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ORIGINAL ARTICLE

Levels of unmet needs among adolescents and young adults (AYAs) impacted by parental cancer

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Abstract

Purpose In this study, we aim to assess types and levels of psychosocial needs in adolescents and young adults (AYAs) who have a parent with cancer. And define and describe the variables analyzing the demographic characteristics.

Methods This descriptive study with cross-sectional design was conducted on 217 participants from five hospitals in Tehran. By use of the "Offspring Cancer Needs Instrument," in adolescents and young adults who had the inclusion criteria, information about the psychosocial needs were collected. Also, a demographic questionnaire was completed by the participants. Mean and standard deviation calculated for each domain and overall scores. Independent *t* test and one-way ANOVA was used for the comparison of needs' mean and demographic variables.

Results Total scores' mean was 126 and among domains, the "information" got the highest and the "support from friends" the lowest mean. Among demographic variables, we found a relationship between parent education (p value = 0.007), treatment statue (p value = 0.015), parent gender (p value = 0.018), and parent-child relationship (p value = 0.027) with the level of psychosocial needs.

Conclusions In this target group of adolescents and young adults, the need for "information" is the strongest domain of psychosocial need during parent cancer trajectory.

Keywords Adolescent · Parents · Neoplasms · Psychology

Introduction

Cancer is one of the most serious diseases with a high incidence rate all over the word. Because of the plethora of risk factors such as unhealthy life style (smoking, lack of activity, unhealthy diet), occurrence of cancer is predicted to further increase in the next few decades [1]. In Iran, cancer is the third leading cause of death [2] and it is estimated that approximately 84,829 new cases and 53,350 cancer deaths occur annually in Iran [3]. A noticeable number of patients get their diagnosis of cancer happens at an age that they have dependent children [4–7].

Cancer in a parent is a potentially stressful event and besides the afflicted parent, the whole family will be distressed [8, 9]. Children of cancer patients are at risk for developing emotional, behavioral [10], and psychosocial problems [11]. Among children, the adolescents and young adults are at a higher risk for experiencing anxiety and depression [12] as they must also adapt to their developmental phase challenges. In many cases, their parents will rely on adolescents and young adults (AYAs) for practical and emotional assistance and offer less support to them than to the younger children [13–15]. Moreover, older children understand more about the consequences of their parent's disease. A number of psychosocial problems like anxiety/depression, confusion, sadness, anger, feelings of uncertainty, and loneliness are reported in this population [16]. Until up to 5 years after the parent's cancer diagnosis, adolescents suffer from post-traumatic stress symptoms [7, 13]. Over the first year, feelings of uncertainty [13] and helplessness remain high in children [17]. Uncertainty may also arise during the patient's transition to the follow-up phase [13].

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Not all AYAs affected by parental cancer need psychological interventions [12], so assessment and identifying self-expressed psychosocial needs will help to plan and provide targeted psychosocial intervention for those who have higher needs [18]. Psychosocial needs are defined as a desire or requirement for help or support imperative for a person's emotional and psychological wellbeing [19]. The kind of needs in AYAs with a parent with cancer is reported to include honest communication, receiving information about the cancer, help in coping with emotions, the need for their friends to understand them, support from other young people who have had similar experiences, and the need to be able to continue with their regular interests and activities [20].

Studies on psychosocial needs of children who have a parent with cancer have been executed mostly in developed countries. However, in a community with different types of family systems, religious/cultural attitudes and beliefs, and health care equipment, like the targeted community in this study, assessing the needs will be useful and essential. So, the objectives of the current study were to describe the proportions of needs reported in each domain by offspring and identify the needs reported as unmet by most offspring and to describe the relationship between these variables and demographic characteristics.

