

Adolescents' Experiences When Living With a Parent With Cancer: A Qualitative Study

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Abstract

Background: Cancer affects not only the patient but also their entire family, especially adolescents. 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. There has been very little research about the effects of cancer on adolescents in Iran.

Objectives: The purpose of this qualitative study was to explore the Iranian adolescents' experiences when living with a parent with cancer.

Patients and Methods: In this research, the descriptive-exploratory approach was used. There were a total of 27 participants. Purposeful sampling was used and data collection methods were semi-structured deep interviews. Constant comparative analysis was used to study the data.

Results: The findings of this study showed that the main experiences of these adolescents were categorized into seven themes: 1- psychological problems of adolescents; 2- supportive-educative needs; 3- cancer as a two edged sword in family relationships; 4- stages of confrontation with the parent's cancer; 5- effect of cancer on social dimensions; 6- affective and helpful supportive agents; 7- Need of support for education under special conditions.

Conclusions: This research showed that Iranian adolescents had the same experiences as other adolescents in other countries in many aspects yet in some issues, such as religious strategy, they had strong religious beliefs that would help them cope with their parents' cancer. Also it was shown that we must plan a program in which education and support should be provided to enable adolescents to cope with this detrimental situation with minimal disruption.

Keywords: Adolescent, Neoplasms, Experience, Parents, Qualitative Research, Iran

1. Background

Cancer is one of the most challenging problems in developing countries. About half (51%) of cancer incidence worldwide was from developing countries in 1975. This proportion increased to 55% in 2007 and is expected to reach 61% by 2050. It was reported that cancer incidence rate in Iran is 98 to 100 per 100,000 population, annually (1).

Cancer affects not only the patient but also their entire family (2-5). Some references indicate that distress in family members is as great as or even greater than in the person, who has cancer (3, 6). It is normal for families of patients with cancer, to be upset and worried about this crisis. Families with young children or adolescents are often concerned about how children will react regarding the cancer of a family member. How a child reacts to cancer often depends on how their parents or other close adults handle the crisis. Kids learn through their parents' behavior (7, 8). Young children, who have a parent with cancer,

experience many changes, threats, feelings and responses. So far studies have shown that such children become anxious and may run into difficulties that affect their school life, sports, leisure activities, family life and relationships with friends (4, 9, 10).

Adolescents may be more at risk of distress than younger children as they are old enough to be aware of and understand what their parent is going through and have to cope with existential issues that may arise. Between 20% - 32% of adolescent boys and girls were reported to experience clinically elevated levels of emotional and behavioral problems throughout the first year after a parent was diagnosed with cancer (11).

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 (12).

A parent's cancer diagnosis impinges on a child's life by changing family routines, altering parent-child interactions, giving the child additional responsibilities, elicit-

ing a fear of potential parental death and increasing vulnerability, which add to already difficult developmental issues. Children respond differently to the stressors associated with their parent's illness (13).

The impact of cancer on patient's psychosocial functioning has received considerable attention in the literature during the past two decades. A growing number of studies have addressed the psychosocial consequences for the spouse. However, limited attention has been paid to the effects on children when a parent is diagnosed with cancer (14), considering that children 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 (10). Perhaps, in some cultures like the Iranian culture in which family relationships are very strong, there will be differences regarding this issue. Iranian adolescents are reliant on their parents more than other countries, such as western countries. Emotional support may be easily obtained through other family members, friends and communities, especially religious networks, which are available everywhere. Social support allows them to discuss their negative feelings, worries and anxieties; thereby they would experience different aspects regarding this issue.

2. Objectives

There has been very little research about the effects of cancer on adolescents in Iran. The current knowledge on this topic is mainly based on American and British researches, so the purpose of this study was to gain more insight into the psychosocial consequences for Iranian adolescents, who have a parent with cancer.

3. Patients and Methods

The aim of this qualitative study was to explore the Iranian adolescents' experiences about having a parent with cancer. For this purpose, the qualitative approach was used. This approach is particularly appropriate for areas where nurses have little theoretical or practical knowledge (15-19).

