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## Lived Experience of Children with Heart Disease and Cancer about Death Anxiety: A Phenomenological Study

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### Abstract

**Introduction:** Death anxiety is one of the ultimate anxieties of humankind, which is caused by consciousness of mortality and inevitability of death. Considering the fact that knowledge of death and experience of death anxiety arise from childhood, the objective of this study was to explore the experiences of children with heart disease and cancer about death anxiety.

**Methods:** This study was conducted qualitatively with a phenomenological approach. The participants were 15 children with cancer and congenital heart disease (CHD) at Ali Asghar (AS), Modarres, and Rasoul-e-Akram hospitals in Tehran in 2018, whose information was collected through semi-structured interviews. The participants were selected via purposive sampling and the data were analyzed by Colaizzi's method.

**Results:** The analysis of the data led to the development of a main category called anxiety, which consists of six subcategories including imaginary manifestations of death, loneliness and nothingness, fear and anxiety, unknowns, religious beliefs, and sorrow for others.

**Conclusion:** The investigation of the experiences of children showed that death anxiety is a very important concept in the minds of children with heart disease and cancer and it has different aspects. Therefore, proper knowledge of the various aspects of death anxiety can lead to the provision of appropriate educational materials and the use of various sources for reducing the level of anxiety experienced by children.

**Keywords:** Anxiety, Death, Fear, Children, Qualitative research

### Introduction

Developmental psychopathology has always focused on understanding early risk factors in the development of internalized disorders like anxiety (1). Research has shown that among the internalized disorders, anxiety disorders are the most common

clinical problems in childhood and adolescence and about 5% of children meet diagnostic criteria for at least one anxiety disorder during their childhood. The British National Health Service considers the anxiety of death as a feeling of dread, severe fear, or anxiety when thinking about the process of dying, disconnecting from the



world, or what happens after death (2). From an ontological point of view, death anxiety arises from one's awareness of his or her own death. This anxiety may develop as a kind of negative emotional response evoked by anticipating situations that do not exist on their own (3). It has been more than four decades that death anxiety is seen in children with incurable diseases and it seems that children think about death more than it appears. Several studies have indicated that most children have a well-structured understanding of death between the ages of 4 and 7 (4-5) and gradually acquire cognition of death similar to that of adults and their most common reaction to death is usually fear (6). Fear of being replaced (7), being alone, physical problems, and medical treatments (8) are other common fears of sick children. Among different age groups, the age group of 9 to 12 years (latency period) is of great importance. Yaloom believed that children in this period learn to deny reality and as they gradually learn effective and advanced forms of denial, the consciousness of death slips into the subconscious and the apparent fear of death subsides. Therefore, the happy days before adolescence - the golden age of latency - do not reduce death anxiety but are its result (9).

Contrary to the first theories about death anxiety proposed by Feist et al. that considered death anxiety as a substitute for other anxieties, including castration anxiety (10), Motamedi considered it to be the most basic and important human anxiety (11) which plays an important role in one's inner experiences. One of the first and most important tasks for the growth of a person is to face the fear of destruction. Although death anxiety is an experience that exists naturally in all people, it seems to be very common in patients with serious illnesses

such as cancer, regardless of personality traits, religious beliefs or cultural background which means that for these patients, words such as cancer are associated with death (12). Statistics show that children under the age of 20 have a high incidence of various incurable diseases (cancer as the most important cause of death of children up to 14 years old in Iran and the second leading cause of child death in the world and Congenital heart disease (CHD) as the fifth most common cause of death) (13). On the other hand, advances in medical science, by increasing the possibility of longevity, have lengthened our exposure to death-related thoughts. However, studies on death have just focused on the time when children become aware of death and factors affecting it as well as death anxiety correlations (14). In the meantime, the meaning of death and the nature of anxiety caused by the child's understanding of the inevitability of death have been neglected. Therefore, it is very important for these children to understand and interpret death anxiety. The present research was a qualitative one with a phenomenological approach. In fact, this method can help deeply address children's experiences and their anxiety by discovering the meanings of the data. Previous studies have been mostly of a quantitative nature. Identifying human feelings, perceptions, and emotions via quantitative methods is difficult. For this purpose, the present study aimed to examine the lived experience of children with heart disease and cancer about death anxiety using a qualitative method with a phenomenological approach.

