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Identification of Psycho-Social Needs and Coping Strategies in Children with Cancer

Fariba Zarani[1, *], Leili Panaghi[2], Seddighe Mirzaei[3], Sanaz Helmi[4]

ABSTRACT

Background: Studies have shown that cancer creates a variety of problems and issues for children with cancer. It creates unique challenges for both the patients and their families. Despite the severe stress associated with these problems, most children are able to adequately cope with and adapt to cancer. However, some of the patients experience more severe or prolonged problems that require psychological support. The present study investigated the needs and coping strategies of Iranian children aged 9 to 13 with cancer. The goal was to determine the needs, concerns and coping strategies in children after being diagnosed with cancer.

Methods: For this purpose, 12 children aged 9-13 with cancer as well as their mothers were selected from among children admitted to Mofid hospital. Patient selection was conducted in a purposeful sampling method. Data was collected in an in-depth semi-structured interview with the child and their mother and then analyzed using content analysis method.

Results: The content analysis of individual interviews with the child and mother showed that the main concerns of these children were related to the hospital space, support, society, family and educational needs, which were responded to by five distinct types of coping. These coping methods include spiritual coping, admission of support and assistance, visiting relatives (on a regular basis) in a positive manner and negative behaviors such as active and passive aggression and avoiding presence in the community and society. The findings of this study indicate that Iranian children with cancer have special needs some of which have mental and emotional aspects, including worry about being a burden on their families, and they use different coping strategies to cope with their condition. One of the most important means of coping with cancer are family and relatives.

Conclusion: Treatment centers should address these factors in order to improve the mental and physical health of their patients.

Keywords: Psycho-social needs, Coping strategies, Children, Cancer

1. Department of Clinical Psychology and Health, Faculty of Education and Psychology, Shahid Beheshti University, Tehran, Iran.
2. Family Research Institute, Shahid Beheshti University, Tehran, Iran.
3. Shahid Beheshti University, Tehran (SBU) with expertise in: Applied Psychology, Neuropsychology and Intrapersonal Communications, Tehran, Iran.
4. Department of Psychology and Education, School of Psychology, Shahid Beheshti University, Tehran, Iran.

***Corresponding Authors:**
Fariba Zarani
Department of Clinical Psychology and Health, Faculty of Education and Psychology, Shahid Beheshti University, Tehran, Iran.
Tel: (+98)2129905351
Email: fzarani@yahoo.com

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INTRODUCTION:

Cancer is uncommon in late childhood, and when it occurs, it creates unique challenges for both the patients and their families. Suffering from cancer in children has been linked to a deep sense of injustice, psychological challenges and a demand for immediate treatment. Late childhood is also a period of important physical and emotional changes, and the diagnosis of cancer in this period has a major impact on the psychological and physical development of individuals[1]. Therefore, investigation of the psycho-social problems of children who have been diagnosed with cancer at an older age is important because, as Whyte and Smith[2] have stated, "For older children and adolescents with cancer, the problem is not survival in the future, but staying alive right now." While developmental theories build the foundations for the exceptional cases specific to these age groups, they do not take into account the challenges posed by life-threatening and life-changing diseases such as cancer.

In terms of development, older children begin to adventure with a more independent state, leaving behind their strong dependence on their parents, a condition which is observable in early and mid-childhood. Cancer in this period leads to special sensitivity and vulnerability since it forces the child who is trying to be independent to rely on their parents in new and different ways. This new dependence may weaken the developmental effort towards independence and control, and lead to anger over this change in the relationship. Separation from school and other activities may harm friendships and create a feeling of loneliness, precisely at a time where the feeling of connecting to peers has great importance in personal identity[3]. Given the difficulties that older children with cancer face, identifying the psycho-social needs of these patients is of particular importance[4,5].