The medical ethics committee of Isfahan university approved the study with the following identification number; 392256. 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 younger than 18, before each interview and they were free to withdraw from the study at any time.

Participants were sixteen adolescents (ten females and six males). The inclusion criteria for these adolescents were being aged 11 to 20 (adolescent ages according to Hockenbery and Wilson) (20) and living with the parent who had cancer at the chemotherapy or radiation therapy phase. This study was performed during the chemotherapy or radiation therapy phase of cancer as this is the time of particular pressure and frequent hospital visits, physical side effects of treatment (including alopecia, nausea and emesis and fatigue), loss of family income through parent's absence from work and disruption to family routines (21). Children who were the caregiver of their parents and also those who had parents with metastatic cancer were excluded. For further information we interviewed three nurses of the oncology wards, two oncologists, both parents, one friend of the adolescent, one teacher, one psycho-oncologist and one social worker (Table 1).

We used convenience purposeful sampling. Data were collected and tape-recorded through semi-structured in-depth interviews. Interviews were done at two main cancer centers, oncologist's clinic, chemotherapy clinic and public places such as a park and the home of patients based on participants' preference, from April to October 2014.

The interviewer was one of the researchers who was a nursing PHD candidate and attended a qualitative research workshop and did assignments about qualitative research and was familiar with interview techniques.

The first participant was a girl whose mother had uterus cancer and she was a relative of one of the researchers. For adolescents, each interview began with an open question, "Please tell me about your family and your life." The next question was, "Please tell me about your experiences or changes that occurred after your parent was diagnosed with cancer", and according to the answers, some clarifying questions were asked. All adolescents were aware of their parent's diagnosis. The parents weren't present at the time of adolescents' interview and if a family had two participating children, they were interviewed separately. For the other participants the main question was, "In your opinion, what is the effect(s) of cancer on adolescents' behavior and life?" The length of the interviews was 10 to 60 minutes. Data collection continued until no new information emerged. Data saturation was achieved through 27 interviews.

Constant comparative analysis was used to study the data. The interviews were transcribed verbatim and analyzed concurrently with data collection. Coding was carried out line by line, and comparative analysis of the excerpts was performed in two phases. In the first phase, categories and themes in the data were identified and grouped into domains. The coding process was iterative, and categories and themes evolved (added, deleted and merged)

Table 1. Participants' Characteristics ^a

Participant's Number	Gender	Age	Relationship With the Patient	Type of Cancer	Birth Rate
1	F	20	Daughter (mother)	Uterus	5.7
2	F	18	Daughter (father)	Intestine	1.1
3	M	12	Son (mother)	Breast	6.6
4	F	19	Daughter (mother)	Kidney	1.2
5	M	14	Son (father)	Intestine	3.3
6	M	16	Son (father)	Intestine	2.3
7	F	13	Daughter (mother)	Breast	3.3
8	M	15	Son (father)	Larynx	2.2
9	F	20	Daughter (mother)	Lymph node	1.2
10	M	16	Son (mother)	Breast	4.5
11	F	19	Daughter (father)	Colon	2.2
12	F	15	Daughter (mother)	Breast	3.3
13	M	19	Son (mother)	Breast	2.2
14	F	14	Daughter (mother)	Ovaries	3.4
15	F	12	Daughter (mother)	Chest	2.2
16	F	24	Nurse	NA	NA
17	F	34	Parent (patient)	(Chest)	NA
18	F	52	Nurse	NA	NA
19	M	54	Nurse	NA	NA
20	M	45	Social worker	NA	NA
21	M	68	Parent (spouse)	(Breast)	NA
22	M	42	Oncologist	NA	NA
23	M	50	Oncologist	NA	NA
24	F	20	Daughter (mother)	Breast	3.3
25	F	20	Friend	NA	NA
26	F	45	Psychiatrist	NA	NA
27	F	42	Teacher	NA	NA

Abbreviations: F, female; M, male; NA, not available.

