiety or stress, or many changes in quality of life's aspects, the sample was introduced to one of the researcher team that who was a psychiatrist for additional supportive or treatment program. Supportive- educative program was extracted from some references, similar programs like Kids Inquire, We Inform (KIWI) or Kids Can Cope (KCC) and by consulting the oncologist and onco-psychologist and oncology nurses[13-17]. A booklet and compact disc of this program was given to the adolescents after the education and also for further information a weblog ([www.zendegi-ba-saratan.blogfa.com](http://www.zendegi-ba-saratan.blogfa.com)) that was designed by researchers was introduced to them. At this weblog we presented a lot of information about cancer, types of cancer, treatment of cancer, prognosis and managing cancer, living with cancer parent, coping with cancer, its complications and also confronting with death. By the chat room of this weblog the adolescents could talk together about their problems, and some of them used this chat room for assisting and cooperating with each other. The supporting group organized by a psychiatrist and a psycho-oncologist helped the adolescents who needed support at some issues and the researcher's cell phone was also given to all of the adolescents for answering their questions at any time. Descriptive statistic like frequency, mean and standard deviation and also paired sample T-test and ANOVA were used for analyzing data by S.P.S.S (ver16) software.

## RESULTS

**Table1- Demographic characteristics of samples**

	Frequency	Valid Percent	Cumulative Percent
<b>Age</b>			
<b>11</b>	2	6.7	6.7
<b>12</b>	2	6.7	13.3
<b>13</b>	4	13.3	26.7
<b>14</b>	2	6.7	33.3
<b>15</b>	3	10.0	43.3
<b>16</b>	4	13.3	56.7
<b>17</b>	4	13.3	70
<b>18</b>	3	10.0	80
<b>19</b>	3	10.0	90
<b>20</b>	3	10.0	100
<b>Mean=15.80</b>	<b>Std Deviation= 2.747</b>	<b>Variance=7.545</b>	
<b>Sex</b>			
<b>Boy</b>	13	43.3	43.3
<b>Girl</b>	17	56.7	100
<b>Knowledge</b>			
<b>School student</b>	19	63.3	63.3
<b>Diploma</b>	3	10.0	73.3
<b>University student</b>	8	26.7	100
<b>Birthrate</b>			
<b>1</b>	8	26.7	26.7
<b>2</b>	8	26.7	53.3
<b>3</b>	9	30.0	83.3
<b>4</b>	2	6.7	90.0
<b>5</b>	2	6.7	96.7
<b>6</b>	1	3.3	100

The findings of this study showed that the samples were at the age 11-20 with mean 15.80( $\pm 2.747$ ) that 13(43.3%) of them were boys and 17(56.7%) of them were girls. Most of them were school students [19(63.3%)] and the birthrate of them were from 1 to 6 (Table 1). In the pretest phase 4(13.3%) of adolescents in depression, 13(43.3%) in stress and 3(10%) in anxiety were in the normal range and 11(36.5%) in depression, 4(13.3%) in stress and 18(60%) in anxiety were in the extremely severe range. But in the posttest phase 14(46.7%) in depression, 22(73.3%) in stress and 12(40%) in anxiety were in normal range and 3(9.9%) in depression, 1(3.3%) in stress and 8(26.7%) in anxiety were in extremely severe range. In the pretest phase the mean of depression was 12.03( $\pm 7.77$ ), the mean of stress was

10.33( $\pm 7.40$ ) and the mean of anxiety was 13.70( $\pm 8.47$ ) and at the posttest phase there were 6.16 ( $\pm 6.36$ ) for depression, 5.60( $\pm 5.23$ ) for stress and 6.56( $\pm 6.30$ ) for anxiety. The paired sample T-test showed the statistical significant differences between pretest and posttest depression, stress and anxiety mean (Table 2). There were no significant statistical differences between age, sex, education level, birthrate of samples and depression, stress and anxiety in pretest and posttest (Table3).