## Methods

The present study was a qualitative one with a phenomenological approach carried out in

Tehran hospitals in 2018. The objective of this study was to investigate the experiences of children with heart disease and cancer about death anxiety. The participants were selected via purposive sampling from among children aged 9 to 12 years who were hospitalized due to cancer and congenital heart disease in Ali Asghar (AS), Modarres, and Rasool Akram (AS) hospitals. The data collection continued until the saturation point so as to assure the adequacy of the sample. Finally, 15 children were interviewed with each interview lasting from 30 to 55 minutes in average. The data were collected through semi-structured interviews in such a way that the researcher allowed the free flow of information with an open mind and without any tension.

For each interview, the researcher talked briefly with the mother of the child and after an initial introduction and stating the purpose of the interview, obtained her permission to conduct the interview with the child and record the conversations. Due to the sensitivity of the issue and to reduce anxiety, an attempt was made to question child about anxiety in various fields including school and relationships with friends and family. Then, questions such as "What do you think death is like?" or "What do you think will happen after death?" were asked and based on each response, the next question arose.

The interviews were recorded using a tape recorder and then transcribed verbatim by the researcher. The texts were carefully read several times. Reliability is concerned with expressing the credibility of a study from the perspective of the reader, the participant, and the researcher. According to Creswell, a qualitative researcher must use at least two strategies to evaluate his or her research. In the present study, to achieve reliability,

member check and audit technique (control by colleagues) were used. The researcher presented some of the interviews and extracted topics to four expert colleagues who had experience in qualitative research and field work and asked them about the correctness of the categories and codes. In fact, with their comments, the concepts and categories were revised and finalized (15). In the member check, the concepts and categories extracted from the interviews (research results) were presented to several participants and they were asked to rate the themes and categories and comment on their accuracy, and finally, the results were confirmed.

The inclusion criteria were being 9 to 12 years old, fully conscious, and willing to be interviewed as well as having no mental illness. The exclusion criteria were not being willing to continue the interview, showing the symptoms of fatigue and weakness, or needing medical treatment.

During the interviews, the main topics were discussed with the help of two psychologists and a phenomenologist. Moreover, communication with interviewees continued to re-examine the interview findings. Written consent form was obtained for recording the voices and allowing the participants to withdraw from the research at any time they wished. The data were analyzed using Colaizzi's seven-step method. First, the descriptions of all the participants were read in order to understand their feelings. Then, all notes were checked and important phrases were extracted. The meaning or concept of each important phrase was formed in the third stage, which was presented as formulated concept. In the fourth step, the formulated concepts were organized into thematic categories. The findings were

then integrated into a comprehensive description of the phenomenon. In the sixth step, a comprehensive description of the phenomenon under study was obtained in the form of a clear statement. The final validation step was performed based on the criteria of validity and reliability.

## Results

The participants in this study were children with heart disease and cancer within the age range of 9 to 12 years. The demographic characteristics of the participants are presented in Table 1.

**Table 1. Demographic characteristics of the participants**

Participant	Duration of illness	Type of disease	Age
1	3	cancer	12
2	4	CHD	12
3	5	CHD	10
4	5	cancer	11
5	2	CHD	9
6	3	cancer	12
7	2	cancer	9
8	4	CHD	9
9	4	cancer	11
10	2	cancer	10
11	4	CHD	12
12	2	CHD	12
13	2	cancer	11
14	2	CHD	10
15	1	cancer	9

The analysis of the data led to the creation of a major category called anxiety and six subcategories including imaginary manifestations of death, loneliness and

nothingness, fear and anxiety, unknowns, religious beliefs, and sorrow for others as presented in Table 2.