^aN=27.

as re-readings were completed and analyses progressed. In the second phase, the categories and domains were re-grouped into major themes. During the data analysis, two more researchers were involved to enhance the data interpretation. Transcripts were read to confirm the coding and categories and check the primary researcher's interpretations. Some of the participants were contacted after the data analysis and given a full transcript of their coded interviews to determine whether they were accurate according to their experiences.

According to Streubert Speziale et al. (2011), credibility was enhanced through member checking, validation of

emerging codes and categories in subsequent interviews, and debriefing with two supervisors. Transferability was enhanced by thoroughly describing the research context and the assumptions that were central to the research. Peer checking and maximum variation of sampling attested to the confirmability and dependability of the findings (22).

4. Results

The findings of this study showed that the main experiences of adolescents having a parent with cancer could

be categorized into seven themes: 1- psychological problems of adolescents; 2- supportive-educative needs; 3- cancer as a two edged sword in family relationships; 4- stages of confrontation with the parent's cancer; 5- effect of cancer on social dimensions; 6- affective and helpful supportive agents; 7- need of support for education under special conditions (Table 2).

Table 2. Frequency and Percentage of Themes

	Theme	Frequency Percentage of Codes
1	Psychological problems of adolescents	(36.00) 311
2	Supportive-educative needs	(18.40) 159
3	Cancer as a two-edged sword in family relationships	(13.54) 117
4	Stages of confrontation with the parent's cancer	(11.34) 98
5	Effect of cancer on social dimensions	(8.91) 77
6	Affective and helpful supportive agents	(6.37) 55
7	Need of support for education under special conditions	(5.44) 47
Sum	NA	(100.00) 864

Abbreviation: NA, not available.

4.1. Psychological Problems of Adolescents

One of the most important experiences of adolescents was psychological problems, which were divided into four interrelated subthemes: 1- negative feelings, 2- confused mind, 3- sign and symptoms of psychological problems, and 4- stress, anxiety, fear, and worry.

In this research, adolescents had feelings such as loneliness, loss of support, depression, lack of protection, disability, guilt, and identity disorder. For example, one of the participants stated, "I think if my father dies, I'll have nobody else." (p11), "I can't do anything" (p13).

Bewilderment, emotional involvement, nervousness and thoughts of adolescents about parent's disease were the other indications expressed by most participants. For example, one of the cases stated, "My brain doesn't work." (p9), while another said "I am bewildered; I don't know what I should do for my mom." (p24)

Almost all the adolescents of this research spoke about depression, impatience, changes in sleep pattern, changes in appetite, social isolation, aggression and other aspects of psychological problems' sign and symptoms. Some recorded phrases in this regard were as follows, "I am in my own world, I don't want to speak with anyone, and I want

to be lonely" (p6), or "Every time my mom wants to go to the hospital I hug her and I cry" (p12).

The fear of parent's death, fear of the future, stress about the disease and its progress, worry and anxiety about incompetence of treatment, fear and stress of the adolescent about being attacked by cancer in the future were the main experiences of the adolescents regarding this issue.

"I fear", (interviewer: "Of what?"), she answers in a very low voice: "Death of my mom" (p15), "I didn't sleep that night, I cried till the morning, I thought, if my mom dies, what will happen? I had so much stress at the hospital. I stood near her bed and looked at her each minute during the night till the morning, I was stressed" (p24).

4.2. Supportive-Educative Needs

Supportive-educative needs were one of the most noticeable issues of the adolescents. For example, one participant said, "Please tell me about cancer and about its prognosis, I don't know about its treatment, who can cope with cancer and so on" (p1). Another participant said: "They (adolescents) need to know about the disease, how this disease can grow, and the role of genetics in this disease, about the issues that we can and can't control regarding cancer, about stress and how it could be controlled. They need a supportive program for their psychosocial problems" (p26).

"First you must familiarize us with this disease so that we know how this disease affects adolescents and their lives, and then we should learn how to speak with these children and what we can tell them about this matter" (p27).