Although all cancer patients go through a common set of disruptions in life, they experience them differently, focus on different issues, and attach different levels of importance to different aspects of the experience, depending on the age at which they were diagnosed[6,7]. Rowland[8] has identified a comprehensive set of cancer-related problems that occur in all age groups and stages of life, throughout the range of care that begins with diagnosis and continues in the course of treatment, and ultimately, recovery or end-of-life. These problems include: 1) changes in interpersonal relationships, 2) dependence/ independence issues, 3) achieving life goals, 4) concerns about body-sexual image and integration, and 5) existential issues. The experience of these problems varies based on age-related social roles and duties and the responsibilities associated with these roles. Additionally, beliefs, attitudes, religious values, disease, medical treatments and health care professionals also affect behavior and experience. Therefore, there is a huge difference between and within cancer patients with different age, ethnic/ racial backgrounds or cultures, gender orientations and sexual identities. Therefore, with regard to the universal problems arising from cancer and their variability based on the stages of age-related life, psycho-social adjustment refers to the extent to which patients can cope with these problems and their effects[6,9].

Overall, studies have shown that in spite of the severe stress associated with the diagnosis and treatment of cancer, most children are able to adequately cope and adapt with cancer. However, some of them experience more severe or prolonged problems that require psychological support[10,11]. It has also been shown that success in adjustment is a complicated interaction between the characteristics of the threatening situation, individual characteristics, coping resources, and time; there is no optimal way to deal with all situations. Despite the obscurity of this issue, the complexity of this matter highlights the need for further research, as well as the need for trained mental health professionals in clinical settings to help in assessing adjustment methods and providing sensitive interventions appropriate to the person and the situation[10].

Simms, Kazak, Golomb, Goldwein and Bunin[12] point to clinical distress in differentiating with psychopathology when describing the severe emotional reactions of children and their families. Their terminology is indicative of the inevitability of disturbance in the diagnosis of cancer. They state that a high level of distress in the context of a severe danger, such as cancer, is an appropriate response rather than a pathologic response. This is also true during diagnosis and in cases of potential and actual medical danger, such as stem cell transplantation or recurrence. In these situations, susceptible and sensitive professionals can differentiate appropriate reactions from poor coping and unstable emotional states. In these cases, anger is not strange, but at times, this anger is too intense, and it addresses deeper problems that require more attention. As treatment continues, stressful situations continue to emerge, and identifying specific stressors that one has to deal with and are associated with the context become important. For example, after diagnosis and at the beginning of treatment, children are faced with unfamiliar, painful and annoying treatments, side effects, separation from school, peers and social activities. They often have to cope with distance from their families and friends and compromise with the hospital environment. Even when treatment ends, children and their parents need to balance between happiness and relief from treatment and loss of therapeutic support. After a long period of time, the reorganization of family, work, school, and social life is very difficult, while people try to maintain optimism about the patient's health in the future, with the knowledge that recurrence may occur at any moment[10].

In summary, understanding the needs and perceptions of older children with cancer contributes to providing them with holistic treatment. A study that examines the unique point of view and experience of older children with cancer at the time of diagnosis is the first step towards achieving this goal. This step allows health care professionals to provide the most appropriate evidence-based treatment for this population[5]. Therefore, in the present study, considering the research gap in the study of the needs and coping strategies of children with cancer, especially during the critical age of puberty, the needs and coping strategies of older Iranian children who have recently received a diagnosis of cancer will be addressed.

METHODS:

In this study, a qualitative method has been used to extract the needs and coping styles of older children with cancer. After interviewing the research sample, content analysis was used to extract the needs of the group and their coping strategies.

Participants

Data collection in this research was conducted through in-depth, semi-structured and face-to-face interviews. The duration of the interviews was between 30 and 45 minutes. After the interview, telephone contacts were also taken to ensure that the interview had no negative psychological effect and that they would be able to call the interviewer for additional information if needed.

Method of Research

In the present research, content analysis method was used for data analysis. Qualitative content analysis is a method for analyzing written, spoken or visual messages, and as a research method, it is an objective means of describing a phenomenon. This method allows the researcher to test theoretical issues to enhance understanding of the data. In qualitative content analysis, raw data is based on inference and interpretation, which is extracted, summarized and located within the classes. In the content analysis of classes and their names, they flow from the text of the data. In fact, the researcher immerses himself in the data to create new insight[13]. The classes obtained in this study are shown in **Table 1**.