Methods

Setting and participants

In this descriptive study, inclusion criteria of the participants were being an adolescent or young adult between 12 and 24 years old that had a parent diagnosed with cancer of any type and at any stage in the previous 5 years. The AYAs themselves were not diagnosed by any chronic disease ever. The afflicted parent must be alive and the offspring living with him/her. All the participants had one parent diagnosed with cancer while the other parent had not been diagnosed, or died with cancer. Exclusion criteria were to fill out questionnaire incompletely witch happened only for two persons. The sick parents were under treatment or follow-up in one of the five referral hospitals in Tehran, Iran. The convenience sampling method was used. Sample size calculated by statistics methods as mentioned below.

Considering $\alpha = 0.05$, $z = 1.96$, $\sigma = 15$, and $d = 2$, sample size was calculated using statistic formula of $n = \frac{z^2_{\alpha/2}\sigma^2}{d^2}$.

Measures

The instrument, which is used for assessment of psychosocial needs in this study, was the Persian version of the "Offspring Cancer Needs Instrument (OCNI)," the first measuring tool which has been developed specifically for assessing psychosocial needs of adolescents and young people who have a parent with cancer. Translation to Persian and psychometric evaluation of this instrument was done by the current research group after receiving permission from the developer. Face and content validity evaluated using qualitative methods and some minor grammatical modifications were done to make the scale more readable for Persian population. Confirmatory factor analysis confirmed construct validity of the Persian version of the instrument and its seven subscales. Cronbach's alpha was 0.96 for the total instrument and 0.76–0.93 for its seven subscales. There are different reports about the acceptable values of alpha, ranging from 0.70 to 0.95 [21]. Intraclass correlation coefficient (ICC) calculated to evaluate the test-retest reliability, which was 0.83. Based on the 95% confidence interval of the ICC estimate, values less than 0.5, between 0.5 and 0.75, between 0.75 and 0.9, and more than 0.90 are indicative of poor, moderate, good, and excellent reliability, respectively [22]. The OCNI has 47 items in 7 domains (information 9 items, family issues 4 items, practical assistance 7 items, time out 5 items, feelings 13 items, support from friends 4 items, and support from other young people 5 items) and each item has 4 points (1, no need; 2, low need; 3, moderate need; 4, strong need). The possible scores are between 47 and 188, while higher scores stand for stronger needs. In addition, a 19-item questionnaire was completed by the participants on the demographic information (age, gender, job, and education statues) of the AYAs and their parents as well as the status of their illness and treatment.

Procedure

From the AYAs with a parent with definite diagnose of cancer at the selected hospitals for this study, those who had inclusion criteria were invited to participate in this study. AYAs completed the demographic and need questionnaires. AYAs that accompanied their parents to the hospital completed the questionnaires at the hospital, and for the AYAs of those who did not, we asked the parents to take the questionnaire to them. The completed questionnaires were later collected electronically or at subsequent treatment sessions of the parents. Electronically means with any contact ways such as email, fax, or applications that they could send us a file of completed questionnaires. AYAs could complete the questionnaires anywhere they were comfortable and they had as much time as they needed for completing these self-reporting questionnaires. One of the research team members was available to AYAs by phone or directly if there was any question or problem.

Ethical considerations

The study as well as the study method used was approved by ethics committee of Shahid Beheshti University of Medical Sciences. Permission for the translation and use of the instrument (OCNI) was obtained from the developers by means of an email form. All participants as well as their parents were informed about the reason, methods, and their role in study directly or by electronic ways. Written informed consent was taken from all the participants as well as the parents of the children younger than 18 years old. All the participants were already aware about the type of disease and volunteered to participate.

Statistical analyses

Data collected from the participants were analyzed by SPSS version 16. Mean and standard deviation were calculated for each domain and overall scores. Normality of data assessed and independent *t* test and one-way ANOVA was used for the comparison of mean and demographic variables. p value < 0.05 was considered statistically significant. Each domain's mean is divided in numbers of domain's items to be comparable with each other. Based on Patterson et al.'s study [20], the combination of moderate/strong is considered as unmet needs, and reported unmet needs are calculated for each item.