4.3. Cancer as a Two Edged Sword in Family Relationships

Some of the participants believed that cancer had a negative effect on family relationships; the following are some examples of what the participants said in the interviews, "Since my mom has faced cancer, our family relationship has been worse than before; my mom is in a bad mood, therefore, she argues with us and we prefer to go out than to stay at home" (p10), "Nobody asks me what I have been doing? Nobody asks what do you eat? Or what do you wear? Or where have you been? Before the disease of my father when I was late, everybody asked me about it, but now I am ignored at home. Cancer changes the family" (p11).

On the other hand some participants believed that cancer could be a positive agent in family relationships. "Before the cancer of my mom, my father and my mother had a bad relationship with each other. They had many challenges with each other and every day there were many quarrels at home, but after my mom got cancer, everything has changed; now my dad cares about my mom and they

are at peace. I think cancer can change the family positively” (p4).

Some participants stated that their children became more attentive after they were diagnosed with cancer. “Since I got cancer, my daughter has become very sensitive with me, when I cough, she runs hurriedly towards me, asking, “What is the problem?”” (p13).

4.4. Stages of Confrontation With the Parent’s Cancer

This theme was divided into four interrelated sub-themes: 1- primary confrontation with cancer diagnosis, 2- denial of cancer, 3- considering cancer as a destructive agent, 4- adaptation by the passage of time. These sub-themes showed that confrontation with the parent’s cancer was a process similar to the mourning process. At first, the adolescents are shocked about parent’s cancer and after that they will deny it but by the passage of time, they notice that they must accept this disease and will adapt to it.

Participant number five, whose father was in the hospital for the first time for chemotherapy stated that: “I don’t want to know about it (father’s disease), I just want this disease go and pass”. However participant number nine whose mother was on radiation therapy stated that: “At first when she lost her hair it was so scary, I feared to look at her, I couldn’t believe that my mother is in this form, I was afraid of her, but now it is normal for me.”

4.5. Effect of Cancer on Social Dimensions

This theme was divided into three subthemes; 1- cancer as a disrupter of life order, 2- cancer as a disrupter of family economy, and 3- cancer as an agent, which gives adolescents new roles. “In the past, I was seldom at home, I was with my friends, I didn’t think about home and its tasks, but now that my mother is sick, I must be at home all day and do the shopping. I have no time for myself” (p13).

“When my dad was diagnosed with cancer, he couldn’t go to work, and then my brother and I had to work and earn money for his treatment” (p6). “I must wash the dishes, sweep the floor, and all the work that my mom can’t do” (p24).

4.6. Affective and Helpful Supportive Agents

The participants believed that there are agents that could help them face cancer. They were categorized in three groups: 1- friends and close families, 2- hospital staff, and 3- religious strategies. For example they said that; “I have prayed for her, this calms me” (p7). “The health workers in hospitals are like firefighters, they can fight against cancer that is ruinous and burns life” (p9).

4.7. Need of Support for Education Under Special Conditions

Most of the adolescents expressed that they had difficulties at their school because of their parents’ disease and almost all of them mentioned that their teachers and the staff of their schools didn’t understand their condition. One participant said: “At first when my mom had surgery, I didn’t go to school for some days. Our exams were when my mother had chemotherapy; therefore, I didn’t pass my exams well. I was a good student last year and my mean was 18 but this year it was 16” (p10). Another participant said: “This year my mean was 15, our teacher asked me why? I told him that my father has laryngeal cancer, but he said: you should pay more attention during class. He doesn’t understand me and my condition” (p8).

5. Discussion

This is the first qualitative study that has described Iranian adolescents’ experiences when living with a parent with cancer and highlights the important aspects of this issue. According to the findings, one of the most important aspects of adolescents’ experiences was the psychological aspect. The claim that cancer of parent will affect the psychological well-being of adolescents has been a very common finding of many researches (9, 11, 14, 23, 24). Helseth and Ulfsaet (2003) stated that: anxiety and depression symptoms were found to be higher in adolescents than in preadolescent children (9). This was confirmed by our study with the most important problem of Iranian adolescents being anxiety and depression symptoms.