Table 1. Categories related to the needs of children with cancer and the main themes of the categories

The main categories	Needs related to hospital space	Supportive needs (psychological, medical, financial)	Social needs	Family related needs	Educational needs
The main themes	Provide food tailored to child's interest and needs	Psychological Services and Permanent presence and Access to Psychologist	Communication with healthy peers	Informing and educating the family about the disease	Social skills training
	Lively, open and green space	Nutrition advice	Staying in contact with friends and classmates	Preparing the family for treatment	Teaching school lessons with the presence of the teacher
	Existence of an entertainment room and games appropriate for each interest and age	Financial support from institutions	Social support from the society (hospital, school, friends)	Being in contact with other children	Sexual education (puberty and reproduction)
	Equipment and facilities (maintenance room with light and appropriate temperature and as airy as possible)	Appropriate treatment and empathy from the hospital staff with child and their family	Training and raising the awareness of patient-related social environments (school, hospital staff, friends and relatives)	Contact with siblings	

In analyzing the content of the collected interviews, positive and negative coping strategies were identified that were related to the distress caused by cancer, as shown in **Table 2**. While analyzing the content of the collected data, it was found that the caregivers (mothers) of these children also used coping strategies, including speaking to and empathizing with each other as well as strengthening spiritual beliefs to deal with the present situation.

Analysis of findings

The purpose of this study was to provide awareness regarding the psycho-social needs and coping resources of Iranian children with cancer. Analysis of the experiences and statements of participants has led to the identification of five main categories of needs, including hospital space needs; psychological, medical and financial support needs and social, family, and educational needs. As reviewed by their main categories and themes, the psycho-social needs and issues of children aged 9 to 13 years arise from two sources of development and disease.

Psycho-social needs with developmental origins

From Piaget's point of view, children in this age have mentally and intellectually entered or passed the operational stage and They can deal with issues (such as a cancer diagnosis) from different perspectives and regardless imagination (this is where his needs are for cancer)[14]. In this examination, the role of development is outstanding, as in the category of educational needs, we see children's concern for acquiring skills and com-

Table 2. Categories of coping strategies for children with cancer and the main themes of the categories

Positive coping strategies (positive coping, acceptance, and communication).		**Negative coping strategies (negative behavior and avoidance).**	
Categories	**Main themes of the categories**	**Categories**	**Main themes of the categories**
Spiritual coping	Strengthening Spiritual Beliefs (Divine Testament, Greater suffering due to being closer to God)	Active and passive aggression	- Sighing - Inappropriate encounters with personnel - Not eating food and medicine - Physical and verbal aggression
Acceptance of support and assistance	- Acceptance of financial support from relatives - Receiving gifts from well-known and favorite characters for children, especially TV characters.	Avoiding social activities	- Avoiding peer groups - Not attending school because of teachers and students' behaviors - Not going out due to inappropriate appearance
Visiting relatives (on a regular basis)	More contact with relatives and their children		

petencies, and in the categories of social and educational needs, we see them worried about peer communication and being accepted among the opposite sex. In other words, the main tasks at the end of childhood and adolescence, namely, the acquisition of identity, life skills and emotional separation from parents[15], are among the main needs identified by children in this sample.

Psycho-social needs arising from a cancer diagnosis

The needs identified by the sample group of this research were categorized into five main categories:

Hospital Needs: The main needs of this category were nutrition related needs, the hospital's open space, the entertainment room, the thermal and lighting equipment and a room for the caregiver to rest in. All participants had to spend a lot of time in the hospital space, and the hospital's cultural and welfare constraints were their main complaints, as well as the depressing hospital environment, which made the patient and their caregiver feel worse. In this regard, some contributors state:

- *Providing food tailored to the interest and needs of the child and an appropriate place to eat:* She has vomited here and cannot eat in this bed" (Mother of a 12-year-old girl); "He says the foods are bland and that he does not like them" (Mother of a 9 year-old-boy).

- *Open and green space:* "I like to walk in green areas" (a 12-year-old girl); "The rooms here are so awesome" (a 13-year-old girl).

- *Room of entertainment and games based on different interests and ages:* "The room decorations do not fit my age and are for much smaller children, I'm not a baby" (a 12-year-old boy); "There are no games and toys" (a 9-year-old boy).