**Table 2. Categories extracted from interviews**

Main categories	Subcategories	Codes
Death anxiety	Imaginary manifestations of death	The resurrection of the dead with horrible faces, Hell as a land of Fire, Devil sitting in hell, Devil waiting, Devil looking at left and right
	Loneliness and nothingness	That world is scary if no one is ahead, Fear of being forgotten, Fear of being alone
	Fear and anxiety	Fear of the physical symptoms of death, Being scared if the dead person has a bloody face
	Unknowns	Darkness and being in a cemetery, The presence of a ghost in the cemetery, Ghosts becoming alive again, The jinn coming at night
	Religious beliefs	The resurrection is so scary that no one remembers you at all, on the Day of Judgment, God will ask questions, you join the loved ones who have been lost in the past
	Sorrow for others	To attribute the grief caused by your death to those around you, Our friends are saddened by our death

### Imaginary manifestations of death

Part of the anxious thoughts of the children participating in this study was about various

manifestations of death and the events after death. These thoughts were mainly focused on the idea that ghosts were harmful, the hardships and painful features of hell, and

the resurrection of the dead in horrible faces and it seemed that children try to fill their knowledge gap of the concept of death with horrifying beliefs, imaginations, and fantasies. In this regard, participant 5 stated, *"Those who die move; this is how zombies move, they stop the cars, do not let people go; they come out of the grave; it is very dangerous; I saw it in the movie; this is what people do outside the grave"* or "Hell, the land of fire, the red castle, the devil is sitting on top of it, he is waiting, he is looking at left and right. Participant 4 stated, "They kill people; for example, they go for him. They want to find him. Take him. They annoy people. I'm afraid of jinn. It kills people; It makes you miserable". Participant 13 stated, "I haven't seen it, but they say it is scary. They say it looks like a monster".

### **Loneliness and Nothingness**

The children in the study described loneliness and abandonment as horrific consequences of death. Being forgotten or being left in difficult circumstances were the obvious and significant fears of children in this study. For example, participant 8 expressed the fear of being alone as follows, "We go to that world, the loneliness is scary. There is no one else, that's very bad". Moreover, the fear of being abandoned was described by participant 13, "What if I get lost and nobody finds me. It is scary when no one is with you". Participant 2, "If we have done something wrong, we will go to that world, we will grow old, we will suffer, we will no longer see our parents". Or "I'm afraid of the cemetery especially in the evening, at dusk, at midnight. A dead body that has just been buried has no tombstone at all, no pit. He was left like this and dumped". Participant 10 commented about fear of the consequences of death and resurrection, "On the Day of Judgment,

everyone can see their loved ones, but they do not know each other, no one knows anything. They don't even think about you".

### **Fear and Anxiety**

The participants in this study referred to a variety of concerns and fears in their conversations about death. Fear of sudden and unpredictable events as well as all the events that may happen unintentionally in life and may lead to death. Moreover, how death occurs, pain and suffering at the time of death, or quick and painless death were discussed in this category. Participant 8 said in this regard, "I am afraid of a dead person, if her/his face is bloody, I am very afraid. For example, my grandmother had no problem. I'm afraid if it's someone else that dies in such a way that everyone who looks at him is scared. It was as if he had been tortured to death". Participant 11 expressed her fear of death as follows, "Bombing is very scary if you are injured and suffering. A truck accident is very scary if we are in a car".

### **Unknowns**

One of the themes mentioned in this study was unknowns. Ignorance, whether it is part of the nature of the issue or caused by the lack of identifying factors in the living environment, is one of the factors that increases the likelihood of danger and makes humans vulnerable creatures. In this regard, the participants 10 and 11 introduced darkness and being in the cemetery as factors of the presence of ghosts and stated, "It is true that they say there is no ghost, but they say that there are usually many in the cemetery". "I'm afraid of the cemetery at night. They say at night the jinn is among you. Ghosts become alive again". "On the Day of Judgment, they will ask each other what happened? You are somehow there and

you are not". Participant 1 referred to the ghost, our inability to see it, and how to prevent its harm, "Nothing spectacular. No one can see it. Because we cannot see the invisible and tell it not to harm us".

### **Religious beliefs**

Religious beliefs of children were effective in creating three mental paths for them in the face of death. The first path was denial of death and related issues such as the soul, "I saw a lot in the movie that people die, I am not afraid of them. Although they are white, I am not afraid of them" (Participant 6). The second path was fear and anxiety about responding to the deeds and rewards of bad deeds as clear in statements such as "Doomsday is so scary that no one remembers you at all, you just want to save yourself" (Participant 8), "Doomsday is the day when everyone dies, God will ask questions on the Day of Judgment" (Participant 13). The third path was hope for a happy ending, immortality, recovery from illness, fulfillment of desires and aspirations, and of course, reuniting with loved ones who have been lost in the past as is evident in the following statements, "People who die are always in your heart, they will never leave you" (Participant 13), "Good things are in heaven. For example, they can do whatever you want there, but you can't have them here. For example, if someone is sick, she tells God to take care of her, she no longer needs to go to the hospital" (Participant 1).