Results

Two hundred seventeen offspring impacted by parental cancer were recruited in the study (boys = 96, girls = 121). Demographic information is summarized in Table 1.

Based on results, 99.5% had one or more unmet need and 94.4% had ≥ 10 unmet needs. Table 2 shows the average mean proportion of unmet needs in each domain. All needs of the "Information" and "practical assistance" domains were unmet by more than 50% of offspring. Six unmet needs endorsed by more than 50% of offspring related to the feelings domain and three to the "family issues" and "time out" domains. All needs of the support from friends and support from other people endorsed by less than 50% of offspring.

Among the domains, the "information" got the highest (mean = 3.27) and the "support from friends" the lowest (mean = 2.19) scores (Table 2). Overall scores' mean was 126, and 172 individuals got scores more than half of maximum possible scores, which is 94. Numbers of AYAs who reported unmet needs for each items among a total of 217 are shown in Table 3. Among demographic variables, we found a relationship between parent's education (p value = 0.007), treatment statue (p value = 0.015), parent gender (p value = 0.018), and parent-child relationship (p value = 0.027) for the level of children's psychosocial needs.

Discussion

Overall level of unmet needs in the population of this study was higher than the amounts in the similar studies [12, 20]. Other studies on the unmet supportive needs of patients with cancer and their families in Iran show that they have a higher rate of unmet needs in domains of information, support, and health care in comparison with West populations [23, 24]. This could be as a result of the lack of a holistic, patient and family-centered care in Iran. Some sporadic activities to empower and support the patients [25–27] in Iran are reported which are focused only on patients, and based on our knowledge, there is no specific program to support the AYAs with a parent with cancer in Iran.

The results of the study support the similar studies using the same tool on other populations [12, 20] that information needs appeared to be as the most prevalent unmet needs of offspring with parental cancer. All the needs for information about cancer, treatments, side effects, and parent's condition seem to be very important for children and despite the improvement in accessibility to sources of information such as books and the internet, it remained unsatisfied. One of the reasons might be that the topic of cancer as a disastrous word [28] always is discussed very conservative between the members of a family and most of the AYAs were not included in the family discussions in this regard as a protective method. Therefore, the lack of information with the children can be the result of the parents' effort for keeping their children far from disease and their condition. This is concurrent with the results of similar studies on this population [29]. One of the obstacles in conducting this study was that the parents were reluctant to have their offspring participate because they thought this study might make their children overthink about the illness. However, it may hurt children if they think or understand that they have been excluded from something important in family [30]. On the other hand, for many reasons such as the lack of resources and a qualified system of support for patients with cancer in Iran, most of the parents affected by cancer do not get enough and proper information themselves. Normally, this lack of knowledge affects the amount of information their offspring will take. A connection has been found between children's level of anxiety and informing them about their parent's disease [31]. Other studies also found that the need for information, despite its importance for children, may stay unmet [32]. Children want detailed and comprehensive information from the moment that their parent gets the diagnosis and throughout the course of their parent's illness [33]. Children may hide their needs and feelings from parents because they are scared to distress them [31] but a valuable and trustworthy source of information for children

Table 1 Demographic characteristics of participating offspring and their family member with cancer ($n = 217$)