- *Equipment and facilities of the building (a maintenance room with light and appropriate temperature and as airy as possible):* " Sometimes it's too cool and sometimes too hot " (a 12-year-old girl); "it is dark here" (a 9-year-old boy); " I wish the ceiling of my room allowed me to see the sky "(a 10-year-old girl);" The windows are small and the sun does not shine in "(a 9-year-old boy).

- *The rest room for the caregiver and the family:* "There is no place for us to rest" (the mother of a 9-year-old boy); " When someone comes to see my child, they have to leave early and she will be listless and cry " (the mother of a 13-year-old girl); " Many times, we do not have much to do here, and we do not know what to do. I wish an educational class was held or that there were books to fill our leisure time" (Mother of a 12-year-old boy).

Psychological- medical- financial support needs:

The requirements in this category were the need for permanent access to psychological services, nutrition counseling, financial support and support from hospital staff. According to a content analysis of the participants' statements, it was found that hospital personnel such as doctors, nurses, medical advisers and mental health professionals play a very important role in supporting patients and their families, often referred to as a second family. Patients demanded help from these people in being understood, to provide them with a state of tranquility in this crisis condition and to help maintain and regain their sense of being normal. One of the important concerns of the participants was that they not only failed to gain independence from their families, but became more dependent on them and made their work harder, including the cost of treatment as a heavy burden on the family, and called for financial support from relevant institutions. Examples of their statements have been presented:

- *Permanent access to psychological services:* "Someone should tell us what to do with our overactive and aggressive child" (mother of a 12-year-old boy); "Sometimes we do not know how to answer our child's questions." (Mother of a 12-year-old boy); " There are issues about puberty and we do not know what to tell them" (mother of a 12-year-old boy); " " I don't know whether I should talk about her siblings or not " (mother of 13-year-old girl).

- *Nutrition counseling:* " We do not know whether to give her whatever she wants " (Mother of a 10-year-old girl); " I do not know if this food will be harmful to him " (mother of a 12-year-old boy); " My mother thinks everything is bad for me and she does not give me anything "(9-year-old patient).

- *Financial support by the institutions:* "It is best for charity to be organized so that their support is not limited to Tehran and only for patients in the city" (mother of an 11-year-old girl); "The costs of treatment are backbreaking for my dad" (a 13-year-old patient).

Social Needs:

The main needs in this category were communicating with healthy peers, keeping in touch with friends and other patients, and social support from the community. This need and concern was often raised in various ways, such as the desire to return to school, anger due to separation from friends and a feeling of loneliness and isolation. Another important issue for these children was the fear of describing their illness to their friends, and they requested help in providing education and information to the school staff, and especially their friends. Some participants said:

- *Communicating with healthy peers:* "I would like to go to the park with other children and play with them" (a 10-year-old girl).

- *Keep in touch with friends and classmates:* "I want to see my classmates" (a 10-year-old girl); "I miss my friends" (a 9-year-old patient); "I say to myself, what do my friends do when I am here?" (a 10-year-old girl); "My cousin and I are close friends and l will feel better when he comes to visit me" (a 12-year-old boy); "I don't want to fall behind from my classmates" (a 9-year-old patient); "I miss school" (a 13-year-old girl).

- *Social support from the community (hospital, school, and friends):* "I wish teachers would teach the students to behave normally around my son" (the mother of a 12-year-old patient).

- *Train and raise awareness about the patient-related social environment (school, hospital staff, friends and acquaintances):* "At school they asked me why I do not have hair". Why did you get sick? Are you going to die?" (a 12-year-old boy); " In society, they look at my child in a way that makes her feel bad "(mother of a 10-year-old girl).

- *Relationship with other peers:* "The patient in the bed next to me is nine years younger than I am, I cannot talk to her! I wish patients with the same age were in the same room "(a 13-year-old girl);" I have to go to another room to see my friend" (a 10-year-old girl);" I like to play with my friend, but he is another room" (a 9-year-old boy).