### **Sorrow for others**

Grief for others was another finding in this study. By seeing the worries and anxieties of their parents and the unhappiness of their friends and by understanding and imagining the future without the presence of "me", children extended this worry and sorrow to

the whole life of their parents and friends and they were worried that their future death would always be accompanied by grief and sorrow. Participant 4 stated, "The rest are upset. My father is upset. Our souls understand that they are upset. Participant 1 stated, "The family is upset. They'll miss you". Moreover, participant 9 said, "The friends we have are upset. Their friends are upset that our good friends are dying".

### **Discussion**

The child's perception of death is different from that of an adult and the concept of death is not so much known to children. Each child may react differently to this phenomenon depending on their personality traits. Therefore, the objective of this study was to investigate the lived experience of children with heart disease and cancer about death anxiety whose components were classified into one main category and six subcategories. The first subcategory was the imaginary manifestations of death. This subcategory expressed the child's thoughts, fantasies and mental imaginations about the external manifestations of death. The results of the present study in referring to the influence of the role of mental factor or theory of mind were associated with those of the study by Bering (16). The socio-cultural factor was also consistent with the results of the study by Astuti and Harris (17). Given that the belief in the life after death is formed very early in the developmental period of an individual (18), the child's mind is confronted with questions concerning the quality of life after death and the quality of being present in the afterlife. If children cannot find first-hand evidence to answer their questions, they trust what adults, especially their parents, tell them (19). However, since answering such questions

has always been accompanied by a kind of fear and reluctance on the part of parents to answer such questions, children turn to other sources such as socio-cultural resources and mental developmental abilities to find answers to their questions.

Loneliness and nothingness is another component of death anxiety in children. The fear of being alone, which, in a larger scale, seems to be accompanied by the fear of being forgotten by family and society and nothingness, is consistent with fear of loneliness in the study by Sinoff (20), fear of loneliness and loss of caregiver in the studies by Halpem and Palic (21) and Klein (22), and the category of leaving loved ones and pain and loneliness in the study by Crain (23). Therefore, the advocates of the theory of harm believe that children see death as an obstacle to achieving pleasures or good things such as being with loved ones, family, the power to influence society, and so on. Thus, death, which is the beginning of the lack of such experiences, is harmful and frightening for the child.

Another category referred to children's fears and worries. The children in this study made direct reference to a variety of causes leading to death and how they experienced death, including sudden deaths or deaths accompanied by severe pain and suffering, with high emotional responses. In "*The Social History of Death*", Kellehear (24) considered the desire to identify the dangers that lead to death to be the characteristics of the Stone Age Man. He believed that the two main sources of death during the Stone Age were being killed by predators and being killed by other humans. Thus, it seems that what has existed in the history of human evolution since ancient times can also be seen in the history of individual human development and, according to Hegel, it

repeats the phylogenetic ontology which means that the development of a single organism (ontology) in a concise way repeats the evolutionary history of that individual species (phylogeny) (25). Furthermore, some underlying codes of this category including sudden death and painful death were consistent with the category of violent and premature death in the study by Wong (26). The codes of death by animals and death by modern tools were also consistent with the fear of different kinds of injuries and deaths caused by animals and inanimate objects and the discomfort resulted thereafter as reported by Jung (27).