Child demographics information	Child gender	Child age	Child education	Child working status	Child sequence
	96 males (44.2%) 121 females (55.8%)	Early adolescences: 25 (11.5%) Middle adolescence: 56 (25.8%) Late adolescence: 75 (34.6%) Young adult: 61 (28.1%)	Primary: 9 (4.1%) Secondary: 33 (15.2%) High school: 89 (41%) University: 86 (39.7%)	Working: 36 (16.6%) Workless: 47 (21.7%) Student: 134 (61.7%)	First: 82 (37.8%) Middle: 43 (19.8%) Last: 92 (42.4%)
Sick parent demographics information	Parent gender	Parent age	Parent education	Parent marriage status	Parent working status
	Males: 55 (25.3%) Females: 162 (74.7%)	< 40: 24 (11.1%) 40–50: 119 (54.8%) 50–60: 62 (28.6%) > 60: 12 (5.5%)	Primary, secondary or high school: 110 (50.7%) Finished high school: 79 (36.4%) Bachelor: 23 (10.6%) Master and upper: 5 (2.3%)	Main parents living together: 201 (92.6%) Divorce: 6 (2.8%) Remarriage: 2 (0.9%) Other parent is dead: 8 (3.7%)	Workless: 180 (82.9%) Working: 37 (17.1%)
Family information	Child number	Family financial status	Problem in child-parent relationship		
	1–2: 110 (50.7%) 3–5: 90 (41.5%) > 5: 17 (7.8%)	Weak: 52 (24%) Moderate: 125 (57.6%) Good: 40 (18.4%)	Yes: 26 (12%) No: 191 (88%)		
Parent cancer information	Time from diagnosis (year)	Cancer diagnosis	Cancer type	Treatment status	Treatment type
	Less than 1 year: 138 (63.6%) 1–5 years: 79 (36.4%)	Primary: 171 (78.8%) Recurrent: 46 (21.2%)	Breast: 92 (42.4%) Colorectal: 30 (13.8%) Blood: 17 (7.8%) Lymph: 14 (6.5%) Stomach: 12 (5.5%) Brain: 11 (5.1%) Other types: 41 (19%)	Waiting to start: 13 (6%) Under treatment: 178 (82%) Finished: 26 (12%)	Chemotherapy: 70 (32.3%) Radiotherapy: 4 (1.8%) Surgery: 6 (2.8%) Combination of treatments: 127 (58.5%) Other treatments: 10 (4.6%)

Table 2 The OCNI domain structure, average proportion of unmet needs, standard deviation, mean, and mean/numbers of items in domain of needs reported by offspring ($n = 217$)

Domains (the number of items)	Average proportion of unmet needs (%)	Standard deviation	Mean	Mean/numbers of items in domain
1. Information (9)	79	6.2	29.46	3.27
2. Family issues (4)	61	3.5	10.87	2.71
3. Practical assistance (7)	64	6.0	19.95	2.85
4. Time out (5)	53	4.2	12.96	2.50
5. Feelings (13)	53	10.8	33.40	2.56
6. Support from friends (4)	37	3.7	8.77	2.19
7. Support from other young people (5)	42	4.8	11.44	2.28

could be the health care professional who can provide age-appropriate answers to their questions. So first, this need must be identified in individuals and then further interventions can be applied as required.

The levels of unmet needs in two domains of "support from friends" and "support from other young people" were lower in comparison with other domains. Also, these domains had the lowest percent of unmet needs between all domains. This can be explainable with considering some cultural differences. Other studies showed that in Iran, an informal social support network always is provided for patients with chronic or fatal diseases [34–36]. It is evidenced that social support in some ethnical groups is more than others [37–39]. Some studies suggest that social support predicts better children's outcomes [40].

The choice of demographic variables to be used in this study was based on previous researches on this issue whereby the psychosocial needs were deemed to be effectible by those variables. However, among them, we just found connections between parent education, treatment status, parent gender, and parent-child relationship with needs.

AYAs that reported problems with their sick parent before the illness had higher levels of needs than those who thought that their relationship with parent did not have a major problem beforehand. It has been proven before that there is a connection between parenting quality and the adjustment of children to parent illnesses, and that a positive relationship before the diagnosis helps adolescents to cope with the consequences of diseases [6, 40].

In our study, AYAs whose father was sick also reported stronger psychosocial needs. Lots of studies have examined children whose mother was sick but between those studies that examined both fathers and mothers, the results pertaining to the parent's gender and children outcomes were different [41, 42]. Also, the results of our study did not support the relationship between the genders of AYA with the amount of unmet needs. This is not congruent with some of similar studies [41, 43].