Family-related needs:

The needs identified in this category included the need for informing and educating the family about the disease, preparing them for treatment, maintaining contact with their siblings and considering other children while caring for a child with cancer. The serious concerns of these children were to maintain relationships with the family, especially the parents. This is despite the fact that usually children at this age attempt to emotionally separate themselves from their parents[16]. These children were generally under the full protection of their parents. At the same time, they demanded separation from their parents and wanted to relieve their pain and wanted to continue to be strong in their parents' eyes. Meanwhile, both children and their mothers were worried about their families, and they asked for help in preparing the family and assistance in dealing with other children and their family's mental health. Moreover, the expression of this need by the children reflects their efforts to not bother their families. The remarks of some of the participants were as follows:

- *Informing and educating the family about the disease:* "Doctors think we are doctors too and they don't tell us what to do about the disease and what happens" (Mother of a 12-year-old girl); "Before they do anything, they should tell us what to expect." (Mother of a 10-year-old girl);" Sometimes, after they bring my child from the operating room, we do not know what reaction or event is normal for this operation "(Mother of a 12-year-old girl);" I do not even know the name of my child's disease, when others ask about it I say I don't know and they think it's just a lie that I don't know its name" (Mother of a 9-year-old boy);

- *Dealing with other children:* "Our other children think that we do not love them" (the mother of a 12-year-old girl); "My brother said to me; you're lucky that you have cancer, mom loves you more" (a 12-year-old girl); "My daughter is adolescent and needs me but I cannot stay with her" (Mother of a 9-year-old boy).

- *Contact with siblings:* "When I see my little brother, I get better " (a 13-year-old girl); " I tell myself that I have to get better so I can go home and see my sister" (a 9-year-old boy).

- *Mental health of the family:* "Our family is strained and we aren't together" (Mother of a 12-year-old girl); "My husband is depressed" (mother of a 1-year-old girl); "Sometimes I say to myself I wish I could kill myself and get rid of all these sufferings "(Mother of a 9-year-old boy);" I wish I was dead and I would not see my child in this situation "(Mother of a 9-year-old girl).

Educational Needs:

Children's concerns about diagnosis and treatment are related to their current and future status, so that the learning of life skills and school lessons were a concern for these children. The school is a place that provides social structure and communication, allowing children to develop the skills needed to succeed in the future. While the diagnosis of cancer causes absenteeism and often makes it difficult to return to school and group of peers[5]. Some contributors say:

- *Social skills training:* "When we left the hospital, our child continued to behave at home like she did in the hospital, she did not treat other people properly" (the mother of a 13-year-old girl); "He has stayed at the same age at which he entered the hospital, and doesn't behave appropriately for his age "(Mother of a 12-year-old boy).

- *Teaching school lessons:* "I wish we had a teacher here to teach us" (a 9-year-old boy);

- *Sexual education (puberty and reproduction):* "She hasn't started menstruation and I'm worried about her future" (the mother of a 13-year-old girl); "I do not know if I can get married" (a 12-year-old girl); "I am much smaller than my peers" (a 12-year-old boy).

Coping methods

Coping methods in the research sample were divided into two groups of positive and negative, the positive methods reducing distress and the negative methods increasing distress. Positive coping strategies were: Creating a spiritual perspective (getting a positive outlook and attributing cancer to a test by the Lord, which helped patients to overcome fear, to hope through God and believe in themselves); acceptance of financial, psychological and social support from others was another way of helping meet the needs of patients in coping with the distress of cancer; seeing and visiting family was another form of coping that provided patients with the ability to maintain contact with others, especially peers. These were valuable sources of support and positive strategies to deal with the distresses of cancer. Some of the participants' comments on positive confrontations were as follows:

- *Creating a spiritual perspective:* "I say to myself, trust in God. Maybe tomorrow a drug for cancer treatment will be discovered." (the mother of a12-year-old boy); "when I see the people around me pray for the healing of my child, I feel better " (mother of a 12-year-old patient). "When I talk to God and ask him to help me to get better, I get better" (a 12-year-old girl);" I say to my family, increasing their spiritual and religious beliefs is the best thing they can do to help care for the child. "(Mother of a 12-year-old girl); "the closer you are to God, the more you suffer, which means God love me and I'm close to God "(the mother of a 9-year-old boy);" It is a test from God "(the mother of a 9-year-old boy).