Another aspect that the participants of this research were concerned with was supportive-educative needs. Many researches and guidelines for helping children who have a parent with cancer agree with that adolescents must have knowledge about cancer, its treatment and its complications, so that they propose a supportive-educative program for these children (6, 25-29). It is now understood that children have a greater potential to understand complex concepts of illness than many professionals had previously appreciated. Even if children are not told of the illness they soon become aware of changes in the atmosphere at home and in their parent’s health (30), thus it is recommended to solve this problem with a supportive-educative program. Clinicians are in the best position to explore the implication of illness in a knowledgeable and informed way to promote the well-being of adolescents (31).

The issue that cancer has paradox effects on family relationships has been noticed in some researches. Some researchers like Ohannessian (2007) stated that, families having a parent with cancer may experience more positive

family functioning than normal families (23), yet in some researches, the lack of consistent associations has been observed between adolescents-parent discrepancies and adolescents' adjustment (11). Our research showed this discrepancy for Iranian families. Therefore, clinicians must manage this discrepancy and help with family issues associated with cancer and augment positive relationships.

Our research showed that although Iranian adolescents describe cancer as a fatal disease, a life changer, bad disease, disrupter of life, an earthquake, a leech, scary disease and so on, yet with time, they can adapt to cancer and can help their parents manage it. Teens are old enough to know that their lives will greatly change due to their parent's illness and death, and they struggle to deal with this unmanageable treatment. They may cope in ways that may be seen as inappropriate by their parents, such as refusing to talk about the illness or trying to take control. Others may adapt, try to get closer to their parents, and try to restore order at home (32).

Regarding the effect of cancer on social dimensions, the findings of our research were the same as some previous studies, for example Watson et al. (2006) stated that: "Adolescents, who have a parent with cancer must change their lives. They must change their normal life style" (21). Their needs will be unfulfilled because the routine of everyday life is disturbed by treatment schedules and repeated hospital admission and visits. As a consequence, parents will not be able to give as much time and attention as usual to their children. Frequently, children and adolescents take over the parental tasks during the illness. These new responsibilities can reduce the time available for normal daily activities, or doing homework. Therefore, children of patients with cancer must also adapt to the new family situation (10, 28, 33-35).

Using religious strategies has not been investigated in other countries. However, Iran is an Islamic country and here people have strong religious beliefs, therefore religious strategies were used by some of the adolescents (2, 35-39).

Many researchers reported that school-aged children were unable to concentrate and complete assignments at school. Some adolescents showed a decline in school performance and attendance (13, 14, 37, 40). This further emphasizes the need of support for education under special conditions that was one of the findings of this research.

5.1. Conclusions

This qualitative study provides insight into adolescents' subjective world when a parent has cancer and thereby the adolescents' experiences were noticed. This research showed that Iranian adolescents who have a parent with cancer have the same experiences as other adoles-

cents in other countries in many aspects yet in some issues like religious strategy they had strong religious beliefs that are a positive agent for helping them cope with their parents' cancer and must be taken into consideration. This research also showed that, the healthcare team must plan a program in which education and support should be provided to enable adolescents experience this detrimental event with minimal disruption. They should also help them view life in a more positive way, and encourage them to revitalize their spiritual or religious beliefs by reading inspiring books or poetry and taking part in social welfare programs and support them with social and emotional issues. The experience of adolescents associated with cancer patients is still a relatively new research topic; further studies should be conducted to investigate adolescents' experiences when a parent has cancer.

The limitation of this study, which does not affect its main findings, but influence how they are interpreted, was 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 participate in this research, so the sample of this study was small. Due to the small sample size, the results cannot be generalized to similar populations. The maximum variation sampling method was used to minimize this problem.

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Footnote

Authors' Contribution: Mehrdad Azarbarzin: study concept and design, acquisition of data, analysis and interpretation of data, and drafting of the manuscript; Azadeh Malekian: study concept and design, analysis and interpretation of data, critical revision of the manuscript for important intellectual content and study supervision; Fariba Taleghani: study concept and design, acquisition of data, analysis and interpretation of data, critical revision of the manuscript for important intellectual content, and study supervision.

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