Christ in 1983 identified main transition points in cancer trajectory which are diagnosis, treatment initiation, treatment completion, cure, treatment failure, recurrence, decision to discontinue treatment, terminal illness, and death [44]. Treatment status—which, in our study means three points of treatment and diagnosis of cancer: 1. Waiting to start treatments (diagnosis), 2. During treatments (treatment initiation), and 3. Treatments finished (treatment completion)—was also connected by needs. Those AYAs of which their parent was under treatments had the highest needs. Recurrence of the disease was also assessed separately in the study but no connection was found between recurrence and psychosocial needs. There are evidences that show recurrence and more intensive treatment regimens are associated with poorer outcomes among AYAs and increase the amount of their unmet psychosocial needs [43, 45]. Although it seems that because of some methodological issues, more studies are needed to examine the variations of AYA psychosocial statues by parent's disease-related factors [40].

Even though the level of parent education was found effectible, and the highest level of parent education got the lowest level of children's needs, it is not possible to get to a conclusion, because, the number of individuals with a high level of education was limited in our study. Moreover, a direct connection between the different levels of parent's education and the need's mean could not be established.

This study is subject to certain limitations. The accessibility to children was difficult and most of the time we got in contact with them through their parents. One limitation in this study was that in many cases, family hid the kind of disease, especially in younger children. Another barrier was the attitude of parents that completing the questionnaires may have an emotionally negative influence on their children. Suggestion for further researches is evaluating these needs in other chronic conditions of parent in Persian languages population. Designing and providing proper interventions for this vulnerable group.

Table 3 Numbers of reported unmet needs for each item of each domain reported by offspring ($n = 217$)

Domain	Numbers of individuals reported unmet needs for each item	Domain	Numbers of individuals reported unmet needs for each item	Domain	Numbers of individuals reported unmet needs for each item	Domain	Numbers of individuals reported unmet needs for each item
1. Information	N1 = 163 N2 = 181 N3 = 167 N4 = 146 N5 = 164 N6 = 189 N7 = 175 N8 = 183 N9 = 191	2. Family issues	N10 = 159 N11 = 105 N12 = 114 N13 = 154	3. Practical assistance	N14 = 135 N15 = 128 N16 = 159 N17 = 146 N18 = 136 N19 = 142 N20 = 132	4. Time out	N21 = 136 N22 = 149 N23 = 85 N24 = 99 N25 = 109
Domain	Numbers of individuals reported unmet needs for each item	Domain	Numbers of individuals reported unmet needs for each item	Domain	Numbers of individuals reported unmet needs for each item		
5. Feelings	N26 = 162 N27 = 146 N28 = 146 N29 = 85 N30 = 100 N31 = 106 N32 = 91 N33 = 86 N34 = 95 N35 = 104 N36 = 156 N37 = 108 N38 = 112	6. Support from friends	N39 = 99 N40 = 67 N41 = 83 N42 = 78	7. Support from other young people	N43 = 85 N44 = 97 N45 = 102 N46 = 82 N47 = 100		

Conclusion

Regardless of the demographic variables of which their effectiveness may be found different among the studies, psychosocial needs always exist and their level proves to be considerable. This means that there is a need for accurate assessment and identifying types and level of this kind of needs with planning of measures and appropriate interventions toward satisfying these needs. Especially in less developed countries, with a lack of sufficient health and specifically mental health facilities, identifying the most important areas for interventions will help to increase the mental health situation in the country. Besides the above, the families and health care professionals must learn and be aware of this kind of needs in children of cancer patient, especially this vulnerable age group.

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Compliance with ethical standards

The study as well as the study method used was approved by ethics committee of Shahid Beheshti University of Medical Sciences.

Conflict of interest The authors declare that they have no conflicts of interest.

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