- *Acceptance of financial, psychological and social support:* "When the financial burden is lighter on the shoulders of the family, it can be easier to handle distress (the mother of a 9-year-old boy); "I was very happy to receive an award by Mahak (a charity constitution), and I promised to stay for the treatment" (a 12-year-old boy); "Uncle Poorang (an actor on a children's program in Iranian television) came and took pictures with me. He told me if I took my drugs he would come back to see me again "(a 9-year-old boy);" Sometimes my sister takes my place in the hospital, and I can stay with my other children in my hometown, that way it becomes easier to manage "(Mother of a 11-year old girl)

- Seeing and visiting family: "When my uncle and aunt are here, I feel very well" (a 10-year-old girl); "I took her to her grandmother's house in the city and invited the people she liked, she felt better, and agreed to come to Tehran and be admitted to the hospital "(mother of a 12-year-old girl).

In contrast, some participants behaved negatively following the distress caused by cancer, which increased their suffering. These practices included active or passive-aggressive behaviors and avoiding society. Both methods can be explained according to developmental characteristics. As mentioned, independence is one of the main needs of a teenager, the risk of cancer causes the teenager to depend on others rather than to become independent, as a result, instead of acquiring an active position for independence, they take on a passive position that causes anger towards the family and the other people they depend upon. On the other hand, cancer causes children to become socially isolated rather than interact with their peers, which is one of their most important needs. Teens worry about being in peer groups and their reactions. Having cancer is related to being worried about appearance, competence and ability, and subsequent fear of friends' reactions, leading children to avoid their friends and peers. It can exacerbate distress by failing to meet the child's need for being in peer groups.

CONCLUSION

The findings of this study regarding the basic needs of Iranian children with cancer are somewhat consistent with other studies conducted in this area. In general, nine psycho-social needs in children with cancer have been identified by other studies around the world; (1) health concerns, (2) family relationships, (3) issues of sexual maturation and fertility, (4) relationships with peers, (5) physical image, (6) interruptions in school, (7) interaction with the treatment team, (8) goals and employment in the future, and (9) positive changes in life[1,4,6,15,17,18]. Despite the similarity in needs with developmental origins, it seems that there is a difference in other needs among Iranian and Western children with cancer. This difference can be explained in two ways. On the one hand, according to the Maslow Needs Hierarchy[19], it seems that the needs of Iranian children are more focused on the present and on their biological needs, such as the need for hospital space and financial support for medication, while the needs of Western children are focused on the future and related to higher-level needs-the need for respect (such as interaction with hospital personnel) and the need for self-actualization (such as positive changes in life-related cancer)[1,6,15,17,18]. So, for Iranian children, their physical and psychological needs are more important than their Western counterparts that employment and planning needs for goals and future are basic. This distinction highlights the relationship between the socioeconomic status of patients with their psycho-social needs, and is therefore important in future research. On the other hand, the important difference between these children can be explained with regard to the collective culture of Iranians versus the individualist culture of Western society[20]. Although there is a need for independence and autonomy in both groups, this need among Iranian children has mental and emotional aspects and is not just related to physical separation from the family, but also the fear of being a burden to them. These children consider family as one of the most important means of coping with cancer. However, the lack of the physical presence of families has been introduced as one of the most important problems in diagnosis and exploring cancer for Western children[21,22].

Considering the unpleasant and unpredictable problems experienced by older children with cancer, the important task of the recovery process can be to restore the sense of control over life as a means to long-term maintenance of adjustment and well-being[4]. They are challenged by cancer treatment, as they must face their own mortality and concern themselves about their health, while their peers often ignore or deny these facts[1].

Clinical Implications

Common concerns among children aged 9 to 13 years old in Iran with cancer were hospital care, psychological and medical support services, family, social and educational status.. In addition, these children responded the distress caused by cancer in positive and negative ways. Attention to these needs and coping strategies can help in recognition of these concerns by medical staff and in designinfg effective psychological interventions in the face of biological-psychosocial issues. This can also help with the long-term prevention of problems during the period of recovery.

Study Limitations

This study was conducted in a hospital in a qualitative manner. Therefore, the generalizability of the results is limited and the study needs to be repeated more broadly. Also, the impossibility of holding a focused group discussion prevented the gathering of information from interactions between members of the group. At the same time, this study does not address the needs and coping practices of the patient's family and hospital staff. We suggest that these issues be covered in subsequent studies.

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Conflict of interest

There are no conflicts of interest to declare.

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