Another category related to death anxiety in children was the unknown. Throughout history, human beings have always tried to find appropriate answers and explanations for the unknown phenomena of the world around them. Trying to identify the unknown phenomena provides the power to predict and control them. Thus, the unknown is associated with a sense of fear, panic, lack of control, and confusion in how to deal with it. One of the greatest questions that human beings face very soon during their period of individual evolution is the question of death and life after death. Therefore, anything that evokes the meaning of death in the mind is accompanied by a feeling of fear by reminding the unknown and the uncontrollable. One of the most obvious symbolic and universal cultural meanings is darkness (28). Rajabi and Bahrani (29) considered darkness to represent a kind of death. Another meaning mentioned in this study, which was associated with death and nothingness in children, was small and closed spaces, as one of the children in this study likened his bed and room to a grave and showed a fearful reaction to it. Although Motamedi introduced the fear of the

unknown only as a result of the ignorance of the decline of self, being, and identity, and did not bring unknown death into this realm, the present study showed that children consider one of the factors influencing the horror of death and its associations to be simply the unknowns and the presence of an identifier can greatly reduce their fear of encountering death (11).

Religious beliefs was another component identified in this study. The desire for immortality has existed in humankind since the beginning of the creation. Therefore, human as a being conscious of death and aware of his/her own attenuation and the inevitability of death, sees death as an obstacle to immortality and is afraid of it. Thus, as Becker pointed out, one of the ways to reduce death anxiety is to use symbols of immortality (30). Moreover, one of the greatest resources that provides the path to salvation and immortality for human beings is religious and spiritual beliefs and rites. The results of the present study were consistent with the results of the study carried out by Jung (27) on the causal relationship between the variables of religion and fear (especially fear of death). Jung believed that a large part of the history of Western rationalism has to do with the relationship between religion and fear, especially the fear of death, with two causal claims: fear motivates religious beliefs and religious beliefs reduce fear. Concerning the beliefs related to the life after death, the children in this study first pointed to the fears arising from religious thoughts about the Day of Judgment, resurrection, and encountering the letter of their deeds. Fear of change, turmoil, and abandonment on the Day of Judgment also causes a lot of anxiety for the child since how it happens is unpredictable. However, this fear is not

permanent and the child will experience a mixture of fear and hope. An important point in children's thinking about their fate in the afterlife is the role of the concept of individual responsibility. Based on religious teachings, children learn that they can strive to attain heaven and its rewards and avoid the bitterness of hell by engaging in religious and spiritual practices. Although religious concepts are associated with a mixture of fear and hope for children, they present ways for people to gain immortality and salvation and pave the way for the hope of immortality as one of the greatest human aspirations from the beginning of the history.

Another component of the present study was sorrow for others. Despite the fact that a child from the age of 5 to 7 gradually realizes the inevitability of death (29), the child thinks that heroes or having special forces are able to overcome or postpone the force of death. One of the main reasons the children in the study gave for the fear of death, referring to the concern over their death, was the possibility of upsetting family members or upsetting their souls due to suffering. This finding was consistent with the results of Becker's study (30) which showed that the most important cause of Iranian anxiety about death is the suffering of family and others from the event of their death and the fate of their family. According to the present study, children's worries about family grief is a way to delay death. In other words, children consider the grief and sorrow of those around them as a mediator or intercessor and they think maybe they can postpone death this way. In other words, the special force through which children try to avoid scary death is relying on the emotional dimension and projecting their fear on others, especially family members. As



Becker believed, when people realize the inevitability of their death, they instinctively try to suppress it in their fears (30). The method of repression generally seeks to rely on external support, rather than on the issue itself, by directing the mainstream to cultural beliefs.

### Limitations

One of the limitations of this study was that in addition to the lack of cooperation of some medical centers to access the sample, due to the qualitative nature of the research, the results were of limited generalizability. To overcome this limitation, sampling continued until the data saturation point.

### Conclusion

The findings of the present study indicated that the concept of death anxiety in the minds of children with heart disease and cancer had different dimensions including imaginary manifestations of death, loneliness and nothingness, fear and anxiety, unknowns, religious beliefs, and sorrow for others. Therefore, the concept of death preoccupies the minds of children more than it seems. Despite the fact that talking about death is always considered difficult for children and prevented by parents, the results of such studies underscore the need for this research. Hence, it is suggested that by correctly understanding the various dimensions of death anxiety, appropriate educational materials and various resources be provided by families and authorities to reduce the level of anxiety experienced by children. Moreover, considering that the present study was performed on children with heart disease and cancer in a non-random manner, the possibility of extending it to other sick children is limited. Thus, it is suggested that the concept of death anxiety

be examined from the perspective of other sick children too.

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