**Table 2- Depression, stress and anxiety before and after presenting supportive-educative program**

pair	Paired Differences					t	df	Sig(2-tailed)
	Mean	Std.Deviation	Std.Error Mean	95% Confidence interval of the difference				
				Lower	Upper			
depression	5.86667	6.46867	1.18101	3.45123	8.28211	4.967	29	.000
Stress	4.73333	6.59118	1.20338	2.27215	7.19452	3.933	29	.000
Anxiety	7.13333	7.07952	1.29254	4.48980	9.77687	5.519	29	.000

**Table 3- Analysis of Variance of Depression, Stress and Anxiety pre and post of presenting supportive-educative program**

	Depression1		Depression2		Stress1		Stress2		Anxiety1		Anxiety2	
	f	sig	f	sig	F	sig	f	sig	f	sig	f	sig
age	1.525	.240	1.185	.362	.625	.818	1.041	.454	1.150	.417	1.589	.360
sex	.739	.725	1.189	.359	.681	.772	.523	.863	.675	.778	.586	.806
knowledge	1.347	.312	1.240	.331	1.165	.402	.762	.671	1.220	.377	1.000	.477
Birth rate	1.475	.258	1.273	.333	1.323	.316	.970	.504	2.067	.110	1.389	.258

In the investigation of quality of life, paired sample T-test showed that, before and after presenting program there were no statistical differences between role limitation due to physical health ( $p = .118$ ), and role limitation due to emotional problems ( $p = .169$ ), but there were significant statistical differences between physical functioning ( $p = .014$ ), energy/fatigue ( $p = .000$ ), emotional well being ( $p = .000$ ), social functioning ( $p = .001$ ), pain ( $p = .000$ ), general health ( $p = .016$ ), subcategory of physical health ( $p = .000$ ) and subcategory of psychological health ( $p = .000$ )(Table 4).

**Table 4- Paired T-test between aspects of quality of life before and after presenting Program**

pair	Before presenting		After presenting		t	df	Sig (2-tailed)
	Mean before	Std. Deviation	Mean after	Std. Deviation			
Physical functioning	93.6667	9.55324	98.3333	6.47719	-2.603	29	.014
Role limitation due to physical health	92.5000	22.88464	99.1667	4.56435	-1.610	29	.118
Role limitation due to psychosocial health	92.2222	24.26440	97.7778	12.17161	-1.409	29	.169
Energy/fatigue	56.1667	12.50402	68.8333	9.25532	-6.327	29	.000
Emotional well being	57.3333	17.49351	67.3333	14.13563	-4.165	29	.000
Social functioning	77.0833	20.78299	89.5833	18.30163	-3.577	29	.001
pain	89.0833	13.52653	97.7500	6.20588	-3.994	29	.000
General health	66.8750	23.90658	76.0000	19.97412	-2.570	29	.016
Subcategory of physical health	85.5312	12.51350	92.8125	6.97855	-4.007	29	.000
Subcategory of psychological health	70.7014	15.20811	80.8819	10.43602	-5.189	29	.000

The finding also showed that before presenting program there were significant statistical differences between general health by age ( $p = .080$ ) subcategory of psychological health by sex ( $p = .075$ ), energy/ fatigue ( $p = .056$ ), social functioning ( $p = .067$ ), general health ( $p = .024$ ), subcategory of physical health ( $p = .094$ ) and subcategory of psychological health ( $p = .055$ ) by knowledge, general health by birthrate ( $p = .018$ ) and after presenting program social functioning ( $p = .011$ ) and subcategory of psychological health ( $p = .035$ ) by sex, general health ( $p = .068$ ), subcategory of physical health ( $p = .095$ ) by age, physical functioning ( $p = .060$ ), energy/fatigue ( $p = .016$ ), emotional well being ( $p = .006$ ), social functioning ( $p = .001$ ), general health ( $p = .014$ ) subcategory of physical health ( $p = .014$ ) and subcategory of psychological health ( $p = .001$ ) by knowledge, and general health by birthrate ( $p = .062$ ). Subcategory of psychological health before presenting program ( $p = .049$ ) and subcategories of physical health ( $p = .002$ ) and psychological health ( $p = .004$ ) after presenting program had significant statistical differences by knowledge.

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## DISCUSSION

The present study is the first project in Iran that directs attentions towards the problems of adolescents whose parents were diagnosed with cancer during the last year and also the effects of supportive-educative program on psychosocial aspect of these adolescents. The goal of the study at the quantitative phase was to investigate depression, stress, anxiety and aspects of quality of life in adolescents before and after presenting the program and comparing them.

The results showed that before presenting program, depression, stress and anxiety in some adolescents, were at severe to extremely severe range and there were no statistical significant differences between their age, sex, education and birthrate. This finding that adolescents who have a parent with cancer face many psychological problems was similar to some previous studies [2,3, 6].

Some previous researches had shown that there were differences between sex and that daughters had more problems in these aspects [18, 19], but in our research the findings showed no difference between sex. Cultural aspects of Iranian families might have been the reason for this difference. In spite of many countries, Iranian adolescents regardless of sex usually live with their parents until they marry and they are very dependent on them, so they really get involved about their parents' cancer and this might have been another reason; we should also consider that with more samples we could have detected the gender effect more accurately. After presenting supportive-educative program, the mean of depression, stress and anxiety at severe to extremely severe range were rare in adolescents. There were significant statistical differences between pre and post results and it is supposed that supportive-educative program would be useful for reducing depression, stress and anxiety of these adolescents. This result is in line of similar researches [18].

The results showed that the quality of life of adolescents before presenting program 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 the 100. This matter that families with a parent with cancer may experience more positive family functioning than normal families had been noticed in some other researches and were in line with our research [3, 20]. In some aspects like energy/fatigue the score of samples was about 56 and in emotional well being it was about 57 that were in the middle range. Huang and colleagues (2014) stated that: "many children described reduced energy, emotional vulnerability and negative behaviors of the ill parents" [18] that it is in line with our findings, but in contrast to Gazendam-Donofrio et.al and Ainuddin et.al researches in which they had not noticed a decrease in adolescents' emotional functioning[3, 7].

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 will be more positive functioning in many aspects, and perhaps for this special case 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 will experience many problems, and this will have serious effects on some aspects of their quality of life, like emotional well-being and energy/fatigue.

Our finding showed that there were no differences between age, sex, knowledge, birthrate and subcategories of physical health and psychological health before presenting program, that it was in contrast with some other researches in which they asserted that quality of life of female adolescents was more affected than male adolescents [2, 7].

After presenting program the results showed that, all aspects of quality of life had an elevation in scores, and in many aspects this elevation had significant statistical differences. This issue showed that our program could enhance the aspects of quality of life. Visser and et.al (2004) in a review of literature research 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" [2]. Since, our supportive-educative program had emphasis on open communication and coping strategies in families facing cancer, this might the reason for elevation of the scores of quality of life, although the elapse of time and elevation of adolescents' coping with parent's cancer could be some other reasons. This issue that

level of education of adolescents could be an agent for differences in the subcategory of physical and psychological health was the issue that had not been mentioned in other researches.

Although many articles and references asserted that giving information and emotional support to children who had a parent with cancer could reduce their stress and other psychological problems like fear and anxiety [1, 8, 21-24] but they hadn't pointed to the subjects of this information and support and also there were not any supported research on this matter about Iranian's adolescents. Therefore, in our supportive-educative program, we focused on giving these information and also the ways that adolescents could use for coping with their parent's cancer. Our findings supported that our program could reduce anxiety, stress and depression, and also it had positive effects on aspects of quality of life, although the elapse of time and elevation of adolescents' coping with parent's cancer might have been some other reasons.

The limitation of this study, which does not affect its main findings, but bear on how they are interpreted, need 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 adolescents were not informed about the diagnosis, and did not let them to participate in this research. Therefore the sample was limited and the findings had minimum value for generalization to all adolescents living with a parent with cancer.

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